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"Making It Work":
Navigating the Politics Around ART System Implementation In Ethiopia

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Around ART System Implementation

In Ethiopia

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TABLES OF CONTENTS

CHAPTERS AND SECTIONS **PAGES**

LIST OF TABLES

LIST OF FIGURES

ACRONYMS

AACGHB	**Addis Ababa City Government Health Bureau**
AAHAPCO	**Addis Ababa HIV/AIDS Prevention and Control Office**
AAU	**Addis Ababa University**
ADLI	**Agricultural Development Led Industrialization**
AIDS	**Acquired Immunodeficiency Syndrome**
AMPATH	**Academic Model for Prevention and Treatment of HIV**
AMREF	**African Medical and Research Foundation**
AMRS	**Automated Merchant Reporting System**
ART	**Antiretroviral Treatment/Therapy**
ARV	**Antiretroviral**
CADCAM	**Computer-Aided Design and Computer-Aided Manufacturing**
CD4	**Cluster of Differentiation Four**
CDC	**Centre for Disease Control**
CPU	**Central Processing Unit**
DACA	**Drug Administration and Control Authority**
DHIS	**District Health Information System**
DHS	**Demographic and Health Survey**
E.C.	**Ethiopian Calendar**
ECA	**Economic Commission for Africa**
EICTDA	**Ethiopian Information Communication Technology Development Authority**
EMR	**Electronic Medical Record**
EMSAP	**Ethiopia's Multi-Sectoral HIV/AIDS Control Project**
EPRDF	**Ethiopian Peoples Revolutionary Democratic Front**
ETAEP	**Ethiopian AIDS Emergency Plan**

FDC	**Fixed-Dose Combination**
FHI	**Family Health International**
FMOH	**Federal Ministry of Health**
FOSS	**Free and Open Source Software**
GDP	**Gross Domestic Product**
GMH	**Gandhi Memorial Hospital**
HAART	**Highly Active Antiretroviral Therapy**
HAPCO	**HIV/AIDS Prevention and Control Office**
HIPC	**Highly Indebted Poor Countries**
HIS	**Health Information System**
HISP	**Health Information System Program**
HIV	**Human Immunodeficiency Virus**
HMIS	**Health Management Information System**
ICT	**Information Communication Technology**
IHAMS	**Integrated HIV/AIDS Management System**
IHAMS-ART	**Integrated HIV/AIDS Management System- Antiretroviral Treatment/Therapy**
IS	**Information System**
IT	**Information Technology**
JHU	**Johns Hopkins University**
JSI	**John Snow International**
M&E	**Monitoring and Evaluation**
MMH	**Menelik Memorial Hospital**
MOH	**Ministry of Health**
MOU	**Memorandum of Understanding**
MTCT	**Mother to Child Transmission**

NAC	**National AIDS Council**
NACP	**National AIDS Control Program**
NACS	**National HIV/AIDS Prevention and Control Secretariat**
NGO	**Non-Governmental Organization**
NHAPCO	**National HIV/AIDS Prevention and Control Office**
NNRTI	**Non-Nucleoside Reverse Transcriptase Inhibitors**
NRTI	**Nucleoside or Nucleotide analogue Reverse Transcriptase Inhibitors**
NTF	**National HIV/AIDS Task Force**
OHAPCO	**Oromia HIV/AIDS Prevention and Control Office**
OI	**Opportunistic Infection**
OSS	**Open Source Software**
PEPFAR	**President’s Emergency Plan for AIDS Relief**
PHC	**Primary Health Care**
PI	**Protease Inhibitor**
PLWHA	**People Living With HIV/AIDS**
PMTCT	**Prevention of Mother to Child Transmission**
RAM	**Random Access Memory**
RHAPCO	**Regional HIV/AIDS Prevention and Control Office**
RHB	**Regional Health Bureaus**
RHINO	**Routine Health Information Network**
RHIS	**Routine Health Information Systems**
RPM Plus	**Rational Pharmaceutical Management Plus**
SNNPR	**Southern Nations and Nationalities Peoples Region**
STI	**Sexually Transmitted Infection**
TB	**Tuberculosis**
TSEHAI	**Technical Support for the Ethiopian HIV/AIDS ART Initiative**
UiO	**Universities of Oslo**
US	**United States**

USA	**United States of America**
USAID	**United States Agency for International Development**
UN	**United Nation**
UNAIDS	**United Nations Programme on HIV/AIDS**
UNECA	**United Nations Economic Commission for Africa**
UNDP	**United Nations Development Programme**
UNGASS	**United Nations General Assembly Special Session on HIV/AIDS**
USD	**United States Dollar**
VCT	**Voluntary Counseling and Testing**
VL	**Viral Load**
WHO	**World Health Organization**
ZMH	**Zewditu Memorial Hospital**

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ABSTRACT

This thesis investigates the processes of practically making work Information Systems (ISs), specifically Health Information systems (HISs) to support HIV/AIDS management, in developing countries. The investigation is based on ongoing action research intervention efforts aimed at improving the pre-existing situation of ART (Antiretroviral Treatment) management in Ethiopia. The research has been carried out as part of the Health Information Systems Program (HISP) initiative, an international research and development initiative based in the Informatics Department of the University of Oslo, Norway.

The study was informed by qualitative methods, and was carried out within an action research framework. A multi-site longitudinal action research design approach was adopted to help understand deeply and in context specific manner what issues constitute the challenges of practically making work ISs, in particular HISs, in developing countries.

Theoretically, we consider IS failure in developing countries to be rampant, and hence to have remained as an area requiring larger research focus with respect to adequately understanding the full complexity of this phenomenon. While the phenomenon has been dominantly understood as *socio-technical*, we especially focus on the issue of *politics* and its profound impacts on IS projects in these countries and also on the failure phenomenon. We conceptualize ISs as political artifacts, and hence consider the politics around them to be a matter of serious concern and at most importance. We thus took a *socio-technical-political* perspective in the effort to practically make work ISs in developing countries, and developed a theoretical framework, which we conceptualized by the metaphor of *"Making It Wok"*, to help us deeply understand and address these triple and interrelated issues.

Empirically, the analysis of practically making work ISs was based on the existing condition of HIV/AIDS and ART management in Ethiopia. Through our empirical work, we identified three key problems influencing the information management of this application domain which used to run largely manually. The empirical focus of this thesis is on the design, development, implementation and use, scaling up, sustaining, and on practically making work of an HIS to support ART management in Ethiopia. The overall set of these processes, socio-technical-political, which has its end objective to ensure that systems are embedded in organizational routines and produce outputs that are beneficial to the users, is what we call as "making it work". Through these processes, we identified the domain of HIV/AIDS and ART management to be technically demanding and strongly political. With our normative research goal of making the ART system work, we especially found the politics surrounding it to be a key challenge, particularly in the processes of gaining entry and scaling up the system. We found the scope of politics around such systems to include various distinct *driving factors*, *ways of manifestation*, and also *resulting outcomes*. In the course of our empirical effort, we adopted five sets of approaches to address the socio-technical-political issues that challenged our effort and ten sets of strategies to making our project (the system) work politically, and through our empirical analysis we derived three key implications for "making it work".

Overall, in contrast to previous approaches, *the "making it work" paradigm stretches the scope of practically making work ISs, in particular HISs, in developing countries to include the addressing, with prolonged effort, of the complex and multifaceted socio-technical-political challenges comprehensively, systematically, steadily, and continuously in the full spectrum of the project processes.*

1 Introduction

This thesis investigates the processes of practically making work ISs (information systems), specifically HISs (Health Information Systems) to support HIV/AIDS management, in developing countries. The investigation is based on ongoing *multi-site longitudinal action research* intervention efforts aimed at improving the pre-existing situation of ART (Antiretroviral Treatment) management in Ethiopia. While we focus on the issue of *politics* and its profound impacts on the project studied, within the theoretical framework we developed of *"Making It Work"*, the thesis takes a *socio-technical-political* perspective in relation to the development and implementation of such systems. The discussions in the thesis thus revolve around basic issues and concepts under the theme of *"Making It Work"*.

The research has been carried out as part of the HISP (Health Information Systems Program) initiative, an international research and development initiative based in the Informatics Department of the University of Oslo, Norway. This initiative aims to develop and implement sustainable HISs in developing countries through building local professional and technical capacities within the context of a global research and development network. The two authors of this thesis, members of the HISP initiative ongoing in Ethiopia since 2003, hope that the thesis will contribute to the action research efforts both within Ethiopia, and also globally.

In trying to describe the various facets of the thesis, this chapter is organized as follows. In section 1.1, we introduce our research motivation which concerns understanding and addressing the challenges of practically making work ISs, specifically HISs to support HIV/AIDS and ART management, in developing countries more broadly and in Ethiopia in particular. We also position the research investigation within existing debates and the challenges identified by researchers. We then describe both our research objectives and the research problems in section 1.2. In section 1.3, we introduce our research domain, HIV/AIDS and ART management in developing countries more broadly and in Ethiopia in particular. In section 1.4, we articulate the theoretical considerations that guide the research. This is followed by summaries of the research methods adopted (section 1.5) and the empirical basis (1.6). Following this, in sections 1.7 and 1.8, we present the expected contributions of the thesis, and the structure and features of the entire document respectively.

1.1 Research Motivation

The research landscape of IS in developing countries is packed with stories of failures (Heeks, 2002). In particular, there exists *"plenty of …evidence that …most"* HISs in these countries, our broader application domain, are failures (Heeks et al., 1999, p. 2). As the research in this domain has matured over the years, researchers have found more elegant and theoretically sophisticated ways of describing these failures (Lucas, 1975; Lyytinen and HIrschheim, 1987; and Sauer, 1993), while not placing equal emphasis on describing how things can be made to work. Moreover, we argue that even lesser importance is given on elaborating approaches for averting failures and making the systems practically work given the various adverse conditions that are experienced in the context of IS projects in developing countries (Sahay, 2001). This point was underscored by Donaldson and Jenkins (2000, p. 4) when they wrote:

> *"Why is there such a problem when so much is known about failures? ...Why, if much is known about what has gone before, is this problem so difficult to overcome? The simple answer is that while much has been done to improve systems practice … a relatively small amount of research has been specifically devoted to addressing the subject of software systems failures."*

Granted, IS failure especially in the context of developing countries has long been identified as one of the major issues by various researchers including those engaged around HISs (Heeks, 2002). Though the challenge of averting the failures has increasingly become a common theme in IS researches, efficient strategies to make the systems practically work are yet in short supply (Donaldson and Jenkins, 2000). This deficiency importantly emanated from the inability to adequately understand and portray the full complexity of IS failures. In fact, the attempt to investigate the actual factors for IS failures in developing countries, a vital step to averting them, has been reported to be limited by various constraints (Heeks, 2002). Consequently, when investigating failure causes, researchers have often typically emphasized dominantly the various socio-technical factors, and did not depict the entire complication of failures as a combination of technological and socio-political issues. In fact, many researchers have perceived IS development and implementation as a politically neutral process, only to be severely criticized (Knights and Murray, 1994; Markus, 1983).

Of course, as it has been done in a number of research studies, it is undoubtedly very important to recognize the impacts of socio-technical factors in the effort to make ISs work. For example, in our project effort, some design issues, ambitious expectations of the users and their past experiences with ISs, the multiplicity of stakeholders involved, workload, and scarcity of resources, were some of the main socio-technical issues we identified and needed to deal with. Nevertheless, while the impracticality of making work ISs without successfully addressing such orthodox factors has been widely acknowledged, the political dimension of IS projects which we argue to be an essentially key issue in point, and also the major theme of this thesis, has been given inadequate attention in the IS literature (Gladwin et al., 2003). True, in the context of the West, researchers have described the impacts of the issue of politics in IS implementation (Kling, 1978; Keen, 1981; Markus, 1981; Markus, 1983). There is also increasing emphasis given on this topic in the context of HIS in developing countries (Chilundo and Aanestad, 2003; Byrne, 2004; Braa et al., 2004b; Puri et al., 2004; Mosse, 2004; Nhampossa, 2006). Apparently then, many of such projects undoubtedly needed to struggle and deal with politics to some degree, in parallel with the core activities. Yet, arguably, the political aspects of IS projects need further unpacking and understanding.

For example, while the influence of political conditions in shaping IS projects has been recognized, they are often condemned as mere impediments (Keen, 1981), and the associated opportunities are often ignored. Moreover, the role and interests of the key actors involved in IS projects, the implications of the technology itself, and also the approaches to adopt it to a specific environment have been inadequately discussed with politics at the backdrop. Further, though they are fundamentally related, socio-technical and political issues were often treated independently, and their interrelation and how they influence each other has rarely been discussed, and thus remained largely poorly understood. Furthermore, the particular political challenges of introducing and making work HISs in the highly political (Nega et al., 2007) area of HIV/AIDS and ART, our main research focus, has not been explicitly discussed in IS research.

By and large, literature on the issues of politics around IS implementation is relatively limited (Keen, 1981; Bull, 2003; Gladwin et al., 2003). Bull (2003, p.1, 3) noted:

> *"We badly need more understanding of these [political] issues."* – Keen (1981, p. 32)

> *"There remains a dearth of attention in respect of the political aspects of ... software. .... The academic literature relating to the issues associated with political apathy in information systems is relatively scarce, despite the increased incidents of such phenomena in other political environments."*

Why the scarcity? Keen (1981, p. 32) argues that this is due to the fact that *"politics are hard to study. They involve many hidden agenda … and in most instances a skilled observer has to ferret out and interpret what has happened."* This, we argue, requires intensive scrutiny of the unfolding of events from the natural settings where the phenomenon takes place throughout a reasonably adequate period of time. In any case, the available knowledge about the politics of IS implementation is comparatively limited. No wonder, then, that Keen (1981, p. 32) emphasized that *"we badly need more understanding of these issues."*

Given this status on the understanding of the political conditions around IS projects, we argue that without deeply understanding the full complexity of political phenomena including the various *driving factors*, the different *ways of manifestation*, and also the *resulting outcomes*, it is certainly difficult to understand and address the failure phenomenon completely with a mere focus on socio-technical issues. What is more, the practicality of IS implementation approaches, whatsoever, becomes questionable if they are not comprehensive enough to also actually take political issues into account. Hence, in this thesis we will argue to take up socio-technical and political issues in conjunction rather than in isolation. When these issues are taken up in conjunction, it is possible to clearly identify the actual factors that challenge IS projects and their interrelations, and also to devise working approaches that can comprehensively address the real issues involved. It is thus this need for comprehensive approaches to make systems work practically and in a sustainable manner that served as a driving impetus for us to contribute theoretical approaches and strategies to the practice of HIS development and implementation in developing countries. These approaches and strategies are idiosyncratically constituted in a theoretical framework which we conceptualized by the metaphor of "making it work" (see section 1.4).

> *"A relatively small amount of research has been specifically devoted to addressing the subject of software systems failures."*– Donaldson and Jenkins (2000, p. 4)

From practical point of view, the empirical setting of HIV/AIDS and ART management in developing countries, an area that desperately seeks supporting HISs (RHINO, 2004b), also motivated us to conduct this empirical research and make pragmatic contributions in this area. As discussed in section 1.3, HIV/AIDS and ART management in developing countries, our research domain, is a complex process that calls for the coordination of a large number of initiatives and resources, "high on priority" being the management of information (RHINO, 2004a). The issue of supporting it with ISs is thus becoming a need that is increasingly finding voice (RHINO, 2004d). For example, in the specific developing country context of Ethiopia, the country in which this study is conducted, ART management was performed manually and suffered from numerous informational problems (see chapters 5 and 6). Hence, the need to have a HIS that supports the management of ART in Ethiopia (NHAPCO/FMOH, 2004b; FMOH, 2005) motivated us to make practical contributions in the area.

While making the practical contributions, we wanted to explore the challenges that surround the making work of such system. This is interesting because, although some efforts were previously made to provide the HISs that support HIV/AIDS and ART management in developing countries (Mamlin et al., 2006), the multiple challenges of introducing and making them work efficiently have not been explored and exposed. More specifically, the various facets of implementation politics in the politically charged case of HIV/AIDS management (Nega et al., 2007), which we argue to be key issues in introducing and making work the supporting systems, have not been explicitly discussed in IS research. For example, in our effort to support the Ethiopian ART management with an IS, gaining entry into the field of HIV/AIDS management and carrying out the subsequent intervention actions have been considerably political in addition to being socio-technical (see chapters 6 and 7).

In addition to these theoretical and practical issues, there were some methodological issues that motivated us to carry out this research. As mentioned earlier, politics, the founding building block of our theoretical framework, is known to be a "hard to study" subject that 'involves many hidden agendas' since, naturally, none of the actors involved in politicking would be keen to divulge their political secrets and the dynamics that help them to promote their own ideas and interests (see the view we take on politics in section 1.4). Given that HISs in developing countries are inherently political (Braa et al., 2004b), and that the situation is more magnified in the highly political domain of HIV/AIDS (Nega et al., 2007) we understood that investigating the political phenomena around HIS projects in this field would not be easy. Hence, we were curious to know how actually we could 'ferret out and interpret' such 'hidden agendas', secretes, and dynamics (Keen, 1981, p. 32), and also to investigate and produce comprehensive approaches which would inclusively address the political issues that would surround our project effort.

Hence, our understanding of the lack of comprehensive and practical approaches to make work HISs, the significance of the topic of politics in both the theoretical and practical world of HISs and how poorly it has been understood and addressed in the existing literature in particular in relation with the HISs that support HIV/AIDS and ART management, and the recognized difficulty to study this phenomenon, provide the key motivation for undertaking this thesis topic. Our motivation thus is to contribute to a firmer and broader understanding of the nature of the challenges to practically make work such systems in developing countries, and also of the approaches and strategies to address them. Without thoroughly understanding and addressing the various challenges involved seriously and comprehensively, future efforts to introduce and make work HISs in this area will continue to be claimed by failures, and to yield not so positive outcomes. We argue that these challenges can be deeply understood and addressed through the "making it work" (see section 1.4) perspective and its constituting approaches and strategies (see chapters 2 and 8).

1.2 Research Objectives and Research Problems

- *This thesis investigates **the processes of practically making work ISs**, specifically HISs to support HIV/AIDS management, in developing countries.*
- *Within the theoretical framework we developed of **"Making It Work"**, the thesis takes a **socio-technical-political** perspective in relation to the development and implementation of such systems.*
- *The thesis focuses on the issue of **politics** and its profound impacts on the project studied.*

- *Foundation for our theoretical framework: IS failure and the classic factors identified (socio-technical)*
- *Theoretical consideration: Politics, the major theoretical building block of our perspective.*

- *Research approach: Multi-site longitudinal action research design approach informed by qualitative methods.*

- *Empirical basis: Ongoing action research project to implement a HIS to support ART (antiretroviral therapy) management in Ethiopia.*

With the background and motivation mentioned above, we turn to outlining the specific research aims of this thesis.

The Research Objectives

Given the above briefly mentioned practical condition of HIV/AIDS and ART management in Ethiopia, our research has four overall interrelated objectives. These are:

1. *To understand the workings of the ART initiative in Ethiopia and assess key information related challenges in its management,*
2. *To develop a patient-based ART management database system that helps alleviate these problems,*
3. *To implement the system in pilot clinics and attempt to then scale it up; and,*
4. *To develop an overall understanding of what is actually required to make HIV/AIDS management supporting ISs work in practice within the context of Ethiopia, and draw broader implications.*

The Research Problems

While endeavoring to practically meet the above stated research objectives, we also wanted to explore the following research questions, and try and theoretically build the knowledge on IS implementation.

1. *What does "making it work" mean for ISs to support HIV/AIDS management in Ethiopia?*
2. *What key conditions especially shape the processes of "making it work" in the context of ISs to support ART management in Ethiopia?*
3. *Practically, what are some approaches and specific strategies of "making it work" around ISs to support ART management in Ethiopia?*

The empirical setting for the analysis of these questions is provided by an ongoing action research project to implement a HIS to support ART management in Ethiopia (see section 1.6).

The issue of practically making work HISs in the specific context of HIV/AIDS and ART is thus the focus of this research, in terms of theoretical understanding, and practical and methodological approaches and strategies to deal with them, and also the implications. More specifically, our focus is on understanding the nature of the political conditions around such systems, and also how to try and practically address them. This research is thus expected to contribute not only to the ongoing HISP efforts in Ethiopia, but also more broadly to the research and practices of HIS and IS in developing countries. On a more philosophical note, our research also seeks to respond to the call by Geoff Walsham (2001) to IS researchers to use technology to make our world a better place to live in.

Before describing the various facets and attributes of this thesis, in the next section, we briefly introduce the problem domain area of our research, HIV/AIDS and ART management in developing countries with a focus on some key issues specifically around the Ethiopian ART management. The section will also compare some issues around the information management of HIV/AIDS and ART with those of other diseases and their treatments, and the implications on the supporting HISs. This will provide an additional motivating reason to conduct this research, though from a different perspective.

1.3 HIV/AIDS and ART Management: The Research Domain

The scale of the AIDS crises now outstrips even the worst-case scenarios of a decade ago. More than twenty six years after the world first became aware of AIDS, it is now quite clear that humanity is facing one of the most devastating epidemics in history – one that threatens development in major regions of the world. HIV/AIDS marks a severe development crisis particularly in developing countries and is acting as the single biggest barrier to their development. The future holds the frightening prospect of a much more widespread illness. The epidemic's full effect is obscured by fear, denial, limited treatment and a lack of public health resources. Today, around the world, an estimated 12 000 people are newly infected with HIV everyday. In 2006 alone, AIDS claimed an estimated 2.9 million lives – more than in any previous year – and an estimated 4.3 million people were newly infected with the virus, 530 000 of them being children. To make matters worse, more than 95% of these new infections are in low- and middle-income countries. Overall, in less than two decades, more than 65 million people have contracted HIV globally. Currently, more than 39 million people are infected with HIV (UNAIDS/WHO, 2006). Without effective treatment and care, they too will join the ranks of the more-than-25 million people who have died of AIDS since the first clinical evidence of HIV/AIDS was reported in 1981. By and large, globally, the epidemic continued to expand, reducing world population estimates by 0.4 billion to 8.9 billion for 2050 (Schlagenhauf and Ashraf, 2003). No wonder that it has become a prominent issue at international gatherings.

The devastating figures of people living with HIV/AIDS (PLWHA) along with the prospect of an alarming growth rate (see chapter 4), made fighting the HIV/AIDS pandemic to be both an urgent global and national priority. Given this backdrop, it is not surprising that there exist a number of initiatives and stakeholders towards alleviating and also eradicating the problem particularly in developing countries. For example, HIV/AIDS management in Ethiopia comprises of a multiplicity of programs including ART, PMTCT, TB, VCT, Home-Based Care, ART pharmacy, STI, and OI[*] (see chapter 5). A number of agencies – government, non-government, missionary organizations, international and also private – are in different ways, trying to provide support services to the implementation of these different programs. These different agencies often operate with their own budgets, reporting systems, manpower, and are minimally coordinated with each other, contributing to the proliferation of a plethora of systems.

Despite increased investment in HIV/AIDS-related researches nationally, regionally, and internationally, *"the peculiarities of the HIV virus makes finding a vaccine difficult"* (UNAIDS/WHO, 2002). Thus, alongside the various initiatives to prevent and control the epidemic, the ultimate currently available treatment to reduce and reverse its impacts, as numerous studies have shown (Koenig, Leandre, and Farmer, 2004; Wools-Kaloustian et al., 2005), is antiretroviral treatment (ART), our research background. ART concerns the administration of at least three different medications known as ARV (Antiretroviral) drugs in order to suppress the replication of the HIV virus. Since ARVs are so effective in controlling the virus, and even reducing its level to a point where it is no longer possible to detect it the blood, ART is proved to transform a uniformly fatal disease to what is called a complicated but manageable chronic disease. The successful use of ART considerably boosts the body's immune system, consequently slowing down disease progression and delaying mortality. Thus, while ART is not a cure, it helps to prolong and enhance the quality of life of PLWHA and enable them to lead full and more productive lives (Hogg et al., 1998; Palella et al., 1998; Marins et al., 2003; Koenig, Leandre, and Farmer, 2004; Wools-Kaloustian et al., 2005). For example, in the United States

[*] ART (Antiretroviral Therapy), PMTCT (Prevention from Mother to Child Transmission), VCT (Voluntary Counseling and Testing), STI (Sexually Transmitted Infections), OI (Opportunistic Infections), and TB (Tuberculosis).

and Europe, its use has reduced AIDS deaths by over 70 percent (see more in chapters 4 and 5). In the absence of massively expanded ART efforts, it is expected that the AIDS death toll especially in developing countries will continue to rise. Not surprisingly, ART is now being scaled up globally and in particular in developing countries where the impact of the pandemic is more sever including in Ethiopia (see chapters 4 and 5).

However, unlike the treatments of other diseases such as TB and malaria, the treatment of HIV/AIDS– ART – is quite unique. Once ART is started, the treatment has to be taken for life with a better than 95% adherence to achieve viral suppression; and this is extremely demanding and challenging, as well as being costly. Being a lifelong treatment that requires exceptionally extremely high level of adherence, the management of ART is very complex especially at the level of health facilities in developing countries where the number of clients kept increasing (see chapters 4 and 5) (Hardon et al., 2006). For example, in just one of our research sites (an ART clinic) in Ethiopia, more than 12 000 patients were enrolled. As a matter of mandatory requirement in ART, each of the thousands of patients in one clinic, has to be necessarily visited regularly (at least once a month) and huge amount of follow up information has to be tracked to learn the treatment progress of each individual patient which has to be clearly presented in the next round visit. As a result, in addition to the multiplicity of initiatives, stakeholders, and agencies, the nature of ART made the management of information in this area, our application domain, a very complex and demanding process unlike the case of other diseases and their treatments (see chapters 4, 5 and 8) (RHINO, 2004b). Bearing these peculiarities of the research domain in mind, we wanted to explore how the design, development and implementation of the HISs to support HIV/AIDS and ART management would differ from those of other HISs. This, therefore, provided further motivation to conduct this research in addition to the ones mentioned in section 1.1.

Nevertheless, despite the various efforts to prevent and control HIV/AIDS and also to treat the PLWHA with ART, initiatives to strengthen the information support for the management of this disease and its treatment, has been sadly lacking, even though it is universally recognized that it is an urgent priority (Crawford and Lester, 2004). For example, with regard to ART management in Ethiopia, the specific application domain, the Ethiopian Federal Ministry of Health (FMOH, 2005, p. 23) stated:

> *"All key players need to be informed on the latest development concerning ART. Therefore, a mechanism to disseminate accurate and timely information to these various stakeholders … must be set-up. A well developed information management and communication…becomes a crucial component of the ART program because:*

- *It is a very complex treatment program which is being scaled up very rapidly;*
- *Treatment is to be taken for life and high rate of adherence is expected, allowing no room for supply interruption. Information is thus required over time and is patient specific; …*

Therefore…Strong information management…will serve as a backbone for this program."

Direct implications of this FMOH statement are as follows:

1. *An urgent need for a computerized ART management system;*
2. *The need for patient specific system which can follow the patient over the lifecycle of a long drawn treatment program; and,*
3. *To integrate the ART program with other related interventions (such as PMTCT, VCT etc).*

In addition to this local call, that ART has to be taken for life once it is started and that a virtually perfect adherence is expected is underscored by many researchers. This requires effective patient-based systems to follow up on individual patients, including their drop out and adherence rates. For example, an alarming, but rightly cautionary statement was made by Drs. Robert Gallo and Luc Montagnier, co-discoverers of HIV, at the onset of discussions on making ART available for millions in resource-poor countries (WHO, 2005, p. 5):

"If compliance [adherence] and careful follow-up of patients is not achieved, we will see a dramatic increase in multidrug-resistant HIV mutants whose further spread will only exacerbate the epidemic."

Thus an ART clinic has to make sure, not only that patients are being regularly followed-up but also that they are strictly meeting the required level of adherence. Adherence is an extremely vital issue in ART because a patient not adhering as expected may open room for drug resistant viruses, which has devastating economic and social impacts. Finding an effective patient-based electronic system that can help in managing drop outs and adherence is thus an urgent challenge for many developing countries including Ethiopia. Further, as various countries are desperately going for a "rapid and mass scale-up" of their ART programs so that to be able to enroll more positive cases into the treatment perse (FMOH/NHAPCO, 2005), there is the concurrent need to also scale up their supporting HIS to be able to better track patients over their course of the treatment so as to analyze issues such as drop outs and adherence to treatment. In fact, from our study we have seen that such a system is highly required at all levels of ART management in Ethiopia – health facilities (ART clinics), provinces (called regions), and federal (FMOH, 2005, p. 23) (see chapter 5).

Yet, as mentioned above, despite the alarming increase in the levels of incidence of HIV/AIDS in developing countries, the value of information in strengthening its management has not been explicitly recognized. Typically, conferences around this topic focus on clinical issues or the politics of drugs and pharmaceutical companies, with nearly no discussion on how information can play a vital role in supporting monitoring and treatment. Typically, the routine reports in many developing countries for example, as seen in Ethiopia, India, and South Africa, the countries where we have been in the course of our research (see section 1.6 and chapter 3), dominantly contain cursory information on how many patients were counseled for HIV/AIDS or referred for treatment, and these statistics are rarely used for supporting disease management. Given this setting, it is not surprising that the supporting HISs are consequently deprived of attention. Yet, by and large, facts on the ground (see chapter 6 and 8) clearly show that HIV/AIDS and ART management demands supporting electronic HIS with solid reasons to justify the desperate need for such systems in many developing countries (RHINO, 2004a). For example, as mentioned earlier, our investigation in Ethiopia showed the prevalence of numerous serious problems that arose from the absence of such systems (see chapter 6).

Still, there are limited examples we have seen or read about of efficiently working patient specific information systems around HIV/AIDS and ART management, which is a matter of urgent concern. One interesting example in this regard concerns a system called OpenMRS (www.openmrs.org) which is an open source electronic medical record (EMR) system for developing countries focusing primarily on managing information to facilitate treatment and management of patients with HIV infection (Mamlin and Biondich, 2005). The core application of this system was originally developed from the AMPATH medical record system (AMRS) implemented in Eldoret, Kenya and, since then, it has been implemented for HIV and TB patient and treatment management in Kenya, Rwanda and South Africa. Several other pilot implementations are still being developed or tested in some developing country contexts, notably in Lesotho, Malawi, South Africa, Tanzania, Uganda and Zambia (Mamlin et al., 2006; Mamlin and Biondich, 2005; Siika et al., 2005; Allen et al., 2006). Thus, there are such limited efforts around the HISs to support HIV/AIDS and ART management.

In addition to the limitedness of the efforts to provide efficient HISs in this area, as mentioned previously, the various issues that challenge the efforts to introduce and practically make work such systems in the context of developing countries, the subject of this thesis, were not explored. However, this should have been interesting given the fact that failure stories are prevalent around such systems. For example, in our investigation of the situation in Ethiopia, the respondents at various healthcare administration levels have told us that there had been repeated experiences of HIS failures around ART management, our analytical focus. Further, as indicated by the following quotes which were taken including from the (American) *President's Emergency Plan for AIDS Relief (PEPFAR) Software Inventory Report*, there are lamentations about the availability and suitability of such systems, and also about duplication of efforts around them:

> *"We have identified several types of software suitable for HIV care and treatment and programs in resource-constrained settings. All of these software packages fall into the general category of Routine Health Information Systems (RHIS), i.e. systems designed to collect information as a part of the routine operation of health care facilities as services are provided"* (RHINO, 2004b, p. 3).

> *"Why not purchase a system or adopt an existing open-source system? While several open-source EMRs were available … these systems either fell short of our requirement to serve both clinical and research needs – i.e., to collect non-ambiguous, coded data – or were not easily adaptable to our setting"* (Mamlin and Biondich, 2005, p. 3).

> *"The number of ART software programs that can be … used to provide chronic HIV/AIDS care has increased rapidly in recent years. … At the same time, this rapid expansion in the availability of ART software has resulted in confusion and uncertainty for those responsible for selecting and deploying these software tools"* (RHINO, 2004d, p. 4).

Given the particularities of ART management and the accompanying complexity of the information management, and also the involvement of various initiatives and stakeholders including various donors, we thought the duplication of efforts and the associated lamentations can have some implications. This provides the ground for us to explicitly investigate the challenges of designing and deploying such systems. Further, though political scientists have paid little attention to the politics of epidemics, the scenery of HIV/AIDS management in developing countries, a platform for avalanches of parities, provides further impetus to carry out such investigations. HIV/AIDS management in developing countries is especially embedded in a political quagmire created from the pandemic nature of the disease, the reality of death and poverty associated with it, the huge amounts of donor funds being pumped into the treatment of the disease, and the multiplicity of actors that have jumped on to the disease bandwagon including donors, NGOs[*], researchers, politicians and medical specialists, and various stakeholders (Nega et al., 2007). Clearly, in developing and implementing systems to support the management of this disease, negotiating this political quagmire is crucial, and is no trivial task. For example, as mentioned above, we needed to continually go through such an intensely political landscape throughout our effort to make the project work. These topics, which are rarely explicitly discussed in contemporary HIS research, are discussed in this thesis which seeks to address some of these gaps in the literature. In the theoretical chapter (2), we will provide more elaborate discussions on the theoretical issues we considered in our study as they have been treated in the literature, more

[*] NGO (Non-Government Organizations)

broadly in IS research, and more specifically within the context of HIS in developing countries. This will provide the basis for the "making it work" theoretical perspective we adopt in this thesis. In the next section, we provide an overview of our theoretical consideration to guide our research investigation.

In general, as an acknowledgement of the urgent need for patient-based systems, especially those under ART, we wanted to take up this research which revolves around the efforts of design, development and implementation of an "Integrated HIV/AIDS Management System" (IHAMS) with ART as its initial focus. This initial focus thus had to be amenable to scaling (both geographically and functionally) so that it could support the scaling of the ART perse, and also the overall integration and coordination of the comprehensive HIV/AIDS management in the country. Overall, this effort will provide us the basis to meet the research objectives and also to address the research problems mentioned above, thus enabling us accomplish our tasks from theoretical, methodological, and practical fronts.

Having presented our research motivation and the domain area of the research, we now turn to describing the different facets of this thesis including overviews of the theoretical considerations, the research methods, and the empirical basis.

1.4 Overview of the Theoretical Considerations

Theoretically, we consider issues of politics to be matters of serious concern and at most importance in shaping IS implementation, and take a *socio-technical-political* perspective in HIS project endeavors. This will enable us to view the issues that challenge HIS projects in a broader, comprehensive and more holistic manner than what is allowed through a more traditional socio-technical lens of IS which is often dominantly adopted in contemporary IS researches.

Basically, our view on the matter of IS implementation politics is theoretically built on the more general and classical issue of organizational politics which has been adopted by researchers from various disciplines, and constitutes concepts that have evolved through time in a way that they become the primary component of contemporary business practices. Accordingly, the view that we take on politics is that it is a self serving and manipulative behavior played to promote self interests. It is also a process involving many facets that can be manifested through tactics like struggle for resources and also through influencing others to better achieve goals in the domain where the politicking is practiced. Further, it can occur at individual, group, organizational, or inter-organizational levels with resulting outcomes including conflicts, and thus seeks to involve resolution mechanisms like coalition building (Drory, 1993; Drory and Romm, 1991).

Issues of politics in shaping IS implementation have been a common theme underlying classical IS researches which mainly described ISs to have political side especially in a more general sense that they can threaten the interests of actors by intruding territory, and limiting autonomy and influence (Kling, 1978; Keen, 1981; Markus, 1981; Markus, 1983). Political perspectives also represent contemporary thinking within HIS researches, though they were dominantly made with a focus on macro-level issues such as national political arrangements and situations (Braa et al., 2004b; Mursu et al., 2000), and also with respect to the nature and structure of the healthcare sector itself especially in developing countries (Nhampossa et al., 2004; Williamson et al., 2001; Braa et al., 2004b; Alvarez, 2004).

We argue that the HIS studied in this thesis, the IS to support HIV/AIDS and ART management in the specific developing country of Ethiopia, reflects distinctive political characteristics in addition to the socio-technical ones. These political characteristics largely emanated from the political quagmire mentioned above in which HIV/AIDS and ART management is embedded. Hence, while not leaving aside the above mentioned views on the politics of IS in general and HIS in particular, we articulate the scope of politics around the systems in our project to embrace and be complicated by a combination of particular *driving factors or root causes.* It is also magnified by the distinctive and complex tactics and schemes through which the actors *manifest* and realize their politics which results in *outcome* of the systems' being contentious pieces, thus demanding distinctive approaches and strategies to deal with and address. Hence, as our main focus in this thesis, we significantly conceptualize such systems as political artifacts, and are thus better understood through such a theoretical lens as contrasted to traditional IS research concepts that typically relate ISs to be socio-technical endeavors.

Yet, the systems studied in our project also importantly involve socio-technical issues. For example, in our effort to design and develop the HIS that supports ART management in Ethiopia, we found some design issues, the kind of the technology adopted itself, and its features to have considerable implications in making the system work. As mentioned previously, we also identified issues such as exaggerated expectations of users and their past experience with ISs, multiplicity of stakeholders involved, workload, and scarcity of resources to have similar impacts. Therefore, we broadly perceive the efforts around such systems as *socio-technical-political* since they are composed of heterogeneous socio-technical and political components (such as hardware and software, health workers at various levels, government bodies, administrative structures, work practices, administrative rules and bureaucracies, and various actors including donors and other stakeholders with different and divided agendas and interests). Having shifted our perception from *socio-technical* to *socio-technical-political,* we argue that the socio-technical-political issues surrounding our project and also other HIS and IS efforts in developing countries can be deeply understood and better analyzed through the concepts constituted in the "making it work" theoretical framework which this thesis adopts (see chapter 2). Further, as they were in our project, we also argue that such issues can be comprehensively addressed by the approaches and strategies that the perspective adopted distinctively constitutes (see chapter 8). The "making it work" philosophy and the various activities, approaches and strategies it constitutes will be incrementally discussed in detail in chapters 2 and 8. At this point, suffice it to provide a very brief overview of this paradigm.

The "making it work" perspective views IS projects, particularly HIS project like ours, in developing countries as efforts that involve various socio-technical-political issues that present challenges of multiple forms which may be too chronic and time taking to address easily and quickly. For example, the political situations surrounding our project sustained throughout the ongoing intervention and research efforts. The approach thus emphasizes firstly the need to identify and then deal with the various socio-technical issues that shape implementation outcomes which include the material features of the technology, the key actors involved and the nature of the roles they play, and also the various organizational conditions within which a system is implemented and needs to be adapted to and persevere in. It also seeks to be engaged in all the activities that need to be performed from initiating the IS to sustaining it in developing countries' settings. More specifically, the "making it work" perspective takes into account the political nature of such systems which, as mentioned earlier, can significantly be conceptualized as political objects. The perspective thus emphasizes the paramount importance of looking at implementation not just in the technical sense, but also the various political conditions that may impede or enable the system providing real benefits to the stakeholders. Overall, it requires the engagement in the various only steadily but continually addressable dilemmas surrounding these efforts, such as the building of political relationships and the technical system itself, and in embedding and making the system work institutionally. This necessarily involves dealing with both micro- and macro-level interconnected challenges and addressing them with envisioned prolonged efforts. Further, "making it work" emphasizes the interrelationship of socio-technical and political issues in implementation endeavors.

To help deal with and comprehensively address the various socio-technical-political issues surrounding IS projects, the "making it work" perspective yields some approaches and strategies (see chapter 8). More specifically, it underscores the importance of dealing with political conditions by effectively seizing and exploiting such conditions as opportunities. Hence, while not taking for granted the glitch side of certain kinds of political conditions, the approach stresses the exploitation of 'favorable winds of politics' (Williams, 2003, p. 13) to introduce and make work ISs effectively, and thus emphasizes the particular significant roles of politics in making the systems work. Traditional, and often discrete and procedural, approaches of IS projects usually focus merely on specific momentary socio-technical challenges to yield only partial and limited success in implementation efforts, and thus lack the strength to actually penetrate the numerous types of challenges that pop up in the course of the project, for example the political ones. In contrast, ***the "making it work" paradigm stretches the scope of practically making work HISs in developing countries to include the addressing, with prolonged effort, of the complex and multifaceted socio-technical-political challenges comprehensively, systematically, steadily, and continuously in the full spectrum of the project processes.*** This is so especially in the specific context of the HIS to support ART management which is a life time or chronic treatment that requires a supporting HIS which seeks chronic support. Without taking socio-technical-political issues together and performing all the important activities required in the entire continuum of such projects, we argue, a form of failure will claim the system sooner or later at some point in the trajectory of the project, resulting in the wasting of the resources already invested.

Viewing IS projects from the entire socio-technical-political perspective is thus far from seeing them merely as socio-technical, as often is the case, and implies the need to progressively and incessantly address these heterogeneous and longitudinal processes (which inscribe political conditions) comprehensively, thoroughly and scientifically, and with anticipated prolonged efforts. The various processes and conditions around IS projects in developing countries, such as the political ones, have to be addressed gradually but persistently while being understanding and sensitive to the difficulties and complexities inherent in them. In summary, the concepts in "making it work" serve dual purposes by firstly providing us with analytical leverage that allows us to develop a broader and more holistic understanding of the issues that challenge IS projects in developing countries, and also of how they can be addressed in practical settings. Secondly, the activities, approaches, and strategies constituted in this philosophy help us to practically address the multifaceted socio-technical-political issues comprehensively and successfully. In chapter 8, we will discuss how the multiple facets of "making it work" were effectively adopted in our project effort, and also the implications for other HIS and IS efforts in developing countries.

In the following section, we summarize the research methods adopted in this study.

1.5 Overview of the Research Methods

The research reported in this thesis was conducted in a team of two researchers, the authors of this thesis. We joined the HISP team in August 2005 when we were recruited to attend the Masters program at the Informatics Department of the University of Oslo. Since then, we have been working together under the framework of the global HISP, including in the efforts to improve the pre-existing situation of ART management in Ethiopia. In this thesis, we report from these experiences. We now briefly describe the research design, methodology, and approach we adopted.

Since our research focus was firstly to develop a thorough understanding of the challenges around the processes of practically making work the HISs to support HIV/AIDS and ART management in Ethiopia, and secondly, to try and address these challenges, we adopted a multi-site longitudinal action research design approach. Within the action research framework approach, the research was mainly informed by a qualitative methodology. We were directly engaged in the different processes of the research around the multiple sites in Addis Ababa and in some sites in SNNPR. But we have also attempted to exert similar efforts in yet other regions – Amhara, Benishanguel-Gumuz, Oromia, and Somali. Some Masters and Doctoral students under the umbrella of the global HISP were also engaged in similar attempts in some of these regions (see chapter 3), and these attempts have some contributions and implications in our study (see chapters 7 and 8).

The multi-site design of the research was very helpful firstly to understand deeply and in a local and context specific manner what constitutes the challenges of making work the systems in question. Secondly, this design was useful to compare issues and identify similarities and differences so as to develop a broader understanding of what contextual influences do actually contribute to the different research processes. In addition to the multiplicity of the research sites, we benefited from the learning obtained from the attempts made by the other research participants (see chapter 3) such as the ones mentioned earlier which actually fed into the design process to make the product more robust.

The qualitative methodology employed in this research was in line with the socio-technical-political perspective we take on in IS project endeavors where the technology is embedded in a web comprised of heterogeneous socio-technical-political components including people, organizations, practices, artifacts, socio-political relationships, and technologies. The various particular methods we adopted (see chapter 3) had specific contributions in helping us understand the web of these various socio-technical-political relationships (and how they were changing over time) from the perspective of the various actors involved in and surrounding our project– individuals, groups, organizations, and various stakeholders. Developing this situated understanding, especially of political issues, would have been largely not possible through quantitative approaches which comprise of surveys with a focus on measurement and hypothesis testing.

Since our focus was not only on understanding but also on introducing and influencing practical changes as per our research objectives stated earlier, we adopted an action research approach. Such an approach is in line with the broader HISP approach globally, within which this research is based, which has been descried as “networks of actions” (Braa, Sahay and Monteiro, 2003). This approach focuses on system development and implementation, reflecting on interventions which aim to support the sharing of learning and experiences, ideas, and artifacts, both within and across countries in the network. Drawing upon and adapting this approach to our particular setting, from within the country, we benefited from the experiences of the local HISP team, and also the links they already established with the health departments in the regions we worked with and attempted to (see chapter 6), and from the reputations of their efforts. From across countries, we also benefited from the experiences of the various IT professionals, medical doctors, public health specialists, and HIS experts. For example, through these networks, we built our own capacity in various facets of the problem domain including learning the technologies we adopted in our project, and also understanding different public health issues such as the terminologies used in the ART paper formats. Thus, the “networks of action” that we were concerned with includes the processes of gaining both technical and non-technical support.

By and large, the multi-site research design where other researchers also participated, the qualitative methodology adopted with multiple specific methods, and the longitudinal nature of the action research approach employed mutually helped us intensively scrutinize the various issues that enveloped the processes of practically making work our project.

In the following section, we describe issues that constituted the empirical basis for our research.

1.6 Overview of the Empirical Basis

The fieldwork for this ongoing longitudinal research actually started in February 2006. The empirical setting for the analysis of the research problems of this thesis was mainly provided by the action research project to design, develop, implement, scale up, and sustain a HIS to support ART management in Ethiopia. We began the field work by conducting a broader preliminary assessment and situation analysis of HIV/AIDS management in Ethiopia. In doing so, we needed to repeatedly visit the various HIV/AIDS-related initiatives, and stakeholders, and regional health bureaus in the country. In particular, with a focus on Addis Ababa, we worked with the regional health bureau and the ART clinics it subordinates. During the fieldwork, we had interactions with the various officials at the macro-levels including the staff members of the different initiatives and stakeholders including the donor agencies, and also at the federal level. We specifically interacted with the staff of the Addis regional health bureau especially with the regional HIV/AIDS program manager and the bureau’s IT team.

Yet, since our focus was on ART management, we made our interactions with the staff members of the ART clinics – including doctors, nurses, and the more micro-level workers such as data clerks –even more intensive and extended. This was partly necessitated by the absence of useful documentation on ART management. Before our intervention, there was no supporting electronic IS in any of the clinics where we have been which exposed the different processes of the clinics to the various problems in the manual system. During the situation analysis, we focused on the processes of data collection, processing, and analysis. Adopting Free and Open Source Software (FOSS) technologies, we initially developed a supporting HIS called IHAMS-ART, implemented and scaled it up specifically in some clinics in the Addis region as per a MOU we (HISP-Ethiopia) signed with the regional health bureau, and we are attempting to make it work in these clinics. It is primarily based on this empirical setting, and also by navigating the various processes around these efforts that we are reporting in this thesis.

However, the opportunities provided by us being masters students and conducting the research in the HISP action research framework took us to South Africa (twice) and India. This provided new directions in our HIS development trajectories where we started to develop a flexible and customizable IHAMS called Debo which is ongoing. These exposures helped us compare some issues across countries, and hence form the empirical basis.

1.7 Expected Contributions of the Thesis

This thesis seeks to contribute to the theoretical, practical, and methodological knowledge concerning the processes of practically making work HIS in developing countries, with a focus on HISs to support HIV/AIDS and ART management in Ethiopia.

More specifically, through the theoretical framework of "making it work" we contribute theoretically by developing a deeper understanding of the challenges of practically making work ISs in developing countries. These challenges have been identified by contemporary research dominantly as being socio-technical. Our thesis contributes to this gap in theoretical knowledge by more specifically arguing that HISs are political artifacts and that the issues that challenge the processes of practically making work such systems are not only socio-technical but they are fundamentally *socio-technical-political.* Thus, by unpacking the complexities associated with these interrelated triple issues, we make theoretical contributions as to what it really seeks to make a system work practically, and also as to what key conditions especially tend to shape the processes of making it work. More specifically, we contribute some distinctive *driving factors and root* causes, *ways of manifestations*, and *resulting outcomes* that would magnify and complicate the scope of politics around the HISs that support HIV/AIDS and ART management. The various activities, approaches and strategies idiosyncratically constituted in "making it work" that would help comprehensively address socio-technical-political issues constitute the theoretical contributions of this thesis. Practically, we argue that effectively addressing the triple issues can significantly contribute to successfully making work efficient HISs that can support HIV/AIDS management in Ethiopia, and more broadly ISs in developing countries. We thus needed to demonstrate this pragmatically and by delivering a tangible system that would support the information management of ART in Ethiopia. Methodologically, we argue that the adoption of a longitudinal multi-site action research informed by multiple qualitative methods helps to scrutinize and ferret out political phenomena and their dynamics effectively, and also the interrelated socio-technical-political ones at large.

Table 1.1 summarizes the major features of this study.

Major Study Attributes	Brief Descriptions
Research Background	*HIV/AIDS and ART*
The Research Problem Domain Area	*HIV/AIDS and ART management*
Major Research focus/issue **(Research Problem)**	*The Processes of practically making work HISs to support HIV/AIDS management*
Foundation for our Theoretical Framework	*HIS failure is rampant in developing countries. Issues often associated to this phenomenon have been dominantly socio-technical.*
Theoretical Consideration **(The major building block of our theoretical framework)**	*Politics is a matter of serious concern and at most importance in IS implementation in developing countries.*
Our Theoretical Framework	***"Making It Work"***
Our Major Theoretical Perspectives	• ***ISs are political artifacts*** • *IS development and implementation is a **socio-technical-political** endeavor, not just socio-technical* • ***"Making It Work" and the roles of Politics in "Making It Work"***
Major Empirical Basis: The Specific Study Context, Application Domain and Analytical Focus	*ART management in Ethiopia*
Major Research Objectives	*Develop, implement, scale up, and make work an ART management HIS in Ethiopia*
Research Approach Adopted	*Multi-site longitudinal action research design approach informed by qualitative methods*
Types of Expected Research Contributions	*Theoretical, methodological, and practical*

Table 1.1: Overview of the research attributes

1.8 Structure of the Document

Having introduced the various facets of the thesis including the research questions, objectives, and the statement of the research problem, we now turn to describing the way the rest of the thesis document is organized by presenting the specific focus and roles of each chapter, and also some of its features.

In the next chapter (2), we make a review of literature by presenting the theoretical perspectives that constitute the foundation for our theoretical framework of "making it work". The research approach is presented in the third chapter. In chapter 4, we present the research background of HIV/AIDS and ART and their particularities over other diseases and their treatments, and also the information management implications. In chapter 5, we present the research settings in Ethiopia including the situation of HIV/AIDS management, our research domain, and in particular ART management, our specific research context, application domain, and analytical focus. We then go to describing the concrete research activities which we have broadly organized in two chapters. The first part is presented in chapter 6 where we focus on the situation analysis of HIV/AIDS and ART management in Ethiopia, the challenges we encountered when attempting to conduct it, and the strategies we adopted to deal with them. The second part is presented in chapter 7 where, based on the situation analysis in particular of the Ethiopian ART management, we focus on our action research intervention efforts including the attempts to design, develop, implement, scale up, sustain, and make work the supporting HIS (IHAMS-ART). The chapter also presents the various challenges we came across around these processes, and also the approaches and strategies we adopted to deal with them. In chapter 8, we present the analysis and discussion of the empirical material by drawing up on the theoretical issues and concepts articulated in chapter 2, and position our findings within some of the broader debates in the IS literature relating to making systems work. Finally, the last chapter (9) presents some brief concluding remarks including the contributions of the thesis, and identifies some areas of further research.

Each of the chapters starts with a brief introduction which includes descriptions of its structure. Attempt is made to summarize points at each important section of a chapter. In some places tables are used including to summarizing points. Many figures are used in this document including the photographs taken by us during fieldwork. Several graphs also needed to be incorporated. The tables, figures, and, graphs are labeled with captions. Some quotes which we obtained including from research papers and our respondents were kept indented and *italicized*. When quotes and some points seem to us more interesting, we have kept them in boxes. More importantly, using the timeline in the research methods chapter (3), we have attempted to depict chronologically the major events and opportunities seized in the course of our study. The table accompanying the timeline in that chapter complements the timeline by offsetting it with timescale and some details. So when discussions seek to take time and duration into account, please refer to the timeline and this table so as to grasp the full context of the discussion.

2 Literature Review and Proposed Theoretical Framework

"Information systems have the potential to become a political … battleground" – Bull (2003, p. 2)

2.1 Introduction

This chapter makes a review of literature and the underlying theoretical perspectives that drove our empirical efforts, and help to analyze our findings and the accompanying interpretations. The chapter focuses on discussions around basic issues and concepts under the theme of *"Making It Work"* in relation to IS development and implementation in the context of developing countries. We first present some socio-technical issues commonly identified in the IS literature on why systems do not work, and tend to get categorized as "failures". However, in view of the empirical material from our project, we especially focus on issues of *politics* and its profound impact specifically on HIS projects, and frame the discussion within a *socio-technical-political* perspective. With a focus on the roles of politics, we then turn to describe the philosophy behind, and what is idiosyncratically contained in our notion of "making it work" that would help avert the failures. After articulating here key issues and concepts relevant to our study, in chapter 8 we will draw upon them to analyze our empirical efforts and show the applications of "making it work" on the project studied – the HIS to support HIV/AIDS management, specifically related to ART management, in Ethiopia, and also its implications. The chapter, therefore, concludes with a proposed theoretical framework to help the analysis of the empirical efforts.

The rest of the chapter is divided into four main sections. Section 2.2 lays the foundation of our "making it work" perspective. Section 2.3 stresses our argument on the key but relatively neglected impacts of politics on IS implementation and presents, in particular, the different facets of HIS implementation politics. In section 2.4, we elaborate on our perspective of "making it work" and its socio-technical-political implications. A key focus in this discussion is the role of politics, which is positioned as an important theoretical building block. Finally, in section 2.5, we summarize the key issues and concepts that we will use as the analytical framework for our empirical material.

2.2 Failure Stories and Archetype Factors Identified - The Foundation to Our Perspective

Failure of IS projects is not breaking news today. However, the study of such projects reveals new factors and opportunities for analysis and guidance on how to approach future IS development and implementation efforts. This factor of learning from failures assumes a high level of significance in the context of developing countries where it is very important that scarce resources revolving around an IS are optimally utilized. Given this, we discuss some key aspects of IS failures identified in the literature.

Failure Stories – How Abundant?

"For every documented success, there seems to be a clutch of failures." – (Keen, 1994, p. 1)
"It appears that the set of all successful [hospital information systems] is only slightly larger than the null set, and these have usually been developed at academic centers." – (Rosenal et al., 1995, p. 554)

IS failure is a complex phenomenon that is difficult to define. Since 1970, there have been a number of efforts to adequately define the concept (Beyonon-Davies, 1999). Further, the term IS failure itself is influecned by the perception of people who are involved in it (Jiang et al., 1999; Keil et al., 2000; Peterson et al., 2002; Poon and Wagner, 2001). While a group of researchers may perceive the notion of "failure" as termination of an IS due to unbearable accumulation of flaws, others consider the same notion as the inability of an IS to meet its stakeholders' expectations (Beyonon-Davies, 1999). Accordingly, coping with an IS failure seeks behaving differently based on the kind of failure expected to happen if left unaddressed. Broadly, Heeks et al. (1999, p. 2) identified four main forms of IS failure:

- ***Total Failure:*** the situation in which a system is unimplemented or, if implemented, is abandoned immediately such as because of leaving the users incapable of serving clients as required.
- ***Partial Failure:*** failure of the initiative to attain the major goals or, emergence of undesirable outcomes such as implementing beyond schedule or incurring costs more than expected.
- ***Sustainability Failure – a sort of partial failure (Heeks, 2002):*** failure of the initiative that succeeds initially – made to be fully operational and to achieve some partial use – but then gets switched off after a year or so due to, for example, limited enthusiasm from staff for using them.
- ***Replication Failure:*** failure of the initiative which succeeds in its pilot location but can not be replicated elsewhere despite being with wonderful innovations.

Whatever the form, IS failure is rampant. Historically, IS projects have generally been characterized by high failure rates. News papers and industry publications are rife with horror stories outlining huge debacles that cost businesses and governments literarily billions of dolloars on an annual basis. Collecting results of five different surveys from different years, i.e., 2001, 1997, and 1995, a recent report (www.it-cortex.com) concluded that: (1) an IS project is more likely to be unsuccessful than successful, (2) only about 1 out of 5 of such projects is likely to bring full satisfaction, (3) the larger the project, the more likely the failure, and that (4) 40% of the projects failed to achieve their business case within one year of going live. In general, as Keen (1994, p. 1) stated, *"for every documented success, there seems to be a clutch of failures."* True, there are of course a large number of reported implementation success stories from around the world. But many of these stories are believed to be "painting a falsely-positive picture" (Heeks et al., 1999), as the evidence points to a significant majority of IS initiatives being failures (Korac-Boisvert and Kouzmin, 1995; James, 1997; Heeks and Davies 1999).

There also exists similar evidence that many ISs in the area of health, our broader application domain, are failures. Heeks et al. (1999, p. 2) noted that *"there is …plenty of specific evidence that many – even most – health care information systems are failures."* Anderson (1997, p. 90) also mentioned of "studies that indicate half of all computer-based information systems" in this area to be failures. As indicated by Dodd and Fortune (1995), quite many electronic patient record initiatives have failed so that systems in the US "still consist largely of paper records" (Anderson, 1997, p. 89). Emphasizing this for hospital information systems, Rosenal et al. (1995, p. 554) stated: *"It appears that the set of all successful [hospital information systems] is only slightly larger than the null set, and these have usually been developed at academic centers."*

IS failures result in many undesirable consequences and losses. With respect to HIS, Pare and Elam (1998, p. 331) stated: *"Research shows that many health care institutions have consumed huge amounts of money and frustrated countless people in wasted efforts to implement information systems."* In addition to funds, failures can drain an organization of people and vitality. System failures also affect the organizations and individuals involved, directly or indirectly.

> *"IS failure is ... a very real and very practical problem for developing countries that needs to be addressed"* – (Heeks, 2002, p. 4)

Failure stories are especially common in the peculiar environment of the developing world (Heeks et al., 1999; Avgerou and Walsham, 2000), the region on which the discussions in this thesis principally focus. In the first place, this region, especially Sub-Saharan Africa, is regarded as the poorest and technologically least developed area globally due to inheritance of insecurity and antidemocratic governance initiated by slave trade and colonial occupation (Korpela, 1996; Mursu et al. 2000). An overview of the literature related to this region concludes that "successful examples of computerization can be found ... but frustrating stories of systems which failed to fulfill their initial promise are more frequent" (Avgerou and Walsham, 2000, p. 1). It is evident from this body of literature that a substantial portion of total IS projects in these countries ends up as full or partial failures. General results of IS failures in developing countries were reported by researchers. Recently, for instance, after conducting an investigation of e-government projects in these countries, the results of Heeks (2003a, 2003b) survey presented an extremely disappointing position: 35% are total failures, 50% are partial failures, and only15% are successes. However, similar reports also position failure to be the dominant theme in individual developing countries.

For instance, Puri et al (2000) reported of India's Indira Gandhi Conservation Monitoring Centre which was intended to be a national information provider of environmental ISs. However, despite a year of planning, analysis and design work, these ISs never became operational, and the whole initiative collapsed shortly afterwards – a "total failure" (Heeks, 2002, p. 2). Also, Kitiyadisai (2000) reported of the Tax Computerization Project in Thailand's Revenue Department which set out seven areas of taxation that were to be computerized. At the end of the project, only two areas had been partly computerized and five others were not operational. Kitiyadisai also noted that in public sector IS initiative failure cases seem to be "the norm" in Thailand at all governmental levels. Similarly, Heeks and Baark (1999) found that all donor-funded projects in China were partial failures. Concerning Africa as a whole, Moussa and Schware (1992) concluded that almost all World Bank-funded projects in the continent were partial failures.

Examples are especially available regarding the "relatively clear type of partial failure", sustainability failure, which "particularly seems to affect developing countries" (Heeks, 2002, p. 2). An instance in point is the creation of a set of touch-screen kiosks for remote rural communities in South Africa's North-West Province which were initially received by the communities. Less than a year later, however, the kiosks lacked updated or local content and also lacked interactivity which led to disuse and their subsequent close down (Benjamin, 2001). In the context of HIS, Braa and Hedberg (2000) have reported widespread partial HIS failures of high costs in South Africa. Kimaro and Nhampossa (2005, p. 273) have generalized it saying, "most of donor-supported ... projects developed or implemented in less-developed economies ... end up as complete or partial failure or unsustainable."

"The lack of sustainability of working information systems in developing countries is striking." – Braa et al. (2004, p. 359)

In summary, *"IS failure is ... a very real and very practical problem for developing countries that needs to be addressed"* (Heeks, 2002, p. 4), with severe adverse implications on the use of scarce resources. The opportunity costs in this sphere of the world are especially high because of the more limited availability of resources such as capital and skilled manpower. What is more, as Heeks (2002, p. 4) argued, *"the failures keep developing countries on the wrong side of the digital divide, turning ICTs into a technology of global inequality."* Therefore, it is not surprising that IS failure in developing countries is a significant area of research (Nauman et al., 2005). The study of failure stories provide an important site for learning and future action, sometimes even more than what successful projects provide. Successful projects, the ones applauded and then rapidly taken for granted as they deliver their promised benefits owe much of their success to the learning derived from past failures. With that in mind, we discuss some typical failure factors identified in the literature which provides the basis for the articulation of our "making it work" perspective.

Archetype IS Failure Factors

Various factors contributing to IS failures have been identified in the literature (Stokes, 1995; Boehm, 1996; Sauer, 1993), including: problems around requirements elicitation, insufficient resources, human intervention, and a host of others further broken down by their categories and sub-categories etc. to an interesting granularity. What might have gone wrong can involve poor planning, the type of technology adopted and lack of adequate techniques, or incomplete, ambiguous and inconsistent specifications – requirements drift. Thus failure causes are many, complex, and they may interact with one another. In some cases, a single factor may spell out the problem whereas in others a combination of many perhaps small and apparently insignificant factors are to be blamed. It should also be noted that while the reasons for failures are various, they are not always what might have been expected. Hence any analysis has to also take into account those factors which might not at first seem to be connected, or remotely connected with the system in question.

At times, issues of project definition introduce problems at the very beginning (Field, 1997). The scope of a project may not be visualized by all of the stakeholders which influence the system analysts to overlook or not fully understand the requirements of different users. On the other hand, the users' high expectations about the system or project can cause a project to fail (Leicht, 2003). Lack of alignment between a client organization and IT professionals is one of the leading causes of IS project failures (Hoffman, 2003). External problems like procurement, management continuity and optimistic estimations of benefits can also cause project failure (Hulme, 1997). Usually, all these factors exist in a particular project to a certain extent and, at certain threshold, they can interact and further escalate the challenges. Furthermore, a source of trouble can be the varying and often conflicting interests of the different stakeholders involved.

Attempts to investigate failure factors in developing countries are limited. Lack of evaluation resources and the focus on case studies of individual IS projects are mentioned to be particular reasons for the paucity of literature in this area (Heeks, 2002). That is because, if taken alone, a single case study may not provide us insights into the extent of the broader and common nature of the problems involved. Post-hoc rationalization of reasons for failure based on key individuals provides a sanitized and rather one-sided picture of the problems. Nevertheless, there is more than enough evidence supporting the idea that failure rates in the developing world are higher than those of the industrialized ones (Heeks, 2002).

In the specific context of health, lack of infrastructure – technical, physical, and communication (Kenny, 2000; Walsham, 2000) – is a dominant reason for failure of HISs in developing countries. For example, a project was initiated to install an integrated hospital information system for 42 hospitals in Limpopo, South Africa, one of the most deprived and poorest provinces in the country. IBM was awarded the contract for implementation at a cost of 134m Rand (nearly £14m) which represented 25% of the province's health and welfare annual budget. It was intended to improve communal access to patient information and management of hospitals by developing new methods of indexing and tracking patients, regulating appointments, and reporting results. Each hospital was meant to have its own server to manage its own data, which would be sent to a central location. However, the initiative failed due to various reasons including ineffective training and poor responses to technical concerns. Moreover, the organizers of the program found that the users, while instructed thoroughly on how to use the new tools, did not understand why they should. Further, failure to take account of health care cultures, the developers' underestimation of the complexity of healthcare processes, and failure to look for and learn from lessons from past projects were also identified as reasons for the failure of this ambitious and expensive project (Littlejohns et al., 2003).

Research experience in Ethiopia, the country in which this study was conducted, have identified various challenges to successfully implement a district-based statistical HIS called DHIS. From their experience to implement the system in two provinces (called regions) in the country, Addis Ababa and Oromia, Mekonnen and Lagebo (2005) identified many challenges to this effort. The challenges included lack of national level involvement, inadequate public health inputs into the project implementation team, contextual differences in the health systems (of South Africa and Ethiopia where the former was the country from where the software was transferred), differences in organizational structure and functional requirements, and also infrastructural problems. Similarly, in a study of implementing the same system in another region (Tigray), Damitew and Gebreyesus (2005) identified problems including fragmented data flows, high staff turnover and low capacity, and centralized information processing. Furthermore, Braa et al. (2004b, p. 355) pointed out that *"an insufficient supply of technically competent people, in addition to reshuffling of staff at the Ministry of health that cut HISP off, made it difficult to sustain"* the project around DHIS in Ethiopia.

Although the magnitude and nature of conditions that shape HIS projects in individual developing countries tend to be different, some issues are commonly involved including: (1) inadequate infrastructure of different forms (Kenny, 2000; Walsham, 2000), (2) shortage of skilled personnel and inadequate human resource capacity (Walsham et al, 1988), (3) inappropriate system development and implementation strategies (Heeks, 2002; Heeks et al, 2000), and (4) fragmented donor policies (Lippeveld et al., 2000; Chilundo and Aanestad, 2003). Various specific bottlenecks have also been identified including lack of well trained IT professionals; inappropriate or weak culture of using computer based information (Bhatnagar, 1992; Walsham, et al., 1988); the structure of the health system in a particular country, top-down, centralized, and fragmented; lack of coordination and sharing of resources; (Avgerou and Walsham, 2001; Chilundo and Aanestad, 2003); poor quality of information, limited focus on the use of information for action, lack of an overall information strategy, and complex organizational context (Gladwin, et al., 2003; Braa and Blobel, 2003; Kimaro and Nhampossa, 2004); and lack of national IT policy and the prevalence of an unsupportive public sector culture (Korpela, 1996; Kimaro and Nhampossa, 2005). The above list reflects the diversity of the failure problem.

Failures also tend to be socially constructed and may become more difficult to identify as identification may wrestle with subjectivity. Some stakeholders may deem a project to be a failure while others deem it to be a success. This is true also in the developed world. For example, Donaldson and Jenkins (2000) spoke of one United Kingdom Government project which was presented in a very positive light of a particular system is provided on an official web-site, while Hansard (the official record of proceedings in the House of Lord and in the House of Commons) tells a different story. There is always this element of subjectivity in evaluation based on varying interests of who is telling the story. As Heeks (2002, p.

2) says, *"one may see the success of an initiative in which most stakeholder groups attain their major goals and do not experience significant undesirable outcomes."* Yet, this scenario requires the multiple stakeholders to all perceive the system to have brought benefits to their works which, in turn, requires a "relatively sophisticated approach that is absent in many cases" (p. 2).

Furthermore, taking the factors such as lack of resources and infrastructures as given and leaving them aside, other factors related to system development and implementation can contribute to failures. For example, Heeks argues "design-reality gaps", when systems developed in the West are attempted to be unproblematically transferred to the developing world, to have caused plenty of IS failures (Heeks et al., 1999; Heeks, 2002). Likewise, concerns the development and implementation approaches including the degree to which system users are involved in an IS project (Terry and Standing, 2003), and the different roles the local actors play. Really then, the causes for IS failure are many and various, and for the projects to succeed, it seeks to successfully address them accordingly.

Yet, as mentioned in the introduction chapter, despite the abundance of graceful descriptions of IS failures (Lucas, 1975; Lyytinen and HIrschheim, 1987; and Sauer, 1993), practical approaches to averting failures and making things work are in short supply (Donaldson and Jenkins, 2000). Also, while IS researchers have thus far been emphasizing the aforementioned dominantly socio-technical archetype factors behind failures, the political dimension of IS implementation, which we argue to be an essentially key issue in point, has been given inadequate attention (Keen, 1981; Markus, 1983; Sanunders and Scamell, 1986; Cavaye and Christianse, 1996). In fact, some specific aspects of this interesting phenomenon, we argue, especially remain rarely explored. For example, while often condemned as mere impediments, the issue of how political conditions may be exploited as opportunities to make ISs work has not been discerned enough (Keen, 1981). In trying to address this important gap, in the next section, we first discuss how politics, the founding building block of our theoretical framework, is a matter of serious concern in IS projects. Then, we argue for the conceptualization of ISs as political artifacts, and frame our discussion within a *socio-technical-political* perspective. The subsequent section will then focus on the subject of comprehensively addressing these issues and making the systems practically work in the context of developing countries.

2.3 Politics in IS Implementation

> *"The simple, central argument … is that information system development is political as well as, sometimes far more so than, technical nature. When that is accepted, the organizational mechanisms follow naturally."* – (Keen, 1981, p. 28, 31)

IS development and implementation has traditionally been perceived to be a singularly rational or a politically neutral process. For example, those subscribing to the functionalist approach believe that issues in the development of IS are based on technical rather than socio-political issues, a view that has been severely criticized (Knights and Murray, 1994; Markus, 1983). Actually, many definitions of IS failure often assume that ISs are neutral and do not adequately portray the full complexity of IS failure explicitly as a combination of technological and socio-political issues (Heeks et al., 1999). Nevertheless, the evidence that ISs are importantly a political as well as socio-technical processes is considerable (Keen, 1981; Silince and Mouakket, 1998). In fact, while on the surface various IS failures may appear to be related to technical issues, a significant number of them can be distilled down to one common denominator – politics. We now elaborate on this issue of politics.

A Word about Politics – What it Involves

Though a survey of the literature on organizational politics reveals a lack of consensus among authors on a definition of this term (Drory and Romm, 1990), organizational politics has been discussed by researchers from various disciplines over the last two decades. The concepts and perceptions of organizational politics have thus evolved during the 1990's and are considered to be a primary component in contemporary business practices, including matters of IS implementation. Basically, organizational politics refers to *"behaviors that occur on an informal basis within an organization and involve intentional acts of influence"* (Drory, 1993, p. 59). In an attempt to synthesize the literature on organizational politics, Drory and Romm (1991) have provided a more neutral conceptual framework of political behavior, and conceived it as a combination of influence attempts, conflicts, and informal means. Further, decomposing it to various granularities of occurrence, they also distinguished politicking at the individual, group, organizational and inter-organizational levels, and introduced the idea of coalition building. Politics is thus the self serving and manipulative behavior of individuals and groups to promote interests sometimes even at the expense of organizational goals and benefits. It is manifested in various ways including through struggle for resources, conflicts, competition for power etc.

Apparently, politics is an inescapable reality so intrinsically woven with organizational systems that relationships, processes, performances, and outcomes are hugely influenced and affected by it. It is a specific quality of organizational dynamics which impacts all aspects of business life. Yet politics has been only marginally explored in IS research, despite its significant implications. Even so, initiated by the pioneering work of Kling (1978) and Markus (1981; 1983), the topic of IS implementation politics is tending to become an important issues in IS research. For instance, further extending this pioneering research, Romm and Pliskin (1998; 1999) have studied the implications of politics in computer-mediated communication.

How Politics is an Issue in IS Projects

Further in his work, Kling (1980) provided a scheme to examine theories accounting for people's resistance to the introduction and implementation of computer-based ISs. Organizational politics was one of the six distinct theories he identified. Based on Kling's work, Markus's (1983) seminal article helped to emphasize the role of power and politics in shaping IS implementation. She proposed a political variation of interaction theory to try and understand the issue of IS implementation resistance. Applying the above perspective of organizational politics to e-mail, Romm and Pliskin (1998) have demonstrated how ISs can be drawn upon for political purposes in an organizational context. The issue of politics is also gaining prominence in the specific context of HIS in developing countries. For instance, the political nature of HIS design and implementation was discussed by Puri et al. (2004) in the context of India, South Africa and Mozambique, and also by Byrne (2004) in relation to community based IS in South Africa. Similar messages were echoed by other researchers in different healthcare contexts (see for example, Chilundo and Aanestad, 2003; Mosse, 2004; Nhampossa, 2006). These studies have reinforced the assertion of Markus and Robey (1983; 1988) that politics is an important determinant of IS implementation outcomes – success or failures.

Political factors contribute to the problem of successfully implementing IS solutions in organizations which, by definition, are political entities. Government organizations in developing countries have a distinctive political character being largely bureaucratic in nature and filled often with counter-productive procedures, rules, and regulations which lead to conflict of interests and subjective interpretation of rules. There are individuals and groups, both internal and external to the organization, who exert influence on the direction of IS projects. While some motives are rational, logical, and put forth with the best of intentions, others are irrational, emotional and often incomprehensible. There are also times when IS projects become political pawns as project champions spar for limited resources. In any case, the impact of politics on IS project is significant. As Williams (2003, p. 13-14) noted:

> *"Political influences are analogous to the wind with IT projects being like ships on the high seas. With favorable winds and calm seas, the project will travel far and fast. IT managers must beware if the winds change direction, however. The political winds can change direction well after the IT project has left port. Political pressures can destroy morale, cause funding to dry up, and simply crush a project in short order."*

Clearly, as political influences have tremendous impact on IS projects, many failures may be directly attributed to the political environment in which the projects are born and forced to exist. Most commonly, factors such as a lack of top management involvement and support are mentioned as reasons for IS failures. But these reasons are like leaves on the tree of organizational factors. They are not the root of the problem but merely symptoms. Digging deep enough and reviewing the subject thoroughly the root cause could be related to politics. We have not found research providing figures or rates of IS failures specifically in relation to political reasons, even though a significant amount of success and failures of IS projects can undoubtedly be attributed to political situations. Hence, it is crucial to explicitly consider politics as an important issue in IS implementation endeavors.

Diversity of Political Ideologies

Politics is not of one type but reflects divergent ideologies relating to ISs. For instance, what is termed as the negative theory of IS politics is associated with many strands of oppositional politics and is often characterized by counter-resistance. In the negative ethos, actors are said to oppose and counter IS implementations if they perceive them to result in the domination of their interests (Morgan, 1997). The issue of counter-implementation is classically developed by three theories of resistance (Markus, 1983). One of these, the interaction theory of resistance, occurs where systems fundamentally change cultural norms, roles or the balance of power within an organization. The theory has been drawn upon and further developed in subsequent IS research (for example, Broadbent et al., 1991).

Other theories have also been proposed. For instance, Marxist theory is sometimes extended to view ISs as a conflicting political arena contested by the existence of distinct classes and the inequalities of power and influence between such groups. For example, whilst evidence from a case study research of two CADCAM system implementations support elements of Marxist theory, they also reveal that such behavior is not inevitable or the only cause of conflict (Tantoush and Clegg, 2001). Further, the positive theory of IS could be viewed as fairly accommodating to political activity in ISs because of the value it places on open dialogue in order to effectively establish and interpret the true nature of contentious or problematic issues. On the other hand, the neutral ethos supports the view that political issues in ISs are inevitable and therefore need to be addressed, though it is critical of the positive and negative theories because of their attempts to predetermine such complexities. Nevertheless, "classifying political theories is problematic and it is inevitable that many can be criticized for their deterministic tendencies or countered by alternative perspectives and findings," stated Bull (2003, p. 3). As for Keen (1981) and Markus (1983), the real value and purpose of examining the politics of ISs is to broaden our understanding of political issues in order to try and attempt to predict and prevent failure.

Whatever the case, the issue of IS implementation politics is not only gaining momentum but also involving a range of important and complex issues, and it has evolved from the literature on the relationship between information and power which has a fairly long tradition (Wilensky, 1967; Pettigrew, 1972; Greenberger et al., 1976). Studies have emphasized the link between access or control of information and the preservation or advancing of organizational power (Standing and Standing, 1998). In fact, some studies have gone to the extent of cautioning that naive actors in political situations can be seriously disadvantaged (Franz and Robey, 1984). In view of this, it is not surprising that politics around IS implementation has become a recurring theme. In this thesis, we thus argue for the conceptualization of ISs as a political object.

Why an IS becomes a Political Artifact

Information systems have a political dimension for various reasons including because of their potential to induce change in respect of issues such as organizational relationships, influence, access, authority and control. Implementing an IS thus necessarily involves many disputes often resulting in irreconcilable differences between actors. Keen (1981, p. 27-28) observed that IS implementation may *"threaten the interests of individuals and groups by intruding on their territory, limiting their autonomy, reducing their influence, or adding to their workload."* ISs are social systems and their design, implementation, and use inevitably involve dynamic political processes in articulating interests, building alliances and struggling over outcomes. Rightly then, Bull (2003, p. 2) has noted:

> *"Information systems have the potential to become a political ... battleground."* – (Bull, 2003, p. 3)

> *"Information systems have the potential to become a political and tactical battleground where individuals or groups perceive such processes as non-rational or against their interests, thus they seek to counter or undermine projects by trying to divert resources or deflect its goals."*

This is especially so in the specific context of HIS in developing countries which is inherently political. For instance, in a recent research which they explored in the context of their HISP conducted in a number of developing countries including Ethiopia, Braa et al. (2004b, p. 357) have emphasized:

> *"The health care sector in developing countries is intrinsically political. It circles around the inherent scarcity of resources and involves a number of actors with different agendas such as … health activists, non-governmental organizations, vendors, consultants, and politicians."*

Following this, as it will provide the political setting of our domain of application, we discuss why in particular a HIS becomes a political piece.

Facets of HIS Implementation Politics

The various facets of politics around HIS implementation in developing countries may be unpacked within the category of macro- and micro-level factors, and their interconnections. At the macro-level, as the above quote indicates, we find the healthcare sector itself to be essentially political. That the sector consumes larger, and in some cases the largest (David, 2005), share of a given country's economy evidently contributes to making the area even political. Besides this, more macro-level issues can also have political impact on this sector. For instance, Mursu et al. (2000) discussed that the political situation in Nigeria – turbulence and civil unrest, poor governance, and corruption – have pressed the health sector and contributed to creating difficulty to the use of IT in the area. Taken together, all the pressures on the health sector, in turn, in one way or another inject a political dimension to HIS implementation attempts.

Further, national political arrangements and structures can challenge certain HIS implementation approaches. For instance, in a number of developing countries, HISP has been engaged in developing decentralized HISs following participatory approaches. However, when it comes to Cuba, stated Braa et al. (2004b), "it has proven to be more difficult to apply participatory approaches and a local focus in the centralized and politically controlled organizational setting in Cuba, with poor tradition for local improvisation, than in the other countries in the HISP-network" (p. 53) In this situation where there is little local autonomy, "central political support is of outmost importance" (p. 60) in order to get anything done at the micro-levels. Without clear orders from the level above, there is not much hope to get support from people on the next power level and mature a successful project. On the contrary, in our implementation attempts in Ethiopia where federalism is exercised (see chapter 5) providing autonomy to local regions, our project enjoyed a measure of benefits from the arrangement. In fact, the regional autonomy served as an important basis to securing the support of the more micro-level individuals (see chapters 6 and 7).

This does not, however, mean that one political structure is perfectly favorable over the others for HIS efforts to succeed. For instance, the actions of HISP around DHIS which it provided for free to some regions in Ethiopia were officially made to be halted with a circulated letter by the federal ministry which bypassed the authority of regions, thus freezing the regional autonomy. The federal decision was enforced without having an immediately replacing system, and also despite the uptake of the DHIS at the regional, district, and more micro-levels which had been using the system for years. In an informal discussion with the research team, a vendor who won the bid to sell the software that would replace DHIS said *"HISP has developed an excellently efficient system. So with only little modification of this open source software itself, we are winning the bid. …The only problem with HISP was that it could not win the politics."* In any case, political structures of a country can certainly breathe out devastating political spirits to HIS efforts. For example, Braa et al. (2004b) mentioned of the then (July 2002) drastic political change in Cuba where the health minister who supported HISP lost his job evaporating the support. This left HISP revoked and officially shut down its project without any clear explanation from the official who took the position, indicating that the continuance of HIS projects in such countries is largely contingent on the existing political party on the throne and on the goodwill and support of the officials ordained (Braa et al., 2004b).

Having a form of the national political structure, going a level lower, we find the structure of the health sector itself affecting HIS efforts. These structures, which are not entirely divorced from national political structures, are often fragmented and centralized (Nhampossa et al., 2004; Williamson et al., 2001; Braa et al., 2004b; Alvarez, 2004). Drawing from international experiences from the HISP network, Braa et al. (2004b) emphasized that the health sector in developing countries is characterized by fragmentation between different health programs, departments, and that multiple levels exist with different interests and agenda. The consequence is that, when attempting to introduce a piece of HIS, multiple rather diverse participants are involved to politicize the effort (Braa et al., 2004b).

The health area in developing countries is especially proliferated by donors who exercise excessive influence over health units (Gladwin et al., 2003). For both technical and financial resources developing countries have become dependent on these donors. For example, 80% of the budget for the health sector in Mozambique used to come from international aid (Nhampossa et al., 2004). Yet, the uncoordinated structure of the health programs in these countries gave them room to practice their interests in the promise of improving health systems and national benefits, though the lure of such promises is magnified given the existing inefficiencies and failures. Donors are also heavily engaged in politicking, perhaps lying at the nucleus of it, and influencing health official often in a manner that is seen as detrimental to the interests of the recipient country governments at the national and state levels. For example, with regard to the termination of DHIS in Ethiopia mentioned above, a health worker whom we interviewed concerning our project exemplified issues to us saying:

> *"I see the sole reason to be corruption. A very good example for me is the experience of HISP around DHIS. HISP was given just a month to incorporate all the ministry's requirements into the DHIS. I read circulated the letter myself. There were many things they listed down the system to have. Unless they have a hidden motive, how do they think that all these requirements could be incorporated in just a month? DHIS has been used for years and there was no other system in the country readily available to replace it. How can they give a dismissal letter to HISP without first having a working system, perhaps a better one? …As for me, it is not the ministry who wrote the letter. They were definitely influenced. It is Tulane University [an influential donor affiliated with the ministry] who wrote it."*

Clearly, some sense of, sometimes hidden, political agenda is often embedded in the efforts of the initiatives – agendas and interests typically inscribed into the strategies – and these may be diverging, conflicting, competing, or dominating with the efforts of others. And this may block the political support one seeks to secure from the most influential health officials for genuine efforts. Moreover, when approaching the healthcare sector in developing countries, donors typically follow a top down approach where people at the bottom level are systematically excluded from negotiation and decision making processes during the design and implementation of the systems. "This approach creates an environment where by the ownership and control of the project rests with the top level managers and donors, leading to a situation where the users rarely gain control over the technology they ultimately are expected to use" (Kimaro and Nhampossa, 2004, p. 1). Further, in their HIS projects which may take a long time to be fully institutionalized, they often support relatively on short term basis and give poor focus to the building of local capacity (Lungo and Twaakyondo, 2006) which, had it been built, would support the projects after their withdrawal. Yet, none of these approaches help to sustain and make the HISs work. Actually, "the risk of failure of donor supported IS project is very high making sustainability a challenging task" (Kimaro and Nhampossa, 2004, p. 2).

Some health programs like HIV/AIDS in developing countries are exceptionally invaded by donors who are key vehicles through which ISs are introduced in these counties (Kimaro and Nhampossa, 2004). Yet, these actors compete to derive huge monetary benefits by supplying an IS in demand. For example, from their attempt to introduce DHIS in Mozambique, Braa et al. (2004b, p. 357) stated:

> *"The competition between a number of actors representing different strategies and agendas has made it difficult to align the network and develop a coherent strategy based on relative consensus and to achieve sufficient political support. In particular, the competition with the ambitious, costly HIS initiative driven by a major, international vendor proved problematic. Even without establishing funding for this initiative, the surrounding network of supporters both in political and health administrative circles ... blocked further support for HISP."*

Actors may thus be 'threatened' by an IS as they feel their 'territory is intruded limiting their autonomy and reducing their influence' (Keen, 1981). In this complicated terrain of donors, one is viewed as a fierce rival and hence seeks to display a sort of distinctive competence to penetrate the severe animosity and gain entry. Also, having scores of divided and often uncooperative actors in the field of implementation, the HIS takes on a fundamentally political character.

> *Some aspects of politics are "the single most important cause of counter-implementation…Information system development is political as well as, sometimes far more so than, technical nature."* – (Keen, 1981, p. 28, 31)

In short, politics is a very real issue around IS projects, and, if left untreated, it has a very practical impact in implementation endeavors. Keen (1981, p. 28, 31) identified some aspects of politics as *"the single most important cause of counter-implementation in information systems development."* He also emphasized that *"the simple, central argument …is that information system development is political as well as, sometimes far more so than, technical nature. When that is accepted, the organizational mechanisms follow naturally."* Clearly then, IS implementation is not merely a socio-technical endeavor as often emphasized in IS literature but it is a socio-technical-political one. Without addressing political conditions surrounding IS projects, we argue, not only it is difficult to make the systems practically work, but also chances of failure are magnified.

Still, as mentioned in chapter 1, literature on the issue of politics in IS development and implementation has continued to be relatively limited (Bull, 2003; Gladwin et al., 2003) primarily because politics is "hard to study" and "to ferret out and interpret" from what is happening around. Keen (1981, p. 31, 32) observed:

> *"There has been few studies of the political aspects of information systems development. The topic is rarely discussed in textbooks and even the literature on tactical implementation deals with it only peripherally. Yet when one tries to reconstruct or observe the progress of any major project, this is an obvious and important feature. It is absurd to ignore it or treat it as somehow*

> *an unsuitable subject for study …There is some fragmented research available …Most of this work is based on case studies. "*

This message was echoed decades later (Bull, 2003) indicating the persistence of the situation. Thus, we need more understanding of political issues and their impacts on IS implementation since having more researches in this respect *"can immensely add to our understanding both of the implications of information technology and the dynamics of effective implementation"* (Keen, 1981, p. 32). True, as mentioned above, researchers have discussed some aspects of political issues around IS implementation, for example in the area of health. But, very important specific dimensions of such politics still remain largely unexplored. As mentioned in chapter 1, this includes the roles and interests of key actors, the implications of the technology itself, and also the approaches to adopt the technology to a specific environment. Further, the particular political challenges in the highly political domain of HIV/AIDS, our application domain and analytical focus, has to our knowledge not been explicitly discussed in IS research. In this thesis, through our empirical and theoretical work, we will be exploring especially the issue of politics and its particularities in the design, development, implementation, scaling, and sustaining of an IS to support ART management in the specific developing country context of Ethiopia (see chapters 6-8).

In summary, the success of IS projects in general, and that of HIS in particular, in developing countries has been challenged by various socio-technical-political conditions that made failures of different forms to be a dominant phenomenon in these countries. Yet, although some strategies have been identified by researchers to address some specific socio-technical obstructions, not enough attention has been given to practical approaches to make the projects work in practice including politically. Keeping politics in perspective as an issue *"of fundamental importance"* in IS implementation (Keen, 1981, p. 32) and based on our empirical effort, we now suggest an approach to address socio-technical-political issues in a comprehensive manner and make such projects successfully work.

2.4 Beyond Failures: *"Making It Work"*

Different strategies of system development and implementation have been described in the literature including relating to procedural suggestions covering various activities as in the SDLC (System Development Life Cycle). Such strategies prescribe the implementation of specific standardized methodologies which are based on traditional engineering disciplines. Traditional well founded engineering disciplines have developed successful management practices over a long time. But software systems have only been developed during the last half of the twentieth century and their real culture is still immature and relatively unexplored (Bach, 2000). Hence, such strategies are perceived to be more rigorous, predictable, academic, and do not take into consideration local needs, priorities, and realities (Nhampossa et al., 2004). More important, they do not take into account the various difficulties in developing countries within which a system is implemented and is expected to be adapted to.

True, some generic conclusions have been drawn about successful approaches to IS development and implementation in such situations. However, while discrete approaches may help address a specific challenge in an IS project, the real issue that challenge the project may not actually be single and short lived. In fact, in the context of developing countries, the challenges often take multiple forms that can be too chronic and time taking to address with traditional and discrete approaches. For example, the greater use of participative approach is seen to be effective in HIS projects in developing countries (Braa et al., 2004b) as they may help to reduce or overcome some specific challenges such as drifts in requirements and may contribute to the technical effectiveness of a system. Yet, when taken alone, they lack the strength to penetrate especially the complex socio-political conditions through which an IS project seeks to persevere. Thus, they provide only partial and limited success in the trajectory of a project, and may lead it to be ultimately exposed failure. To cope with such scenarios, we stretch beyond failures and propose a shift to a comprehensive approach which we called “making it work” and found practical in the course of our empirical efforts. Following this, we succinctly describe the scope of this approach, the key principles behind it, and its particularities.

2.4.1 *“Making It Work”:* A Paradigm to Achieve

The guiding principle behind the approach of “making it work” encompasses all the activities that seek to be performed from initiating an IS to following it up in order to ensure it keeps being used and sustained in developing countries’ settings. Rather than adopting universal, procedural and more generic strategies, this requires recognition of situation-specific contextual factors and organizational conditions which have remarkable impacts in determining the outcomes of an IS project. It also requires the engagement in the various only steadily but continually addressable dilemmas surrounding IS development and implementation efforts such as the building of political relations, and also the focus on the real challenges of how the system is made to work institutionally.

Held in the “making it work” paradigm, therefore, is the need to deal with various socio-technical issues that shape IS implementation outcomes. Granted, socio-technical perspective has been increasingly acknowledged including in early and influential approaches though important limitations were identified in these approaches. For instance, the web model (Kling and Scacchi, 1982), an important first step in the development of a socio-technical perspective, has been applied in various technology mediated settings such as in the work of Braa and Nermunkh (1997) who used the model to unpack the problems of improving HISs in Mongolia. Nevertheless, it was criticized for being rather static and of taking the context as given (Sahay and Walsham, 1996). Therefore, the approach of "making it work" emphasizes that in a real attempt to make ISs practically work, there is a need to analyze the role of organizational context. It also underscores the importance of identifying various organizational issues (such as top management support) and human factors (such as user acceptance) that influence IS implementation. Further, earlier socio-technical perspectives such as the structuration theory (Giddens, 1984) have black boxed the technology and did not take it "seriously", and have failed to adequately describe how some elements of a technology affect organizations (Hanseth and Monteiro, 1995). As a practical approach to succeed in IS implementation, "making it work" recognizes the fact that technology has material features which can constrain or enable social actions. In fact, some specific features of an IS, for example the way it is designed and the kind of technologies adopted, relate to organizational issues and hence have significant impact in shaping implementation.

Beyond this, the approach of "making it work" also emphasizes the paramount importance of looking at implementation not just in the technical sense as it is traditionally done, but also the various political and institutional conditions that may impede or enable the system providing real benefits to the stakeholders. For example, from our attempt to introduce and make work the ART management system in Ethiopia, we have identified political conditions that are created both at the micro and macro organizational levels to be important issues affecting implementation efforts. Therefore in the effort to make the system work, we needed to gradually but continually address the political conditions surrounding the project. Further, "making it work" emphasizes the interrelationship of socio-technical and political issues in implementation endeavors.

In short, it is this broad and comprehensive approach of addressing *socio-technical-political* issues from incepting an IS to sustaining it that is captured by us under the principle of "making it work". This necessarily involves dealing with both micro- and macro-level interconnected challenges and addressing them with envisioned prolonged efforts. Without taking these issues together and performing all the important activities in the entire spectrum of an IS project, we argue, a form of failure will claim the system sooner or later at some point in the trajectory of the project. Following this, as an important theme of this thesis, we especially focus on the particular significance of politics in "making it work".

2.4.2 *The Roles of Politics in "Making It Work"*

The mere mention of politics may invoke negative thought from most individuals. Politics has also been perceived in IS literature as purely detrimental. Keen (1981, p. 31) noted:

> *"Unfortunately, "politics" have been equated with evil, corruption and, worst of all, blasphemy."*

> *"Politics are the process of getting commitment, or building support, or creating momentum for change; they are inevitable"* – (Keen, 1981, p. 31).

Granted, as discussed in section 2.3, political conditions can be stumbling blocks that hamper IS implementation. Nevertheless, given the fact that politics is an inescapable and intrinsic reality woven to implementation processes, attempts should be made to search out opportunities which, when effectively seized, would support these processes. Exploited this way, we argue, political conditions can play practical roles to make IS sensibly work. As Keen (1981) noted, *"politics are the process of getting commitment, or building support, or creating momentum for change; they are inevitable"* (p. 31). In fact, without averting political conditions to play such roles in favor of an implementation endeavor, it is difficult to introduce and make work particularly health information systems. For example, Braa et al. (2004b, p. 357) have argued that "to make health information more visible and accessible … is often in conflict with the agendas of vested interests that prefer to keep the problem invisible." This then requires the building of a kind of counter-network (Castells, 2000), to try and counter the mainstream power dynamics originating through donor funding and big money vendor interests. In discussing how political strategies to counter these political influences can be made effective, Braa et al. (2004b) argued:

> *"Dealing with the politics of health networks requires strategies that are reasonably open-ended, which encourage improvised action." (p. 357).*

This, in effect, requires dealing with the complex and constantly changing political, institutional, and cultural configurations at various levels of the health care structure, a challenge which researchers need also to take up. The role and involvement of researchers in these countries is, therefore, far from being simplistic and singular – it "has to mirror the variety in the type of actions" (Braa et al., ibid). Given this political nature of the health sector, it requires researchers to establish a measure of alignment and secure the official mandate of the health department in power, and try and mobilize their support and resources. The authors go on to argue:

> *"The delivery of primary health care services is a task mandated by the official health authorities, so a minimum of support is required—or needs to be mobilized—to legitimize any change. … To tip a political controversy in your favor, it is necessary to mobilize your network to gain sufficient support." (p. 355).*

Researchers working in this domain thus need to take power into consideration and gain official support, and then play multiple roles required to make the IS work. In her proposal of the political variation of interaction theory to try and understand the issue of resistance, Markus (1983) argued: "*The best prescriptions for an implementation strategy and for the specific design content of a system will follow from a thorough diagnosis of the organizational setting in which the system will be used" (p.441).* With this, and in support with the advise of Braa et al. (2004b) stated above to "develop strategies which are reasonably open-ended, which encourage improvised action," we argue the need to fully understand and be integrated with the local realities and micro-level practices of people in the ground who are engaged with the everyday work around the HIS. It is through these practices that the more macro-level political structures are constituted, for example, the development of alliances with the national ministries and donor agencies. Without having a grounding in the practices on the ground, we argue, it is difficult to have a firm base to develop political legitimacy and make the systems work. In a similar although within a more theoretical vein, inspired by Structuration theory, Orlikowski (2000) has argued for adopting a "practice turn" in IS studies. This turn concerns the focus on practices and how they are constituted in structures. In our case, the focus is on the practices around the making work of the ART system and their role in the constituting of political structures.

In summary, while still not underestimating the hitch side of certain kinds of political conditions, the "making it work" approach stresses the exploitation of 'favorable winds of politics' (Williams, 2003, p. 13) to introduce and make work ISs effectively. Based on our effort to implement the IS that supports HIV/AIDS management in Ethiopia, in chapter 8 we will discuss the major approaches and activities constituted in "making it work". We will also discuss the specific strategies we adopted to exploit political conditions and make our project work politically, and also the implications.

In the next section, based on the above discussions, we propose our theoretical framework to analyze the issues of systematically addressing socio-technical-political issues and making ISs practically work.

2.5 Proposed Theoretical Framework

By way of building upon the literature we have just reviewed, we articulate here the key principles underlying our theoretical framework and summarize important issues and concepts that will serve us as analytical framework for our empirical effort.

First of all, we acknowledge that ISs in developing countries, particularly HISs, comprise of heterogeneous socio-technical components including health workers, donors, multiple stakeholders and health programs, work practices, and the systems themselves. So in an effort to successfully implement a system in this situation, there is a need to wrestle with multiple issues surrounding such elements which are deeply embedded in specific contextual conditions. Hence, we attribute IS failures to a series of several unaddressed socio-technical issues, and not necessarily to a single factor. Secondly, we conceptualize ISs to have a political side. HIS projects especially in the domain of particularly politically charged cases such as HIV/AIDS can have a potential to become a political agenda, 'a political battleground' (Bull, 2003). Thus, we sensitize political issues to be matters of serious concern in determining the success or failure of such projects in developing countries. Therefore, in an attempt to make systems work in practice, there is a need to exert prolonged effort in the entire spectrum of the project and comprehensively address these socio-technical-political issues that significantly challenge the processes of system development and implementation.

With these background principles, our theoretical perspective to understand and practically materialize our aim of "making it work" has three key interrelated facets. The first is the need to understand the political nature of implementation processes particularly around HISs as well as the multiple socio-technical challenges surrounding these processes. The second is the need to be deeply integrated and rooted with the local realities and micro-level practices on the ground – practices through which the more macro-level political structures are constituted – and also to deal with micro-and macro-level interconnected challenges. To go along with this is the focus on the opportunities (and challenges) that are created through political and institutional conditions, and how these can be used to embed new practices rather than impeding the system from providing real benefits to the stakeholders. The third concerns the focus on the issues of making the system and its outputs seen useful by the actors themselves, and making it become organizationally useful. These three facets have the potential to mutually support one other, reflecting a structurational logic, and provide the basis for the development of a counter network that has been alluded to more generally by Castells (2000), and attempted to be operationalized by Mosse and Sahay (2003) in the context of the health sector in Mozambique.

In summary, these will help us to theoretically conceptualize IS projects as socio-technical-political endeavors, to identify the multifaceted challenges of developing and implementing the ISs, and also to provide guidance on how to address these interconnected challenges and make the systems practically work. These are the aims of the thesis as articulated in the chapter 1. By navigating the various issues around our ART system development and implementation efforts in Ethiopia, in the *Analysis and Discussions* chapter (8), we will describe how the comprehensive approach of “making it work” has been applied in the project, and also how it may be adopted to address the issues that surround and challenge IS implementation endeavors in developing countries.

After this elaboration of our theoretical basis, we turn to describing the methods used to conduct our empirical research.

3 Research Methods

3.1 Introduction

This chapter presents discussions on the various methods employed in this study to try and address our research aims. The discussions include descriptions on the methodology, approach, design, data collection methods, and data analysis techniques used in the research. Further, we introduce the research team, the different research participants and informants, and some key events that shaped the research trajectory including both opportunities and challenges. For example, as mentioned in chapter 1, the opportunities provided by us being masters students and conducting the research in the HISP action research framework took us to South Africa (twice) and India which provided new directions in our IS development trajectories. Also, challenges arising from the political climate within which this research was conducted, gave us insights into the dynamics of IS implementation to the extent that none of our class room education did.

The chapter is organized as follows. Section 3.3 introduces the research team and section 3.4 further expands this discussion by describing the roles that other participants played in the research. Section 3.5 describes how various choices were made in the research processes including the selection of the research domain area and the technologies employed. The research methodology, the research approach, and research design are respectively presented in sections 3.6, 3.7, and 3.8. This is followed by presentations of the actual data collection methods (section 3.9) and data analysis techniques (section 3.10) employed. In the next section (3.2), we first provide an overview of how we tried to meet our research aims which provides a backdrop to the subsequent discussions.

3.2 How We Endeavored to Meet Our Research Aims

This ongoing* research which actually began in February 2006 (see the timeline on Figure 3.5 and Table 3.2 under section 3.8) falls under the framework of a *longitudinal action research* approach where *qualitative* methodology was adopted in *multi-site* design. In its course, we have moved towards meeting the research aims outlined in chapter 1 firstly by conducting a preliminary assessment of the

* Though the intervention efforts were ongoing at the time of writing, we restrict the research reported in this thesis to be based only on what happened from February 2006, the time when the research actually began, to end of August 2007.

management of the broader HIV/AIDS program in Ethiopia. To that end, we visited various regional health bureaus and multiple HIV/AIDS initiatives, analyzed relevant documents, and discussed with key stakeholders knowledgeable about the domain especially about the ART (Antiretroviral Treatment) initiative. Discussing more broadly on relevant issues with medical doctors of public health background, and also with some of the global and local HISP team members helped us further develop our understanding of the issues. This preliminary assessment emphasized how the multiple programs in the Ethiopian HIV/AIDS management are interconnected, and the need to examine the ART initiative within this broader context, and also how various issues impinge upon the broader issue of practically making work a HIS to support the management of this initiative.

Secondly, we tried to meet our aims through more focused and systematic investigations of the needs, requirements, practices, and workings of the ART initiative in Ethiopia, our specific study context and application domain. We also attempted to compare and contrast the Ethiopian requirements with those of Indian and South African. In Ethiopia, we performed the investigations by being in the field particularly in Addis Ababa and SNNPR regions. In India and South Africa, our understanding was built more second hand through discussions with some relevant people (see section 3.4), and also aided by about a two months visit of both of us in each of these countries. We also had a chance to visit one of the ART clinics (at the Tshwane District Hospital in Pretoria) in South Africa. Our discussions with the researchers from India and South Africa primarily revolved around the ART data capturing and reporting formats from these countries. These discussions and visits were useful, as they provided us with understanding of some key similarities and differences across the countries particularly with regard to the information management of the ART initiatives, and also how this would affect the design, development, deployment, and making work of the supporting HIS.

Thirdly, we have tried to meet our research objective of improving the pre-existing situation of ART management in Ethiopia by carrying out various action research interventions including the design and development of a supporting HIS. Initially, we wanted to design this system in such a way that it would be functionally scalable to an eventually Integrated HIV/AIDS Management System (IHAMS) by also linking up the remaining initiatives in the HIV/AIDS program, and not to remain as ART specific. However, as we kept working on it beginning from a prototype and iteratively adding on more functionalities based on ad hoc requirements of users (as there was no proper documentation), the design slowly evolved in a manner which made it not sufficiently malleable to mold into shape. As a result, especially after our first visit to South Africa where we further evaluated the system with some researchers, we initiated a simultaneous process of developing another system with the aim of making a transition to this one in the future. While the first system, which was hard-coded to meet specifically the Ethiopian ART requirements, is referred to as IHAMS-ART[#], the second is called Debo[*]. Unlike IHAMS-ART, Debo was visualized as a flexible and customizable system designed in such a way that it will ultimately integrate the entire management of HIV/AIDS in developing countries including Ethiopia, India, and South Africa. The core of Debo was put in place by us and a research participant form South Africa (see section 3.4), and it is currently under development by an international development team. Nevertheless, we limit discussions in this thesis to revolve around IHAMS-ART except in a few cases where Debo needs to be brought into the picture such as to elaborate on broader design implications of HISs to support HIV/AIDS management.

Fourth, the system development processes have been accompanied with an ongoing engagement of ourselves in various aspects of implementation including socio-technical and political issues that affected the processes of practically making work the systems. While our primary focus was in Addis Ababa, we were also involved in the different processes of the research in SNNPR region, together with another HISP team member whose research was based specifically in this region. Efforts were also exerted to a certain extent by us and other research participants under the global HISP (see section 3.4) to introduce the system (IHAMS-ART) in Amhara, Benishanguel-Gumuz, Oromia, and Somali regions. These efforts helped us compare and gain a broader understanding of the implementation related issues involved. How we have dealt with the system development and implementation issues comprise the content of what we called “making it work”, the theoretical framework guiding this research (see chapters 1, 2 and 8). This included the efforts to gain entry into the management of HIV/AIDS and ART in Ethiopia which we found to be significantly political.

Accordingly, our concrete action research activities are broadly divided into two parts, each in one chapter. These are: (1) gaining entry and situation analysis (chapter 6), and (2) the subsequent action research interventions (chapter 7). The detailed description of our action research interventions (chapter 7) is, in turn, broken up into three parts. These are: the stories of (1) system (IHAMS-ART)

[#] Our ambition was to develop an Integrated HIV/AIDS Management System (IHAMS) for which we started from the ART module, hence the name IHAMS-ART.

[*] “Debo” means cooperation or working together in Amharic, an official language in Ethiopia. Because the detail of shifting to Debo is a wide discussion in itself not interesting to this thesis, we opt not to include it here as we also felt it would make the thesis more unwieldy.

development, (2) its implementation in two regions (Addis Ababa and SNNPR) in Ethiopia, and (3) its scaling particularly in Addis Ababa region which is ongoing as per a Memorandum of Understanding (MOU) we signed with Addis Ababa City Government Health Bureau (AACGHB). The discussions on our concrete research activities, both in chapters 6 and 7, are made with a particular focus on the political facet of the challenges around the processes of practically making work our project which forms the heart of the "making it work" theoretical framework that guides this research.

3.3 A Word about the Research Team

As mentioned in chapter 1, this research is set within the broader framework of the HISP initiative currently ongoing in Ethiopia since 2003. This initiative, based on a formal collaboration between the Departments of Informatics and Information Science from the Universities of Oslo (UiO), Norway, and Addis Ababa, Ethiopia respectively, seeks to link within an action research framework, education, research, and practical support to government for the health sector reform efforts around particularly the HMIS. The mechanism through which this collaboration is being operationalised is scholarships for Ethiopian students, both at the Masters and Doctoral levels, through the Norwegian government. These students, as a part of their thesis, work on solving practical HIS related problems, within an action research framework. The specific research reported in this thesis has been mainly conducted in a team comprising of two of the Ethiopian Masters students, registered at the University of Oslo, and also members of the HISP Ethiopia entity. As part of both the empirical component of our research, and the practical goals of collaboratively spearheading in response to the national urgency around HIV/AIDS management, we focused on various activities relating to the design, development, implementation, scaling up, and practically making work of the HIS (IHAMS-ART) to support ART management.

The two authors of this thesis are students coming from the same place, Addis Ababa, Ethiopia. As a result, it was relatively easy for us to get acquainted with each other while enrolled for the same international masters program in Oslo. During the first semester of our study, we were often in the same group doing projects and assignments which helped to further build mutual familiarity and understanding, and a sense of trust and a spirit of working together. Meanwhile, we came to know that there is in Oslo an arrangement of writing a joint thesis, and after a brief discussion between ourselves on the various pros and cons, we decided to write the thesis together as a pair. Our sense of understanding and trust of each other has steadily grown ever since. In hindsight, we have found the process of joint writing to be a very interesting and rewarding process, providing ample opportunities for conducting joint empirical work, sharing ideas, building synergies of time, and more broadly sharing together the highs and lows of the research processes. In addition to adding to the depth and breadth of the interpretive analysis, there were other logistic benefits gained from the pair model – such as compiling field notes, providing technical support, and answering questions to the health personnel through emails, phones and also making physical visits. On the flip side, while working in pair gave us the confidence to expand the empirical base of our research, our involvement was magnified in a way that it significantly reduced the time we had for reflection and writing. Nevertheless, expanding the empirical base helped to also create a stronger impetus for change where others also participated. Briefly introducing these participants and describing the roles is the focus of the next section.

3.4 Introducing Other Project Participants

Members of the broader and national HISP network were important participants in this research to whom we were connected electronically, by phone calls, and in person during periods of classes and other meetings. Locally, two HISP-Ethiopia employed researchers helped us deal with health personnel in Addis Ababa and Oromia regions, as they were also engaged in implementing a statistical HIS software called DHIS. Various other researchers, doctoral and masters students in either informatics or public health under the HISP framework, have also participated and contributed to this research in different ways. One of these researchers, a Vietnamese Masters student from our batch, came to Ethiopia in Spring 2006 to attend classes along with us. He played an important role by orienting us to the programming tools that we used to develop IHAMS-ART (see chapter 6).

Participating throughout the research process was a Professor at the University of Oslo, Department of Informatics and a fellow HISP member who has also been our primary thesis supervisor. This Professor helped us initiate our project while in Ethiopia and also played crucial roles in establishing links with various Ethiopian researchers with whom we made up a local team for this specific research. He also contributed in data collection (mainly from discussions he made with health personnel in Ethiopia and India), helped us see ART management within the broader picture of HIV/AIDS management. More important, he helped us to deal with various political challenges that surrounded the project and also to understand the implications of the data we mutually secured as he was also many times out in the field with us. Further, he helped us develop links with South African participants from the Meraka Institute and the University of Pretoria. While the researcher from Meraka has been instrumental in evaluating IHAMS-ART and initiating the development of Debo with us, the one from the University of Pretoria facilitated the visit at the ART clinic in Tshwane District Hospital in Pretoria, and also provided us South African HIV/AIDS data capturing and reporting formats with relevant explanations. She also participated in testing the flexibility of Debo by populating its database with South African HIV/AIDS data elements while we did the same with those of Ethiopian. Links with these South African participants led to the further escalation of the networks we became enrolled in such as HISP-South Africa which supported the Debo project.

Two other Ethiopian researchers helped us in our attempts to implement the system in SNNPR and Amhara regions while simultaneously using this experience to conduct the empirical work for their own respective thesis (one masters and the other doctoral). One of these, a medical doctor who was doing his MPH at Eduardo Mondlane University in Mozambique, a program that is also supported by Oslo, joined us as he was interested to do his thesis around our project. Discussions with him were valuable to us both in practical terms of improving the technical system (IHAMS-ART) and also to learn contextual differences in implementation as he was also engaged in implementing the system in SNNPR. In fact, some of his findings which he sent us via e-mails were included in this thesis (see chapters 6 and 7) to help compare implementation related issues. Similarly, the effort made by the other researcher, a doctoral student at UiO, to take the system to Amhara region also has implications in our study (see chapters 7 and 8). Also, participating in the process was a medical doctor, a masters student at the Department of Information Science in Addis Ababa University (AAU), who, after having a little chat with the Professor in one of his classes at AAU, became interested in the project. His contributions, especially at the beginning of the development of IHAMS-ART, were very useful in understanding the medical terminologies used in the various input forms and reports as well as providing very useful insights into understanding the analysis needs of the medical doctors (see chapter 6). Yet contributing in the research were some other members of the local and broader HISP team and various other researchers whom we met at different conferences, workshops, meetings, and discussion sessions held in Ethiopia, India, and South Africa (see Table 3.2 in section 3.8). We found their criticisms, comments, and suggestions particularly on IHAMS-ART rather helpful and constructive. Two Professors from UiO have contributed specifically in data collection (see section 3.9) especially when they visited our sites in Ethiopia, and this data is used in this research.

After having introduced the research backdrop and the immediate and broader research team, in the next section we describe how various choices were made in the research processes.

3.5 Choices and Drifts: The Research Domain and the Technologies Adopted

Being members of the HISP research network, we were to define our research domain within the public health sphere. Working in a pair, we also wanted to identify a specific research area that is of interest to both of us. These conditions molded the processes of making choices with respect to the research domain area and the technologies employed in the research.

Discussions about our would-be research area extend back to the time when we were taking the masters courses in Oslo with some HISP members who were knowledgeable about what has been and needs to be done in Ethiopia. During that time, we were informed that some HISP activities around the development and implementation of a hospital information system and an HIS to support the management of HIV/AIDS were considered for Zewditu Memorial Hospital (ZMH) in Addis Ababa. Care2x (a PHP/MySQL based healthcare practice management system)* was proposed as a candidate tool for customization in both cases. Thus, we downloaded Care2x from the net and analyzed it. When we came back to Addis at the end of our course work in Oslo, we needed to explore it further, and also to zero in on a concrete research topic.

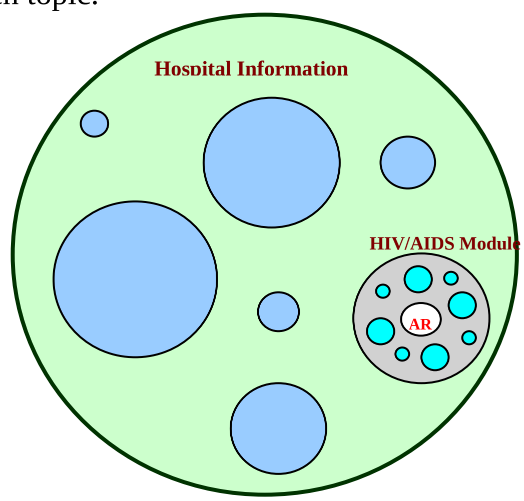


Figure 3.1: Drifts in search of research domain area

However, from our investigations on the ground, we found out that going for a hospital information system would be difficult as it is too big and complex a project to carry out given, among other things, our limited research time and research experience. Thus, narrowing down our research area, we started

* "Care2x … is a smart software for hospitals and health care organizations. It is designed to integrate the different information systems existing in these organizations into one single efficient system." (www.care2x.org) "PHP is a widely-used general-purpose scripting language that is especially suited for Web development" (www.php.net). MySQL is a fast, flexible and reliable database server that is often the natural database of choice when working with PHP. (www.mysql.com). All of these are open source which is "a development method for software that harnesses the power of distributed peer review and transparency of process. The promise of open source is … lower cost, and an end to predatory vendor lock-in." (www.opensource.org). HISP, within which we conducted this research, advocates the use of open source tools.

to think about exerting our efforts around the HIS to support the country's HIV/AIDS management which was also one HISP focus area for Ethiopia. This appeared more interesting to us than the previous one, and was also a national priority (NHAPCO/FMOH, 2004b; FMOH, 2005). Yet, while we were exploring the different components of Care2x, we found out that an HIV/AIDS module, which needs to consist of a multiplicity of initiatives that need to be integrated, was not readily available for customization. So, after discussing with the Professor and our Vietnamese friend, we saw that building this whole module would not be feasible. Hence, having now obtained better experience on Care2x, we still needed to further narrow down our research domain area (see Figure 3.1).

In the meantime, out of the different HIV/AIDS initiatives we had been assessing, we were drawn to the ART program owing to various reasons. First of all, starting from the gate of the ART clinic at the ZMH which we first visited, we had strong compassion and sympathy towards the patients and the extreme conditions they were living in. As a result, we were inspired to find some ways to contribute to the efforts being made to help them. Second, from our initial informal observations, interviews, and discussions with some of the staff members at ZMH and AACGHB, we learnt that the ART clinics were desperately crying for a computer based system as their work was significantly affected by the manual system which, in turn, affected the entire information management of HIV/AIDS. Third, as we repeated our visits to the clinics and studied relevant documents including data capturing and reporting formats, we came to understand that antiretroviral treatment has some particularities (see chapter 4) that stroke curiosity in us and made the case more interesting. Fourth, we felt that it would be relatively easier to develop and implement a system for this program as it was more focused compared to the more complex areas we had been initially considering. However, our subsequent experience belied these earlier expectations (see chapters 6 and 7). Furthermore, we later discovered that there was a national urgency to 'rapidly and massively' scale up the ART program by enrolling more patients into the treatment perse (NHAPCO/FMOH, 2004b) and to integrate the various interventions within the HIV/AIDS programs with ART as a central point (FMOH, 2005). Both these urgencies had serious information systems implications, which further strengthened our determination to contribute to this domain.

As we still kept exploring Care2x even closer to build an ART module in it, we found it to be too complex, and the additional functionalities which were available in Care2x we felt would distract the ART module user. This point was also emphasized by the *Software Inventory Report* and a comment from RHINO (2004b) which provides the underlying reason for Care2x's complexity:

> *"This is a very full-featured software package suitable for hospitals. … This software is recommended for hospitals that need to automate all hospital functions." (p. 20)*

Furthermore, discussing why this software is not suitable to support ART management, the RHINO (2004b) report said:

> *"This is a large software package with many functions that may not be necessary in smaller hospitals and may interfere with effective … use. Although this software can be used for outpatient EMR,it is not designed for that use. The extra features have the potential to cause confusion when they are not used." (p. 20)*

After further discussing these various issues with the Professor and our Vietnamese friend, we saw that Care2x was not suitable for our needs and decided not to use it for our project. Consequently, with a broader vision of IHAMS, we needed to develop an ART module (IHAMS-ART) from scratch based on the requirements we already gathered. The platform chosen was PHP/MySQL to which we came to be more familiar, as a byproduct of the exploration of Care2x. It was only after about a 9 months effort around the development and implementation of IHAMS-ART in Ethiopia that we came to be on the track of meeting our IHAMS vision by embarking on the Debo project. The development of Debo was started with yet another technology called symfony, "an (object-oriented) open-source web framework written in PHP5"[#] (www.symfony-project.com). As mentioned previously, Debo was not just a refinement of IHAMS-ART, but designed in such a way that the other components of the HIV/AIDS program could be incorporated, and was structurally made flexible. Figure 3.2 below depicts how our choices of technologies were shaped by the drifts we made in search of a suitable research domain area.

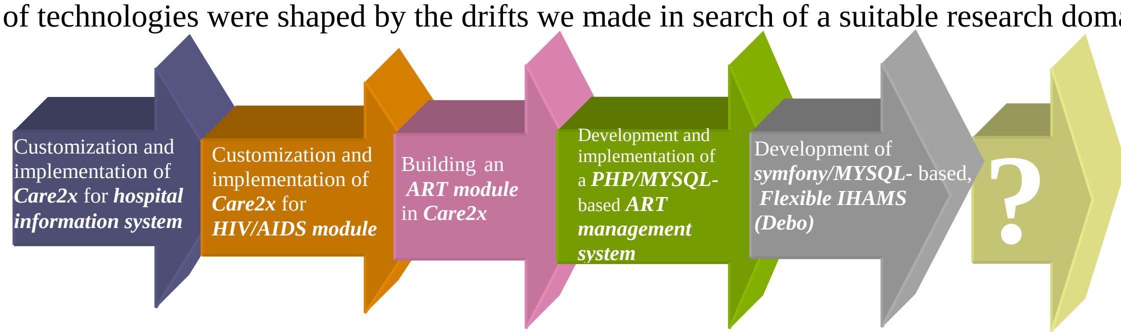


Figure 3.2: Choices of technologies shaped by drifts made in selecting a research domain.

Once the domain area is determined, we started to formalize our research approach which can be seen to be characterized by three key features: *qualitative* research methodology and a *multi-site longitudinal action research* design approach. These features are now elaborated upon.

[#] "A framework adds new mechanisms on top of a programming language, and these mechanisms automate many of the development patterns used for a given purpose. …. A framework is usually developed with the same language that it extends. A PHP5 framework is a set of files written in PHP5. … Symfony aims to speed up the creation and maintenance of web applications…. It also contains numerous tools … aimed at shortening the development time of a complex web application" (www.symfony-project.com).

3.6 Research Methodology

A research methodology is a strategy of inquiry which emanates from certain underlying philosophical assumptions. As Silverman (2005) puts it:

> *"Methodology refers to the choices we make about … methods of data gathering, forms of data analysis etc., in planning and executing a research study. So our methodology defines how one will go about studying any phenomenon. In social research, methodologies may be defined very broadly (e.g. qualitative or quantitative) …Methodologies cannot be true or false, only more or less useful" – (p. 99).*

Quantitative and Qualitative Perspectives

Quantitative research is a form of inquiry into a problem, based on testing a theory composed of variables, measured with numbers and therefore analyzed with statistical procedures. Quantitative methods are also well accepted in the social sciences (Myers, 1997; Creswell, 1994; 2003). Quantitative research approaches are termed as traditional and positivist (Creswell, 1994; 2003). The identifying assumption of quantitative methods is that reality is *objective* (Silverman, 2000), and thus a phenomenon can be measured objectively by using tools such as questionnaires and other instruments. Quantitative methods can provide better comparisons for statistical aggregation of data and are typically characterized by the use of closed questions with *yes* or *no* answers or *a set of predefined* answers which can be measured, quantified, comparable and manipulated to provide "objective" results. However, Silverman (2000, p. 7) mentions that, "Quantitative research methods can amount to a 'quick fix' *involving little or no contact with people or field*" (Silverman 2000, p. 7). Hence, quantitative approaches can give solutions for a problem without direct contact with the people.

On the other hand, qualitative methods enable researchers to study people, and the social and cultural context within which they live (Myers and Avison, 2002), through an emergent and interpretative approach which is shaped by the researcher's social and historical conditions and moments (Creswell, 2003). It is, therefore, seen as a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live (Holloway, 1997). Strauss and Corbin (1990) describe qualitative research as any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification. Focusing upon the social reality of individuals, groups, and cultures, qualitative research is used in the exploration of behavior and the perspectives and experiences of people as they make sense of their *subjective* reality. Qualitative research can be called by such other names as 'interpretive (or interpretative) research', 'naturalistic inquiry', 'field research', 'case study approach', and the overall name 'ethnography'. Qualitative research presupposes examination of processes and meanings that do not gain sufficient description through the use of quantitative methods. Silverman (2000) argues that qualitative researchers seek to map forms of social interactions to develop contextual understanding of a situation. The researcher usually tends to "stress the socially constructed nature of reality" (Denzin and Lincoln, 1994, p. 4). Qualitative methods help to "provide a 'deeper' understanding of social phenomena than would be obtained from purely quantitative data" (Silverman, 2001, p. 32).

Qualitative inquiry is the process of understanding a social or human problem based on building a complex, holistic picture, and reporting detailed views of informants. Qualitative research is conducted in natural settings (home, workplace of the participants etc.) and characterized by the use of data formed mainly with of *words* rather than numbers, and can also be visually coded such as using pictures (Creswell, 1994; Myers, 1997; Silverman, 2000; Strauss and Corbin, 1998). As a result, qualitative researchers are sometimes seen as 'story tellers', presenting often their findings in the form of a story line (Holloway, 1997). Qualitative research often employs multiple methods that are interactive and humanistic, such as open-ended observations and interviews, document review and analysis, emails, scrapbooks (Creswell, 2003). Qualitative methods are particularly useful in determining *how* and *why* specific outcomes occur, for example through self-reflection and introspection (Denzin and Lincoln, 1994). Answers to qualitative interviews can resemble conversations, being more detailed in content and are arguably far richer. Depth and detail is provided in qualitative approaches including through quotations and careful description of situations, events, interactions, and observed behaviors, and also through visual aids.

Some Bases to Serve for Selection

The choice of a research methodology, the means for achieving the goals of the researchers, should not be predetermined, but be derived from the research aims. Both qualitative and quantitative methods have roles to play in developing theories and hypotheses. The issue is not whether to use one form or another but rather how a method might foster an investigation (Strauss and Corbin, 1996). The selection of a particular method thus depends on what the researcher is actually trying to find out (Punch, 1998). "In this sense, your choice of the method should reflect an 'overall research strategy'" (Mason, 1996, p. 19). Basically, it is the nature of the research problems we are interested in that defines the most appropriate method to be adopted. There are, of course, issues we need to think about when fitting our choice of methodology to our research problems. These problems are not absolutely neutral since the way we frame them will inevitably, implicitly or explicitly, dictate a particular model of how the world works. For instance, if we are interested in making systematic comparisons in order to account for variance in a phenomenon, then quantitative method is indicated. Similarly, there are cases where the particular explanatory power of qualitative research is demonstrated. Moreover, the kind of focus and the depth and detail of the desired research determine the choice of method. Also different contexts and situations call for different methods. Hence, "no method of research, quantitative or qualitative, is intrinsically better than any other." (Silverman, 2005, p. 6). Thus one needs to think through exactly what is being tried to achieve rather than being guided by some fashion or trivial preference, for example, for not being comfortable to play with numbers.

As a hint to how to select a method, Silverman (ibid., p. 7) pointed out that the way other researchers have dealt with a certain topic and the extent to which one wishes to align a project with the literature also affect the choice of a research methodology. For example, if it turns out that published research on one's topic is largely, say, qualitative, he suggested, as a rule of thumb, that it does not pay "to swim against the tide". Thus, it makes a lot of sense if one can align a work with a previous, classic study, rather than trying to reinvent the wheel. Furthermore, practical considerations such as the amount of time a study might take, accessibility of the study sites, and the knowledge payoff of a method all shape one's choice of research methodology. In short, each method has its place (Silverman, 2000), and the nature of the research problems shapes the choices. Therefore, we need to think through the research problems we are seeking to analyze before committing to a choice of method.

The Method We Adopted – Why Chosen and How Relevant?

The background to the research problems addressed in this thesis was sketched out in chapter 1. Specifically, we were interested to investigate the various issues that challenge the processes of practically making work ISs in developing countries. More specifically, once ART was chosen as the specific domain area of study, and given the practical condition of ART management in Ethiopia mentioned earlier, we wanted to explore our research problems while trying to meet our specific research objective of improving the situation of ART management in this country. This was to be achieved through introducing and attempting to make work a supporting HIS. We thus needed to choose appropriate methods and approaches that would help us effectively explore and deeply understand the issues that surround our effort around the HIS.

Our theoretical perspective to help address our research problems had three key interrelated facets. The first concerns the various challenges around implementing the HIS, especially those related to the political context, conditions and negotiations. The second concerns the need to thoroughly understand the deeply embedded micro-level practices of the people working practically on the various ART tasks. The third concerns the real challenges of making the supporting HIS and its outputs seen useful by the actors surrounding it, and of institutionalizing it. The thesis takes the view that micro-level practices constitute and are constituted by the more macro-level political structures, and understanding these mutual relationships is the key to analyze the challenges of making the system work in practice. The guiding principle to our empirical efforts has been to try and understand the overall set of interconnected challenges of system development and implementation to make the HIS work in Ethiopia, which is conceptualized in our guiding "making it work" theoretical framework. This necessarily has involved taking an approach which goes beyond the mere technical, and to also incorporate into the analysis the contextual aspects, especially relating to the politics. Thus, our concern was to understand how things work and why they work that way. An implication of our approach, for example at the initial stage of the study, was to understand how the pre-existing manual system was working in the ART clinics, especially the underlying practices shaping the information flows. To gain these insights, we were engaged with understanding how ART staff did their everyday work, especially relating to their informational tasks. We tried to understand a naturally occurring phenomenon in its real settings (Smith, 1991), and explored people's everyday behavior (Silverman 2001). Further, through our initial analysis we aimed to explore the procedures and tools used to collect, store and analyze data and the reporting procedures. Therefore, our data were primarily 'words' that can be analyzed through qualitative methods. Hence, we did not use quantitative methods, which we believed involves "*little or no contact with people or field*" (Silverman 2000, p. 7), and thus less useful to our research aims.

Qualitative method is also suitable to employ in research with emergent characteristic (Creswell, 2003). This was relevant in our case given our own limited initial understanding of the problem domain. For instance, initially, we focused on developing a general understanding of the broader HIV/AIDS management in Ethiopia, followed by a micro-level understanding of the pre-existing manual system in the ART clinics. Due to the flexibility offered by the qualitative approach (Dick, 1993), we later examined the inter-connections of the ART clinics with the other HIV/AIDS such as Pharmacy and PMTCT. For example, we discovered that the lack of proper identifiers for VCT clients adversely influenced the integration of the ART and VCT initiatives. Thus the flexibility provided by qualitative method allowed us to oscillate between the different dimensions and issues in the research that needed to be investigated. The qualitative approach also helped us to develop a rich understanding of social, technical, political, and organizational issues, and an analysis of the impact of the HIS we developed on organizations and people involved (Myers, 1997; Silverman, 1998).

Nevertheless, this is by no means to argue that quantitative methods needed to be completely ruled out from our research. They could, of course, in several situations, have been appreciated for some aspects of the study. For instance, at the initial stage of our study, when investigating how the different users used or felt about the pre-existing systems, we could have developed questionnaires, or conducted systematic observations, which would have enabled us to compare issues. They could also have been applied later in the research, for example, to measure the degree of users satisfaction (of IHAMS-ART) on a scale from one to ten etc. and the results could have been seen together with what we found using qualitative methods. These, however, have been left out due to limitations including both in time and scope. For example, questionnaires should have been made (and perhaps translated), dispersed, and then collected and analyzed which would have consumed time.

We now describe our research approach.

3.7 Research Approach

As members of the HISP research network, our research falls under the framework of an action research paradigm, where we needed to be engaged in concrete intervention efforts including HIS design, development, implementation, scaling up and other accompanying activities such as training. In this study, a longitudinal action research approach was adopted within a multi-site research design. Participatory action research approach has been specifically adopted from the very beginning, and has grown in degree over time. Since our focus was not only on understanding but also on introducing and influencing practical changes as per our research objectives stated in chapter 1, we found the action research approach to be relevant and appropriate.

Action Research – The Philosophy behind as Applied to IS Studies

Action research has been characterized as a way of building theory, knowledge, and practical action by the researcher's own engagement with the world in the context of practice itself – the theoretical assumption behind an action research approach (Kock, 1997; Whyte et al., 1991). Action research is not a discipline, but involves members from both academic and non-academic practices (Greenwood and Levin, 1998). It is often described as a research approach of dual aims – action and research – where the:

- *action is meant to bring about change in a certain program, organization, or community, and;*
- *research is meant to increase understanding of the case on the part of the researcher and/or the client.* (Dick, 2002, p. 1)

Thus, action research aims to contribute both to the practical concerns of people in an immediate problematic situation; and to the goals of social science through joint collaboration within a mutually acceptable ethical framework. The ideal domain of action research can, therefore, be expressed to have three distinct characteristics of the approach (Baskerville and Wood-Harper, 2002 p. 136):

i. *The researcher is actively involved in the research with expected (practical) benefits for both the organization and himself/herself,*
ii. *The knowledge obtained could be immediately applied, and*
iii. *The research is a cyclical process linking theory and practice.*

Though the history of action research dates back to as early as the 1940s (Baskerville 1999), the work by Mumford and Weir (1979) brought it into the field of information systems as a systems development technique. Decades later, Checkland used action research in the methodology of systems development, which also formed a landmark for the approach in information systems research (Checkland, 1981; cited Baskerville, 1999; Checkland and Scholes, 1990; Checkland and Howell, 1998;). Wood-Harper et al. (1985) also incorporated action research concepts into an action-based systems development methodology (Wood-Harper et al., 1985).

Ever since then, action research as a research approach has repeatedly been argued to be well suited to the study of technology in its context (Baskerville and Wood-Harper, 2002). This is due to the fact that actions taken to introduce technology can be largely affected by the organizational context and that the action researchers can progressively identify and devise strategies to its more effective adoption and use. The "learning by doing" practice in action research where, a group of people including researchers and the client organization work together to solve commonly experienced problems, helps the researchers to get well adapted to the organizational context before actually introducing the piece of technology. Also, accomplishing its uniquely identifying dual goals of both improving the organization and at the same time generating new knowledge, both theoretical and practical, where the importance of co-learning as a primary aspect of the research process is stressed (Baskerville and Wood-Harper, 2002), requires the active collaboration of the researcher and client which furthers contributes to making the technology meaningfully used. Furthermore, an action research approach should lead to the development of a stronger linkage between organizations and research centers, and contribute to organizational development and improvement (Kock, 1997) which, at the same time, creates room to ultimately deeply embed the technology and its accompanying new practices in to the organization.

What is more, researchers' perception of the client organization may vary over time, as their knowledge of the organization increases, gathered through formal interaction and also informal conversations and communication between the researchers and the client staff. This also helps to generate more general knowledge that is crucial to solve the problem at hand, and also in adding to the scientific knowledge in particular research domains. The level of knowledge now attained, though, is not to remain confined to a limited community. As a way of expanding it, Braa, Monteiro and Sahay (2003) have emphasized the pivotal importance of "networks in action" as an effective form of action research, especially relevant in developing countries' settings. This creates opportunities for the sharing of the scientific knowledge, experience, technology and value. Basing their empirical study on the different nodes of the HISP network countries including Ethiopia they identify actions in the network to include processes of enabling mutual learning and sharing related to software development, training, and implementation approaches and experiences.

Action Research – As Applied to Our Research

These characteristics of action research, as applied to technology adoption, are relevant to our study in its context. For instance, recognizing the political ramifications of our work around ART, we needed to design appropriate action strategies to deal with political challenges. For example, to secure the help of health workers at ART clinics, we had to first align with the regional health bureau governing them and also with relevant stakeholders. But since political conditions were more abundant at this level, we still needed to devise strategies to build political relations and infiltrate the situation. Once that is achieved (see how in chapter 6), the subsequent actions taken to improve ART management with a supporting IS demonstrated practical organizational benefits, which furthered strengthened our political relationships particularly with the regional health bureau. In time, this led to the situation where the IS became deeply embedded into everyday work of the client to the extent that the users feel that they can't live without it (see chapter 7).

Apart from these practical improvement actions, from active involvement in the issues, we gained insight into the dynamics around gaining entry and system implementation, and also into what it takes to make an HIV/AIDS supporting IS work in Ethiopia. We especially noticed the political dynamics around our project. From deep engagement, we understood the need to primarily penetrate political conditions to gain entry into the HIV/AIDS program, and also to take the subsequent improvement action. In addition, without the progressive actions taken in our effort, we wouldn't have established a stronger link with the client which was vital to handle the political situation. Moreover, without this engagement of ourselves in the fields through actions, we wouldn't be able to practically materialize our aim of making the system work. In short, through the processes of action interventions, we developed knowledge regarding why and why not things work in relation with the introduction and use of HIV/AIDS systems.

The Traditional Action Research Cycle – Why Ours Deviated?

The key assumptions of action research are that "social settings cannot be reduced for studying and that action brings understanding" (Baskerville 1999, p. 7). Hence, the major difference between action research and other research methods is its focus on the real world to solve practical problems by engaging in the processes they call for – including the processes of problem definition and taking, and reflecting on action to address these problems. In the 1950s, Blum explained the essence of action research as a simple two-stage process:

> *"First, the diagnostic stage involves a collaborative analysis of the social situation by the researcher and the subjects of the research. Hypotheses are formulated concerning the nature of the research domain. Second, the therapeutic stage involves collaborative change experiments. In this stage, changes are introduced and the effects are studied"* (Blum, 1955; cited Baskerville and Wood-Harper, 2002, p. 133).

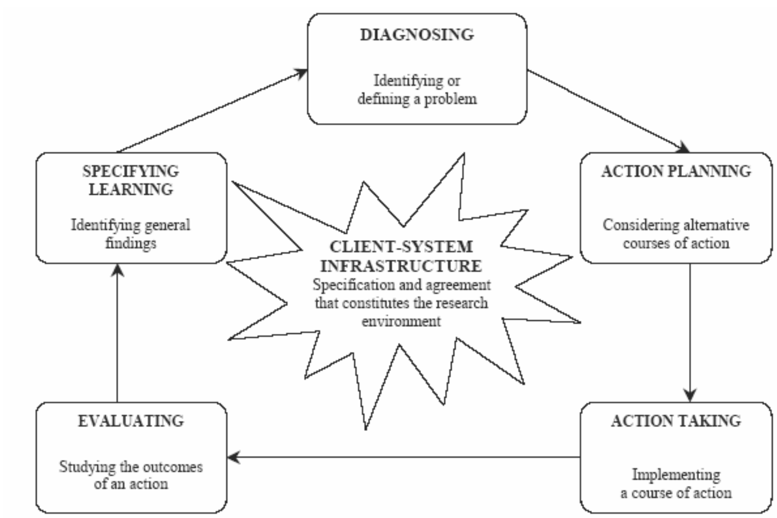


Figure 3.3: The tradition action research cycle (adopted from Baskerville and Wood-Harper 2002, p.134) the variation of which was applied in our study

However, in order to achieve a scientific rigor, additional structure is usually imposed (Baskerville and Wood-Harper, 2002). Consequently, in the 1970s, a detailed list of five identifiable phases of action research approach was mentioned to be: 1) diagnosing; 2) action planning; 3) action taking; 3) evaluation; and, 5) specifying learning. These processes are to be executed cyclically and then also iteratively (Baskerville, 1999; Baskerville and Wood-Harper, 2002; Dick, 2002; Kock, 1997). Regarding the pervasiveness of this fashion, Baskerville and Wood-Harper (2002, p. 133) argue that "the most prevalent description of action research details a five phase, cyclical process which can be described as an 'ideal' exemplar of the original formulation of action research". Firstly, this ideal approach fundamentally requires the establishment of a 'client-system infrastructure' or research environment, which helps to outline the specification and formal and/or informal agreements. Then, the five phases are cyclically executed iteratively as depicted in Figure 3.3.

Likewise, with some variations, our research can also best be described to correspond to this "most prevalent" approach as the study essentially needed to evolve around the five *basic phase*s. In the next subsection, we discuss each phase as corresponding to our action research intervention as depicted in Figure 3.4. However, it is important to note at this point that our research necessarily demanded us of two-fold concrete actions – the underlying reasons for the variations:

(1). Penetrating the political conditions that made difficult gaining entry in to the country's HIV/AIDS program – an obligatory action towards the subsequently indispensable efforts; and,

(2). Performing the intervening improvement activities – solid actions that help tangibly address the problems particularly in the country's ART management.

The need to accomplish these dual actions forced us to deviate from following exactly the traditional action research cycle. As a result, perhaps unlike many other action research efforts, our research traced a 'cycle' which basically consists of 2 diagnosis, 2 action planning, and 2 action taking phases. This scheme resulted in some features distinguishing the research. For instance, although we decomposed our phases to correspond to each of the five basic phases of the traditional action research cycle to simplify the discussion, in realizing our study, there were actually some reversals of phases. For example, the so-called 'client-system infrastructure' or a "conducive" research environment was established only after we already executed the first fragment of the diagnosis phase (from which we originally sensed the prevalence of political challenges), the first segment of planning (to penetrate the political condition detected), and also after we performed the first obligatory aspect of the action taking – infiltrating the political situation. Normally, the establishment of client-system infrastructure should be done before starting to execute any of the action research phases.

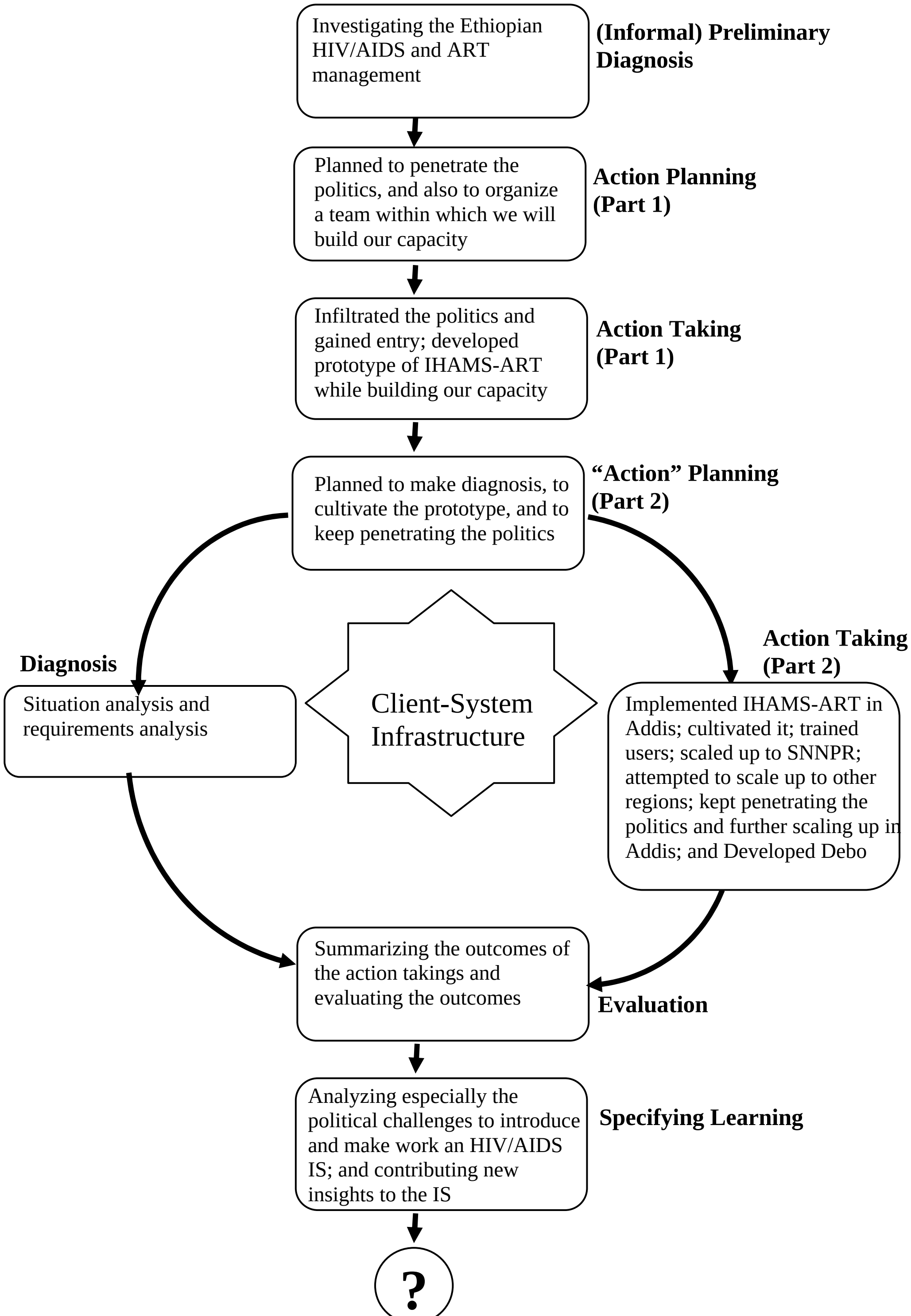


Figure 3.4: The action research 'cycle' as applied to our study.

In addition, the execution of one phase, in our case, was not always made after entirely completing that of the one before and hence there were overlaps of phases. For example, the second segment of the diagnosis phase where we investigated the problems in the country's ART management, took place simultaneously with (not after) the second segment of the action taking which has dual faces –

performing improvement action while keeping to infiltrate the sustained politics. Also, our action planning which has two segments due to the twin actions required was not entirely made after a complete execution of the diagnosis phase in its entirety, as is often the case. Moreover, the evaluation and specifying learning phases, in our case, took place while the research was still ongoing. In effect, it appears as if we were conducting two action researches at the same time – one nested within the other, and not necessarily one entirely after the other. By and large, the study somehow lacks the order and discreteness of phases which are often sensed in most action researches that adopt the traditional five basic phases in the given order.

Decomposing Our Study into the Basic Phases of Traditional Action Research Cycle

In this subsection, we describe our action research decomposing into the fundamental phases of the traditional action research cycle while at the same time discussing the points of deviations in our case.

Establishing a Client-System Infrastructure[*]

"The client-system infrastructure is the specification and agreement that constitutes the research environment" (Baskerville and Wood-Harper, 2002, p. 133). It provides the authority or sanctions under which the researchers and host practitioners may specify actions. It also legitimates those actions with the express expectation that these will eventually prove beneficial to the client or host organization. Baskerville (1999) describes that the client-system infrastructure may also patently recognize the latitude of the researchers to disseminate the learning that is gained in the research. A key aspect of the infrastructure is "the collaborative nature of the undertaking. The research scientists work closely with practitioners who are located within the client-system." (Baskerville and Wood-Harper, 2002 p. 133)

In our case, the client-system infrastructure was established only after we already moved three steps (phases) forward in the research process and took action. Firstly, we informally conducted a preliminary investigation of the country's HIV/AIDS program particularly of the ART initiative during which, from the reactions of people we met in the field, we sensed of the abundance of a political barrier against our attempt to further study, introduce and make work a supporting IS. We thought, without first penetrating this political situation surrounding our efforts (see chapter 6), we would never be able to realize the actual improvement activities. Second, we devised appropriate strategies to that

[*] We brought this here as a phase for the sake of simplifying the discussion.

end. Third, we effectively applied these strategies to infiltrate some of the obligatory political points which provided us room to gain entry (see chapter 6).

Hence, it was only soon after we initiated our action research processes informally alongside some activities, that we came to process and secure a formal agreement between AACGHB and the HISP-Ethiopia entity, of which we are members (see the how in chapter 6). Had we not worked towards establishing this proper agreement, we would not have gained the necessary support from the bureau and clinic staff. Also we might have been hard pressed by the prevailing ongoing strong political undercurrent (see chapter 7). In fact, we would have been pushed aside by resisting parties some of which have been consistently opposing us. However, though it did not mean the end of the political condition surrounding our efforts, once we secured the formal permission of the bureau, we enjoyed a number of privileges which led to beneficial concrete actions (see details in chapters 6 and 7). After penetrating part of the politics this way and establishing the research environment, unlike other action research efforts, we needed to carefully plan with the staff of the client not only the actual improvement actions but also the diagnosis phase itself.

Diagnosing

Baskerville and Wood-Harper (2002, p. 134) describe that the diagnosing phase “corresponds to the identification of the primary problems that are the underlying causes of the organization’s desire for change”. It also involves self-interpretation of the complex organizational problems to develop certain theoretical assumptions about the nature of the organization and its problem domain.

This phase had two parts in our case. The first is the informal preliminary diagnosis mentioned above which we conducted before gaining entry and establishing a conducive research environment. During this time, through a preliminary assessment of the broader HIV/AIDS management program in Ethiopia, we also diagnosed how the multiple initiatives in the program are interconnected, and kept the ART program in perspective. We discovered some of the problems in the management of the disease and its antiretroviral treatment (see chapters 5 and 6). This was achieved by means of some visits, observation, interviews, and discussions made with the bureau and clinic staff as we were moving around the filed along with a local HISP researcher (see chapter 6). It was in this process that we first came to detect the political undercurrent. This part of the diagnosis phase was completed only after we learnt how difficult it would be to perform our would-be action research intervention activities unless we first compulsorily infiltrate and address the political situation we were sensing, hence the need for a wise action planning to that end.

The second fragment of the diagnosis phase was performed through a more thorough and closer situation analysis of the ART program which we conducted after moving aside the major political stones and establishing formal links with the client by implementing the plans we devised. This aspect of the diagnosis phase took place simultaneously with the second segment of the action taking phase (see Figure 3.4) – the improvement interventions which include the development and introduction of IHAMS-ART to some clinics the client granted us. From this situation analysis, while we were at the same time eliciting the ART requirements (since the client said it does not have proper documentation), we identified the primary problems which sought change in order to improve the pre-existing management of the national ART program – our specific study context and analytical focus. Therefore, we were able to associate the major problems we identified both from the preliminary assessment and situation analysis to have resulted from lack of a supporting IS. We came to be able to classify these problems under three categories: magnitude of manual workload; fragmentation; and variations in work practices (see chapter 6 for details). Most important, while we were discovering these problems as we were working around IHAMS-ART during the diagnosis, among other things, we were also still detecting the prevalence of an ongoing political undercurrent against our effort to make work the IS that helps alleviate these problems.

Also, though they were not part of our objectives right from inception (and not discussed in detail in this thesis), the opportunities of our being in SA and India and meeting relevant and knowledgeable researchers from these countries contributed to the diagnosis phase of the research. For example, the visit we made to the (Tshwane) clinic in South Africa and our investigation of the ART data capturing and reporting formats from both these countries with the help of the researchers helped us to understand similarities and differences in the workings of ART and the existence of an immediate need for ART supporting IS across countries. These helped us to develop a much broader view and to discern how an HIV/AIDS system should be designed so as to introduce it to many countries in the most feasible manner and, accordingly, led us to extend our actions to escalate the project – the development of a more flexible system (Debo).

Furthermore, the review of literature we made to learn more generally about HIV/AIDS and ART, our research background, and about the cases in Ethiopia also contributed to the diagnosis. Apart from keeping our study in a much wider perspective, studying in general about HIV/AIDS such as its global devastating impacts; and about the power of ART in reversing these impacts and its peculiarities and challenges unlike other treatments, helped us to see why it is extremely vital to support the management of this disease and its treatment with an IS. Similarly, our study of the conditions of HIV/AIDS and ART specifically in Ethiopia, where this study is conducted, helped us to situate the study in its broader regional context. These issues are discussed in chapters 4 and 5. Following these chapters, our findings from the diagnosis phase are presented in chapter 6. Section 3.9 discusses multiple other qualitative data collection methods used for this phase.

Action Planning

The next activity researchers and practitioners collaborate in after the diagnosis phase is action planning. The discovery of the planned actions may be guided by a certain theoretical framework which indicates both the desired future state for the organization and the changes that would help and lead to the achievement of such a state. The plan also establishes the target for the changes and the approaches to their attainment. In our case, the requirement of dual actions forced us to follow a different scheme in action planning than traditionally used to be. Consequently, like the diagnosis phase, our action planning can well be divided into two segments, and was not entirely made after a complete execution of the whole diagnosis phase, as is often the case.

The first is the one we made immediately after learning the difficulty of ensuing with the research without firstly addressing the prevailing political conditions which we experienced during the preliminary diagnosis phase. This fragment of the planning phase thus had two-fold concerns for which we planned: (1) to penetrate this political condition surrounding our effort and gain entry into the country's HIV/AIDS program so as to establish a formal agreement with the client for actual improvement actions; and, (2) to, at the same time, organize a team within which we build our own technical and domain specific capacity in order to conduct a situation analysis in the unfamiliar domain of ART and elicit requirements – both when (and if) we succeed establishing the research environment. The plan was made between ourselves (the research team), the local HISP team, the Professor, our Vietnamese friend, and the medical doctor from AAU.

After the first segment of the plan was effectively implemented and practical actions were taken to infiltrate the politics, we successfully gained entry. We were, therefore, free to sit down on a table with the client and make action plans. Like the first part, this part of the planning phase had two-fold concerns for which we planned with the bureau staff: (1) to conduct situation analysis while documenting the requirements of the ART program; and, 2) to, at the same time, perform the subsequently required actual improvement actions including system development and implementation while, of course, penetrating the politics which was foreseen to expectedly surround these efforts.

Action Taking

This is the phase during which planned actions are implemented. The researchers and practitioners collaborate in active interventions into the client organization causing certain practical changes to happen. In our case, we moved to carry out the actual dual actions the research demanded of us in this phase.

Firstly, we worked out primarily towards penetrating the political conditions so as to be able to proceed. While performing this, we continued the preliminary diagnosis and also started to building our technical and domain specific capacity within a team comprising of our Vietnamese friend and the medical doctor who was doing his MPH. This capacity building process took place as we were developing the prototype (of IHAMS-ART) based on the requirements we already gathered thus far during the preliminary diagnosis. Ultimately we succeeded gaining entry and established a formal link with the AACGHB. In chapter 6 we have provided detailed description of how we were able to perform these activities simultaneously.

Secondly, we moved to collaborating with the client for the actual improvement activities, to conducting the situation analysis, and eliciting requirements. The IHAMS-ART prototype was installed in some clinics we were allowed to work. The intensive work of properly developing the system, i.e. cultivating the prototype, was carried out in this phase through active participation of the health workers especially those at the facility levels (ART clinics) who helped us elicit the requirements commenting on the system already implemented at their sites. The system was initially adapted to incorporate the basic requirements for ART management. Evolutionary prototyping was used as the system development methodology to introduce the system to the organization gradually, and incrementally cultivate it to help it be adapted to the inevitable changes taking place through this process (Avison and Fitzeberg, 2003; Wiryana, 1998; Sommerville, 2001). Another important action research intervention was the provision of iterative training to users on how to use the system as the system evolved. These successive trainings were through individualized attention at the clinics through the visit of the researchers at each improved version of the system. After the software already implemented in some pilot clinics in Addis got matured, it was also taken to the SNNPR region by the SNNPR implementer, and attempts were also made to do so in Amhara, Benishanguel-Gumuz, Oromia, and Somali regions. We made further attempts to implement the system in more clinics in Addis and continued to penetrate the political situation that continued to surround our efforts. Eventually, we (HISP-Ethiopia) reached to the level of signing the MOU with the AACGHB to formally scale up the system to all (about 67) the ART clinics in the Addis Ababa region the process of which is ongoing.

Evaluating

At the end of the actions, collaborating researchers and practitioners are expected to evaluate the outcomes. This evaluation may include determining whether the theorized effects of the action were realized, and also if the effects relieved the problem. Where changes could not be successfully introduced, a sort of framework for the next iteration of the action research cycle should be established including the adjustment of the hypothesis.

In our case, even while the actions were still going on, we listed down the already achieved outcomes to see whether or not the actions we took had brought about beneficial changes – for example, whether the political challenges surrounding the Ethiopian ART management have been effectively addressed, and if our subsequent efforts alleviated the problems identified through the diagnosis phase. We then planned what should be done in the next iteration of the action research cycle. We have described this in chapter 7.

Specifying Learning

The knowledge gained in the action research effort (be it successful or not), can be directed to three audiences (Baskerville, 1999).

> *"First, the restructuring of organizational norms to reflect the new knowledge gained by the organization during the research, and second, where the change was unsuccessful, the additional knowledge may provide foundations for diagnosing in preparation for further action research interventions. Finally, the success or failure of the theoretical framework provides important knowledge to the scientific community for dealing with future research settings." (p. 14)*

In this phase, again while the actions were still going on, we analyzed the challenges to introduce an ART IS in Ethiopia and to make it work with a focus on the political difficulty that we had continuously been experiencing thus far, and its fundamental role and implications in the subsequent actions of introducing and making an HIV/AIDS management supporting IS work – including the design, development, implementation and scaling up of the system. Accordingly, we argue to have made triple contributions – to the theoretical, practical, and methodological knowledge – to the IS community more broadly, and more specifically to the domain of health information in developing countries.

As implied by the question mark at the bottom of Figure 3.4, the nature of this action research ‘cycle’ may change during the next iteration. For example, the action planning phase may come to its familiar place between diagnosis and action taking since during the just completed action research efforts we’ve already conducted the major parts of the diagnosis and we may need only to go to action taking phase from now on after, of course, properly planning them.

After this description of our action research approach, let us now discuss in the next section the research design.

3.8 Research Design

In the action research framework approach, our study was designed to be a multi-site research (see Table 3.1). Such a design was very helpful firstly to understand deeply and in a local and context specific manner what constitutes the challenges of making work the systems in question. Secondly, this design was useful to compare issues and identify similarities and differences so as to develop a broader understanding of what contextual influences do actually contribute to the different research processes.

Our study was principally conducted in one region in the country, Addis Ababa. However, efforts were also exerted in Amhara, Benishanguel-Gumuz, Oromia, SNNPR and Somalia regions to introduce and make the ART system work, and results were compared. These efforts, some successful and others not, made to scale up the system to the different regions in the country, helped us to compare some issues around the project. For instance, we were able to compare how the socio-political conditions in the different regions differently shaped the implementation of the ART system. While we were physically involved in all the research activities in Addis, our personal involvement in the SNNPR and other regions in the country was not that intensive. Still, the study benefited from the comparisons provided by cognate efforts made by other research participants in different regions. For example, findings and interview results found in the excerpts the SNNPR implementer sent to us which were used in this thesis to compare issues (see chapters 6 and 7).

Research Sites	Number	Type of Site	Region	Admin Level	Country
ART Clinics	5	Hospital	Addis Ababa	Regional	Ethiopia
	1	Health Facility	Addis Ababa	Regional	„
	2	Hospital	Addis Ababa	Federal	„
	1	Hospital	SNNPR	Regional	„
	1	Health Facility	Addis Ababa	NGO	„
	1	Hospital	Pretoria	District	South Africa
VCT Clinic	1	Hospital	Addis Ababa	Regional	Ethiopia
PMTCT Clinic	1	Hospital	Addis Ababa	Regional	„
ART Pharmacies	1	Hospital	Addis Ababa	Federal	„
	1	Hospital	Addis Ababa	Regional	„
HIV/AIDS and ART Supporting Stakeholders	4	HIV/AIDS and ART Stakeholders (including American Universities funded by CDC)	Operate in multiple administrative regions	Supporing Stakeholder	„
Regional Health	2	Regional Health Bureaus	Addis Ababa	Regional	„

Table 3.1: The sites we visited in the research process

Furthermore, the study also benefited from multiple opportunities we seized in the course of the research some of which had considerable significance in strengthening it. The timeline on Figure 3.5 depicts these opportunities while Table 3.2 complements this timeline offsetting it with timescale and details as to how the opportunities impinged upon the issue of "making it work". Springing from all these features of the study, an analysis of the challenges to making HIV/AIDS management supporting ISs work in Ethiopia was made, and some generalizations and conclusions were drawn (see chapter 8).

In the following section, we describe the various data collection used in our research.

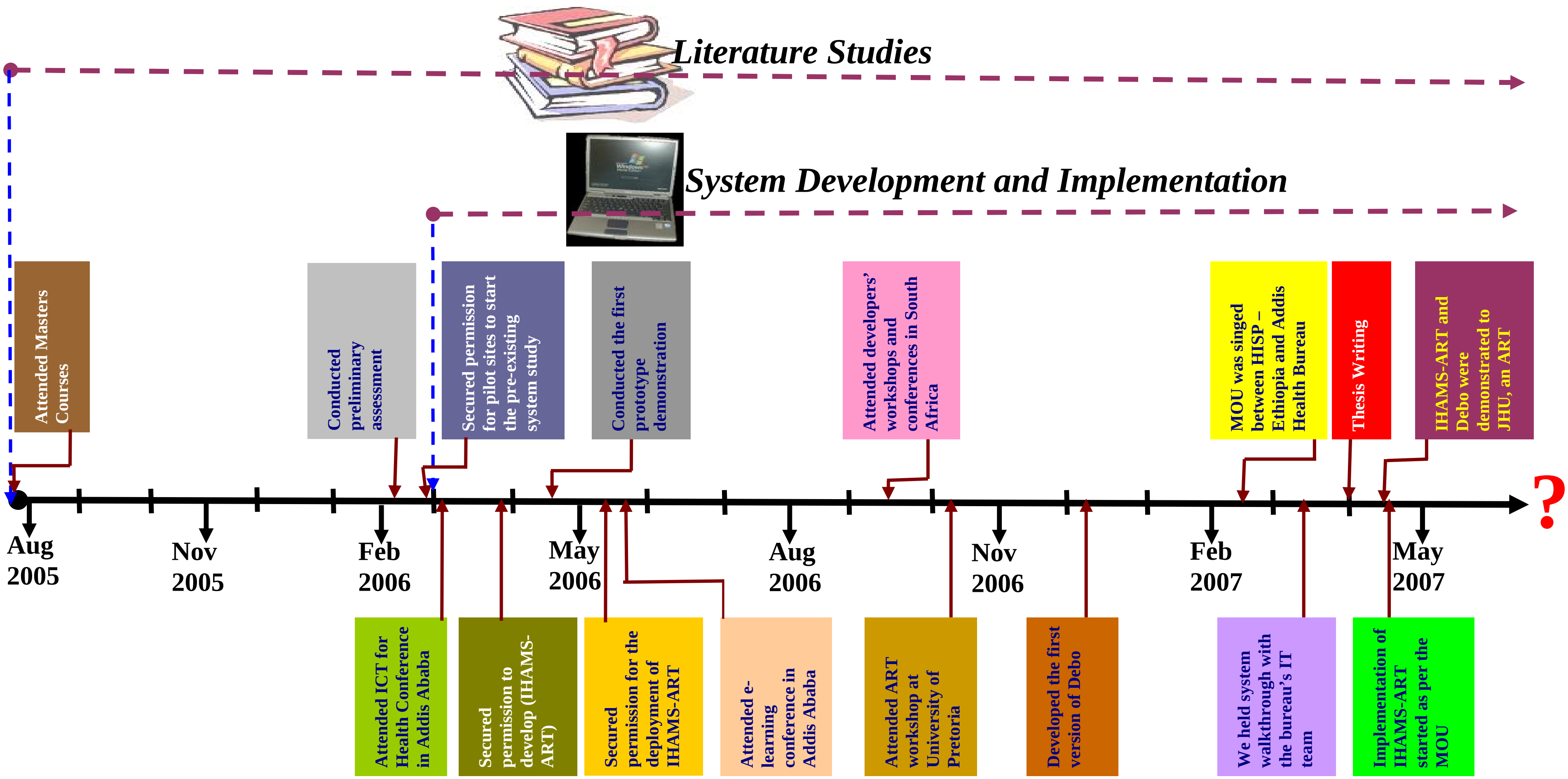


Figure 3.5: Timeline chronologically depicting the major events and opportunities in the two research years (arrows point to starting times if used for processes).

Major Research Activities and Opportunities	Timescale (some are rough estimations)	Remark
1. Attended masters courses	Aug. 2005 – June 2006	Equipped us with theoretical background on how HIS operate specifically in developing countries' context.
2. Conducted preliminary assessment of the management of the Ethiopian HIV/AIDS program including its ART initiative	Feb. 10 – 20, 2006	
3. Processed and secured permission from the Addis Ababa City Government Health Bureau (AACGHB) for pilot sites to formally conduct the study and take the necessary action interventions	Feb. 21 – 28, 2006	See the details in chapter 6
4. Actually started investigating particularly the pre-existing ART management in the country	March 1 – 14, 2006	Uniform monitoring and evaluation guideline is adopted nationally
5. Attended "ICT for Health" international conference in Addis	March 5 – 8 , 2006	HISP-Ethiopia announced the start of a work to improve ART management
6. Processed and secured permission to go ahead with the development of a scalable ART management system (IHAMS-ART) to alleviate the problems already observed	March 15 – 25, 2006	See in chapter 6 how we could systematically penetrate the politics
7. Prototype development, situation analysis, and cultivation of the prototype has been continued	March 26, 2006 – Aug. 2007	The system was being cultivated throughout
8. Conducted the first prototype demo to the regional HIV/AIDS program manager at the AACGHB	April 10, 2006	
9. Processed and secured permission for prototype deployment in some pilot clinics	May 7 – 22 , 2006	Cultivation and situation analysis still continued
10. Attended "e-learning" international conference in Addis which the regional HIV/AIDS program manager officials from the Federal Ministry of Health (FMOH) attended	May 23 – 25 , 2006	• We had a chance to make a presentation and demonstration of the system • *We experienced oppositions and sensed the political situation*
11. Intensely continued to: conduct the situation analysis by working around the prototype; cultivate the system; iteratively train users; supervise data entry and system use; look for more implementation sites in other regions including Amhara, Benishanguel-Gumuz, Oroamia, Somali, and SNNPR.	May 26 – Sept. 24, 2006	We also dealt with different HIV/AIDS and ART stakeholders and regional health bureaus *and continued to experience the political atmosphere.*
12. Attended developers' workshop; Pre-conference workshop; and then the international DHIS Conference at the Mpekweni Beach Resort, Eastern Cape, South Africa	Sept. 25 – Oct. 12 , 2006	• Data entry into IHAMS-ART has been continued in Ethiopia when we were in South Africa • We obtained comments on IHAMS-ART from the international HISP team • Saw the need especially for ART system in other countries too.
13. Attend ART workshop at the Informatics faculty, University of Pretoria, South Africa	Oct. 13– 21, 2006	• IHAMS-ART was evaluated by the Meraka researcher, the researcher from University of Pretoria and other staff and students from this university, and by some members of the global HISP team including those from Ethiopia, India, and Norway. • The process of developing a flexible integrated HIV/AIDS management system (Debo) was initiated
14. Implementation in the SNNPR region took place by a masters student under HISP	Nov. 5, 2006 – Feb. 20, 2007	The system kept cultivated from more comments from him
15. Processed to get a Memorandum of Understanding (MOU) signed between us (HISP-Ethiopia) and	Dec. 1, 2006 – Feb. 15, 2007	Data entry has been going on in some pilot clinics

AACGHB for a regional scale up of IHAMS-ART		
16. IHAMS-ART was evaluated at the AACGHB against a competing system from a local vendor in the presence of the AACGHB's head, IT team and other staff, and people from FMOH	Dec. 5, 2006	• Technical from some HIV/AIDS stakeholders also attended • It ended up with disagreements and inconclusive
17. We developed the first version of Debo with the Meraka researcher, at the HISP-South Africa's working place, in Pretoria, South Africa	Dec. 21, 2006 – Jan. 30, 2007	• The deal for the MOU continued via e-mails and phone calls when we were in South Africa • Some of the basic modules and functionalities of Debo were put in place its flexibility was tested with data elements both form Ethiopia and South Africa
18. MOU was finally signed for implementation and scale up of IHAMS-ART in all (about 67) clinics in the region	Feb. 16, 2007	See the details in chapter 7
19. Assisted AACGHB in the process to get implementation expenses covered by HIV/AIDS stakeholders	Feb. 20 – August 2007	• See, chapter 7, how we are still doing this ongoing effort
20. We made walkthrough of IHAMS-ART in one clinic with the bureau' IT team to attest it once again	March 12 – May 25, 2007	As per the agreement made in the implementation proposal which accompanied the MOU (See chapter 7)
21. Implementation attempt was made in the Amhara region by a PhD student under HISP	March 20 – April 15, 2007	Ended up uncessussfully
22. Thesis writing began	April 1, 2007	• Began immediately after we completed writing a paper for a conference in Brazil • Yet, we still needed to continue the action research efforts
23. IHAMS-ART and Debo were demonstrated at the conference room of John Hopkins University – Technical Support for the Ethiopian HIV/AIDS ART Initiative (JHU/TSEHAI), so as to persuade JHU cover the implementation expenses	April 26, 2007	Agreement was reached to sign a tripartite agreement among HISP-Ethiopia, JHU/TSEHAI, and AACGHB but was eventually unrealized *due to the continued political condition* (see why/how chapter 7)
24. Implementation attempt has been made as per the MOU despite logistic and financial constraints	April 27, 2007 – August 2007	We could not yet realize full-scale regional scale up (see the bottlenecks in chapter 7)
25. Attended international workshops on Debo both in India and Ethiopia	July 20- 23, 2007 and August 18-25, 2007	From the inventor himself, we learnt more on the technology (symfony) used for Debo.

Table 3.2: Summary of major activities performed and opportunities seized in the research, and their corresponding timescale.

3.9 Data Collection Methods

Data collection methods are techniques which take on specific meaning according to the methodology in which they are used. As mentioned previously, considering the problem areas in this thesis, qualitative methodology was applied. Yet, *"when we say that we are committed to qualitative methods,"* said Silverman (2005, p. 6), *"we still need to find answers to at least two further questions: [1] Exactly what methods do we have in mind (e.g. interviews …observations…)? [2] In what ways are these methods relevant to our research problem…?"* The information presented in this study was gathered through a combination of fieldwork methods and literature review. We made the literature review prior to, during and "after" our ongoing fieldwork. We discuss the fieldwork information, which involved going to the field and gathering information regarding different processes that occurred in the research area, as our primary source of information while we do the literature review as secondary. Both the literature review and the findings from the fieldwork together make up the foundation for the analysis and discussion in this thesis – the prime inputs to the reflections in this action research. Following this, we present a brief account of the specific data collection methods we used and their relevance, how we documented the information, and also of the validity, reliability, and reproducibility of the research.

Fieldwork Methods: Understanding through Immersion

As the system (IHAMS-ART) was to be developed and implemented around an existing set of work processes that involved structured interactions between numerous personnel both within and between organizations, ethnographic methods were used. O'Brien (1998) stated that action research is a holistic approach allowing several different tools and methods to be used. Also, Creswell (2003) argues that qualitative research is inherently multi-method in focus as it attempts to secure an in-depth understanding of the phenomenon in question and enhances the reliability of the study. Therefore, based upon the settings where we were immersed, we considered a combination of multiple ethnographic methods (Ellis, Quiroga, and Shin, 2002). Each of these methods contributed to the formation of a rich, comprehensive picture of the social, technical and political conditions that revealed both opportunities and constraints on our efforts. Also an observation measured by one means was confirmed or qualified by another observation elsewhere. Strauss and Corbin (1998) stressed such a combination approach to be useful for supplementary, complementary, informational, and developmental reasons. This was compatible with our purpose of investigating the making work of HIV/AIDS management IS.

Given the nature of the research where we were so deeply embedded especially in the everyday world of the staff in the clinics, we were engaged with multiple conversations, and are thus not able to easily list down the total numbers of each data collection method applied. Indeed, concerning the difficulty of doing so particularly in the HISP action research framework, Braa et al (2004b, p. 346) also pointed out:

> *"In HISP, the processes of data collection and analysis are inextricably interlinked. Because of the very involved nature of research where the HISP team members are literally living on site with the health staff and are continuously engaged in various activities, it is impossible to give*

quantitative details as in traditional research of the number of interviews or repeat interviews conducted. Also, there is no singular and well- defined process of analysis."

However, given this limitation, we have tried in Table 3.3 to provide a summary of the data collection methods followed by brief descriptions on some of the major methods we used.

Data Collection Methods	Numbers*	Average Duration	Major Actors Involved (research team always included)	Remarks – Significance
Visits made at ART clinics	115	1 hour	Clerks, nurses, doctors, clinic heads, some of the research participants, AACGHB's IT team	Helped to elicit requirements and business rules, to understand the different situations surrounding our efforts, and also to understand the interests of the different healthcare personnel
Document analysis/review	NA#	NA	Mainly the research team, some of the research participants, clinic staff	
Observations	throughout	throughout	Some of the research participants, clinic staff, AACGHB's IT team	
Participant observations	4	3 weeks	Mainly the research team and some of the research participants, clinic staff	
Informal interviews	NA	throughout	Clerks, doctors, clinic head, a regional program manager, a regional bureau head, some HIV/AIDS stakeholders, some of the research participants	
Semi-structured interviews	15	30 minutes	Clerks, nurses, doctors, clinic head, AACGHB's IT team, and regional HIV/AIDS program manager	
Meetings and discussions	205	1 hour	Clerks, doctors, clinic head, a regional program manager, a regional bureau head, some HIV/AIDS stakeholders, some of the research participants	Helped to elicit requirements and business rules, to learn the reactions of the health workers, and also to progressively smoothen the political difficulty
Prototyping	NA	NA	Clerks, nurses, doctors, clinic head, AACGHB's IT team, regional HIV/AIDS program manager, regional bureau head, some of the research participants, some staff from regional health bureau, some HIV/AIDS stakeholders, some officials from FMOH	
Presentations	8	30 minutes	Regional HIV/AIDS program manager, AACGHB's IT team, some of the research participants, regional bureau head, some staff from regional health bureau, some HIV/AIDS stakeholders, officials from the FMOH	Helped to gather requirements, revealed and also helped to penetrate the political atmosphere
Demonstrations of our own system/prototype	22	20 minutes	Clerks, nurses, doctors, clinic head, AACGHB's IT team, regional HIV/AIDS program manager, regional ART team leader, regional bureau head, some of the research participants, some staff from regional health bureau, some HIV/AIDS stakeholders, regional ART team leaders, some officials from FMOH	
System demonstrations made by other vendors	6	1 hour	Clerks, doctors, clinic head, AACGHB's IT team, regional HIV/AIDS program manager, regional bureau head, some of the research participants, some staff from regional health bureau, some HIV/AIDS stakeholders, regional ART team leaders, some officials from FMOH, software vendors	
Training sessions	NA	NA	Clinic staff and AACGHB's IT team	Helped to refine the system, to convince the health
Backlog data and report quality	NA	NA	Clinic staff	

* Are estimates of what was done till August 2007.
# Not applicable.

investigations				workers and gain their support
Manual and system generated reports discrepancy study and verification	5	1 day	Clinic staff and AACGHB's IT team	
System walkthrough with the IT team	3	1 day	Clinic staff and AACGHB's IT team	
Experimenting/Playing around the database after data entry	NA	NA	The research team only	
Conferences	3	2 days	Some of the research participants, some members of the broader HISP network, local and foreign people with IS and HMIS background, local healthcare officials, regional HIV/AIDS program manager, regional bureau head, clerks, doctors, clinic head, some officials from FMOH	Revealed the political dynamics especially at higher health administrative levels, comments gained from participants helped to improve the system
Workshops	8	3 days	Some of the research participants, some members of the broader HISP network, local and foreign people with IS and HMIS background	
Telephone calls	230	10 minutes	Clerks, doctors, clinic head, AACGHB's IT team, regional HIV/AIDS program manager, some of the research participants, some staff from regional health bureau, some HIV/AIDS stakeholders, regional ART team leaders, some officials from FMOH	Helped to communicate with users and research participants and to elicit requirements and business rules
e-mails exchanged	90	NA	AACGHB's IT team, some of the research participants	
Photographs	NA	NA	Some of the research participants	Helped to discern some scenes and important sayings of informants in their own words
Audio-video recordings	NA	NA	The research team only	
Literature review	NA	NA	The research team only	Helped to learn more about our broader study background – HIV/AIDS and ART, about our specific research settings, and also about relevant previous works in relation to system implementation efforts

Table 3.3: Summary of means of data collection

Visits and Discussions: *Getting Acquainted and Obtaining Overall Picture of the Environment*

Initially, through a series of visits to the clinics and discussions with clinic staff, attempts were made to get acquainted with the research environment and understand the pre-existing work practices especially at the ART clinics. We were struck by seeing the alarming number of patients who were visiting the clinics, and how poorly the information systems were organized. For example, despite the promise of anonymity, we saw prescription slips and follow-up cards of HIV/AIDS patients just scattered around the table in full view of everyone who visited. We also tried to get multiple perspectives of people involved in ART systems, from clinics, to regional and national level program managers as well as other international researchers and agencies involved in similar efforts.

***Document Review/Analysis**: A Heuristic Device to Obtaining Historical Insights of the Manual Work*

Alongside the above initial efforts to understand the pre-existing work practices, we extensively studied various documents including data capturing forms, registers and report formats, and relevant literatures obtained from ART, VCT, PMTCT clinics and an ART pharmacy from two of the regions (Addis Ababa and SNNPR) in the country. These served as heuristic devices to identify data consisting of words and images which were recorded without our intervention, and also to capture the big picture of HIV/AIDS management. The document analysis in our case was not just a supplementary form of data collection (Creswell, 2003), but it was a mandatory starting point to the system development process as we had to somehow rely on it for the system requirements which were not readily available. Moreover, from reviewing the documents, we obtained historical insights of the data recording, filling, archiving, and retrieval of information.

***Interviews and Discussions**: Learning from Sensational Expressions of Informants*

Conversations are helpful to elicit respondents' perceptions and offer chances to explore topics in depth and to gain appreciation a phenomenon under study (Conford and Smithson 1996; cited Gallis and Kasbo 2002). As one of the most common and powerful ways to understand human beings, interviewing gives room to both the interviewer and interviewee to clarify opinions and points of view through interactions (Creswell, 2003). They are also a very popular form of investigating information systems. Interviews can be performed in several different ways. In a formal interview, the interviewee is aware that the information he/she provides is recorded on tape or paper, and that the interview is a part of a research. A formal interview can have a varying degree of structure. One extreme is that all the questions are predefined – each single word might even have been decided beforehand. If more than one interview is performed, the questions are asked in the same order and same way every time. In a semi-structured interview, however, the investigator has defined some topics he/she wants to talk about but is flexible, can pick up on issues the interviewee wants to discuss, and tries to gather descriptions of the world of the interviewee with respect to interpretation of the meaning of the described phenomena. On the other extreme is the unstructured interview, where no questions are predefined. An interview can also be informal and appears for the interviewee as an occasional chat or discussion. The interviewee might or might not know that the one he/she talks to is an investigator.

In our study, we particularly exploited the powers of informal interviews since, thorough sustained efforts of cultivating and implementing the system, we were deeply immersed in the every work of particularly the clinic and the bureau staff. Data were also gathered through the conduct of semi-structured interviews and discussions, whereby each respondent was asked a series of pre-established questions in the case of the interviews. Elaborations were followed up with additional questions if a question was not understood, thus gaining further explanation and exploring answers and meanings. The interviews and discussions were made at clinics, regional health bureaus, some HIV/AIDS partners, and FMOH. And the people involved were data clerks, nurses, doctors, clinic heads, regional HIV/AIDS program managers, regional health bureau, regional health bureau IT team and other bureau staff, country directors and some IT and other staff of HIV/AIDS partners, and also some officials from the FMOH. The agendas were different according to the informants' position. For example, clerks were asked questions primarily pertaining to the use of register books and formats, ways of recording and processing data, their feelings of data and reporting quality, work load, and their views on the importance of computer-based systems for the work. These issues were cross checked with views from different clerks. At the regional level, the focus of the issues discussed was different from that in the clinics, and the questions asked related primarily to how they have been trying to address their current perceived informational problems, their plans for the future, past attempts to introduce ART software, and the need to integrate the information flows pertaining to the different programs under HIV/AIDS.

The interviews were carried out primarily in Amharic by us (the research team) and in English when others, especially the Professor, were present. A summary of the discussions took place particularly between the research team and the Professor after the meetings when the three researchers were co-located, and through e-mails when not. Discussions, with the data clerks, typically took place at their respective work sites and the lengths of the meeting were adjusted to cater to their very busy work schedules. A number of telephone conversations took place when it was not possible to meet the respondents in person, or when the bureau staff called us to get some clarification mostly on technical issues. Discussions with the clerks, the IT team, and the program manager were also many times made even when meeting them unscheduled, for example on streets and in cafés (see Figure 3.6).

Our study especially benefited from the informal interviews and discussions which took place both within the facility surroundings of the health workers and also outside where they were more relaxed. From these settings we were able to obtain their sensational expressions of their innermost feelings on topics such as the difficulty of the manual work, and also the political nature of implementation endeavors. Some of such expressions which are used word-for-word in thesis (see chapters 6-8) capture the real dynamics of our interactions with the informants which include: *"… At every corner they put hidden ditches for you to make wrong decisions and fall into. …", "...Zewditu is an island...", "...I saw* *a yellow light on the manual system...”* We believe, without such settings where we were deeply involved with our improvement efforts, we would not have got enough discernment on important topics.

Figure 3.6: Informal discussions with regional health bureau staff

However, we also benefited from the semi-structured where we forwarded explicit questions to the respondents. Such formal interviews were especially used to confirm what we already got during the informal ones since we wanted to hear conscious reactions of the respondents on some important topics. Sometimes, although we have already known some facts from our previous informal investigations, deliberately raising the same issues during the formal interviews rewarded us with more vibrant reconfirmations. For example, while we have seen for ourselves that the reports are of poor quality in many aspects, we asked a clerk how confident she was on the quality of her monthly reports. Her answer was simple but swift and firm: *“Zero!”* The expressions obtained through such interviews particularly on the political nature of IS implementing attempts around HIV/AIDS management were also directly quoted in this thesis.

***Observations**: Exploring the Problems for Ourselves*

The other mechanisms for data collection were observations. Observations produce detailed descriptive accounts of what is going on. Silverman (2000, p. 37) argues that, “if one is really to understand a group of people, one must engage in an extended period of observation”. Because there are limitations as to how much can be learned from what people say, direct observation may be the best methods to improve understanding of the program under evaluation. One gets a kind of insight into the program setting that is hard to get only trough interviews. Data derived from observations are qualitative and can take various forms – can come as statements from staff and patients, gestures and other non verbal expressions, characteristics of the physical settings, descriptions of how the work is performed, observations on the amount of the time used on the information system, and portions of time used on other tasks. Observational methods can be non-participant or participant approaches. Bell (1993) defined participant observation as “the transfer of the whole person into an imaginative and emotional experience in which the fieldworker learned to live in and understand the new world”. Silverman (2000) pointed out that “in order to understand the world ‘firsthand’, you must participate yourself rather than just observe people at a distance.” (p. 45) He also argues that extended observation is a better method to really understand what people or a group of people does in their natural work environment.

Both participant and non-participant observations were employed in our case. Especially during the initial phase of the project, we spent more than three weeks directly participating in the clerks’ work. In this time, we usually compared what we were told in the interviews and what we saw in the real situation. Although this was time consuming, we were rewarded by getting a more stunning impression of the working conditions. For instance, we were observing and understanding the forms, data elements and surrounding work procedures while helping the clerks in their actual daily routine work. We also observed how the clerks actually captured data and prepared reports, the time taken for some of these tasks, the number of patients visiting the clinic a day, and other events of interest. These observations helped to develop a richer and deeper understanding of the embedded work practices, the context, and the social and political conditions shaping the information flows. For example, we could better understand how, because of the heavy patient-loads and difficulties in retrieving data, the clerks were often forced to invent their own formats and procedures to ease their work which adversely influenced data quality, and also to compromise on the quality of the reports. Furthermore, through the process of participant observation, we developed a trust based relationship with the data clerks, who soon started to give us intimate details of the problems they faced with previous systems. These insights were very useful to us in defining the scope and details of system design. Also, the relationship we developed with the clerks this way had political significances (see chapter 6 and 7).

***Prototyping**: Gaining Insights into Analysis Needs and Living in the Software Politics*

Yet another very important source of data collection was the system prototyping process. Prototypes are ‘instruments’ used within software development process to elicit user needs and detect problems earlier, and the design is potentially of higher quality and requires less effort to be used (Sommerville, 2001). Prototyping is also a method of data collection within evolutionary system development where system users participate as their requirements are incrementally incorporated during the cultivation process.

During the evolutionary prototyping process, we first focused on developing rapid versions of the system; placing them in the clinics; making demonstrations to the regional HIV/AIDS program manager and his IT team, to the clerks, and to the bureau and clinic staff; and getting their feedbacks. These were very useful inputs for making quick revisions to the system, and also helped to build a sense of involvement and system ownership amongst the users which gradually helped us gain political backing from them. For example, as the frequency of our interactions with the user community increased, we more ascertained the requirements and gained insights into their analysis needs such as of patients who dropped out, missed follow-ups or had poor adherence to the prescribed drug regimes – very important variables in ART, as we will discuss in the following two chapters (4 and 5). Based on these insights, on our own initiative, we designed reports containing key details of the variables that most interest especially the medical doctors. The informal onsite trainings on the prototypes conducted iteratively and the system walkthrough sessions were important means of fulfilling user requirements. Although all the data collection methods we used mutually support and complement one another, our immersion especially in the prototyping processes made clear to us not only the ART requirements but also the socio-political condition surrounding the effort to support ART with an IS as different reacted differently toward our system other systems that emerged in the process (see chapter 6 and 7).

Self Impressions: *What We Felt about Where We were Living*

In qualitative research, what happens in the field, as one attempts to gather data, are themselves sources of data in addition to being mere technical problems. For example, after the regional health bureau's IT acknowledged the effectiveness of the system, it took us a 10 months work processing to get the region sign MOU for regional implementation. Also, even after the MOU was signed it has now already taken a year and we could not yet get the region arrange formal training to clerks and launch the system. These and other happenings we perceived in the course of the research demonstrated and translated by us as to how the development and implementation efforts have been undertaken in a highly bureaucratic and political condition.

Conferences, Workshops, and Other Sessions: *Discerning Software Politics Directly from Platforms*

Of particular significant data collection methods in clearly revealing to us the political dynamics around the attempt to put such systems in place were: presentations we progressively made to the bureau staff and some HIV/AIDS stakeholders in different meetings; system demonstrations we made to various HIV/AIDS partners; system demonstrations made by other venders which we attended as these systems were to be evaluated against ours in the presence of influential audience; and different conferences and workshops we attended together with high level officials and made presentations system demonstrations. In chapters 6 and 7 we have included some quotes which we jotted down or recorded directly from these platforms as we thought they, especially the heated debates in conferences about our system, would vividly exhibit the political manifestations. These sessions also provided us national visibility.

Other Methods: *Qualifying the Data*

Still other data collection methods were photographs, emails, and audio-video recordings. We captured different photographs displaying our observations on data collection tools, infrastructures, filling systems, the informal onsite training sessions. Photographs were also captured during conferences and workshops, presentation and demonstration sessions, visits, and meetings and discussions. We also took pictures of our activities to improve the Ethiopian ART management – system development, installation, training, data entry, report verification, and providing support. Screenshots of IHAMS-ART were taken and used in describing the case. Two Professors from UiO have supplied us pictures of important scenes especially the ones they captured when they visited our sites in Ethiopia and these were used in this thesis. We believe that these photographs help to enrich our description of contexts. The emails we exchanged with informants and some of the research participants were also important source of data for the analysis in this thesis, and we have included some of them in the upcoming chapters. Further, the recordings were also useful as we could, for example, listen to some of them latter to expand field notes and properly analyze specific comments provided such as during interviews after fully understanding their real feelings from the pauses and other characteristics recorded.

Other primary data collection methods – such as our experimenting and playing around the IHAMS-ART database after data entry, manual and system generated report discrepancy study and verification, and also backlog data and report quality investigations – used and their relevance are summarized in Table 3.3.

Literature Review: A Secondary Means of Data Collection

Strauss and Corbin (1998) suggest that literature review is a good way to begin a research as it lets the researcher to enter into the field with a general notion of what is to be studied. At different periods in the research, we did literature review in order to obtain a general understanding of our study background – HIV/AIDS and ART. We also reviewed literature aiming at understanding the situation of both HIV/AIDS and ART in specifically in Ethiopia with a focus on the country's ART management. Moreover, especially after selecting our specific study topic, we did intensive review of various literatures to gain insight on the general theme of this thesis.

Information Documentation: Basis for Interpretation and Analysis

In the course of the research, we organized information both from the fieldwork and literature review. A research diary was maintained to document notes and our individual impressions. Extensive longhand notes were often taken on the spots during each data collection method mentioned above and were more organized often by the end of the day. For instance, during each observation as well as conference and workshop sessions we managed to take notes in brief and expanded the notes immediately afterward including details of responses provided, and this was more enhanced by our working in a pair. The notes were often taken in English except for some words which were initially jotted down in Amharic to later find their appropriate equivalence in English for the writing. These notes were also later developed by summary of discussions especially with our Professor and were typed up in greater detail. The field notes were fundamental for the task of reconstructing the context and understanding the process in the interpretation stage of the research. But they were also very important as we, for instance, depended on them to draw diagrams and flow charts to show the flow of data within ART which we could not otherwise find as the client did not have one. Also, how our research went about and the distinguished research cycle we followed were formulated as realities from our field notes in which we have been properly describing our research trajectories (see Figures 3.1, 3.2, and 3.4).

In addition to hand written notes, our documentation was complemented by other information documentation methods. For instance, when conditions permitted us, automatic audio-video recordings were made, for example during interview, and were used later. Photographs of different scenes, data capturing and reporting formats, and pages of registers were preserved to provide more authenticity to our interpretations. Important, pictures, tables, and graphs obtained from the internet and other materials were documented and used especially in the descriptions of our research background (chapter 4) and the research settings (chapter 5). We also gathered presentation slides and other materials from the clinics. Important emails were marked, and excerpts from some research participants and some letters we exchanged with the health bureau were archived and used later. Further, during literature review, materials were filed in relation to HIV/AIDS and ART, their situation in Ethiopia, and those concerning IS development and implementation conditions. By and large, that we properly and carefully documented the information we gathered from different sources served as a strong point of departure into the analysis.

3.10 Modes of Data Analysis and Interpretation

In this section we discuss our techniques of empirical data analysis – the processes by which we selected, focused, simplified, abstracted, and transformed the data we collected. We first describe the nature of data analysis in qualitative studies in general, then the specific techniques adopted in our case.

Data Analysis in Qualitative Researches – Characteristics and Limitations

In collecting qualitative data, the researcher seeks to capture the richness of people's experience in their own terms. However, the subjectivity of qualitative methods – the subjectivity of the researcher apropos assumptions, meanings and prejudices – influences not only the way the data is documented but also the subsequent analysis and interpretation of results. Qualitative data are not easily comparable. Furthermore, qualitative results are often more difficult to analyze, generalize and draw conclusions since the answers contain very rich information and details, and responses are neither systematic nor standardized. More specifically, concerning the difficulty of qualitative analysis particularly in the HISP action research framework, Braa et al (2004, p. 346), as pointed out previously, stated that *"in HISP, the processes of data collection and analysis are inextricably interlinked … [and] there is no singular and well- defined process of analysis."* Given this innate limitations of qualitative analysis, we provide below our techniques of analysis.

Our Techniques of Data Analysis

Our data analysis techniques were applied on the data we gathered primarily from fieldwork with the purpose of developing an understanding or interpretation of what was going on during the study. The data was mainly analyzed by qualitative content analysis method which is an analytical method of coding and classifying non-numeric data (Denzin and Lincoln, 1994; Downe-Wambolt, 1992; Moen, 2002; Morgan, 1993). We found this method suitable for analyzing verbal and written materials, the form in which most of our data is available, and to set off categories for developing inferences. As we kept identifying and organizing our data some specific issues such as the political nature of software implementation became crispier (Denzin and Lincoln, 1994).

The analysis was conducted as we maintained contact with many of the stakeholders, informants especially from the clinics and the health bureau, and also other research participants including our research advisor. Initially, we reviewed the data with the aim to obtain confirmation of findings through convergence of different perspective which involved testing one source of information against another to improve the quality and accuracy of findings before drawing conclusions. This included the technique of comparing explanations drawn from different sources – our own observations, descriptions of our advisor, explanations of informants, etc. In effect, isolated findings which were not supported by other sources of data were either disregarded or served as the basis for further investigation. After reviewing our data, the analysis typically consisted of grouping written materials into first-order data and second-order analytical concepts.

Kept in the first-order data were the constructions of interviewees and informants, and were developed from interviews, presentations, system demonstrations, and meetings and discussions. Also in the first-order data were the constructions of the research team, our research advisor, and the other research participants. These constructions were developed from such other sources as observations, conferences, workshops, and meetings and discussions. Although, the analysis of first-order data derived from interviewees and informants was inevitably constrained by the interpretation of the research team, bias was minimized, for example, by conducting interviews in an unstructured manner and through sustained interactions over the period of the research, and also through comparisons of data from different sources. This provided an opportunity to develop better understanding various contexts which added depth to the analysis. The second-order analytical concepts were, on the other hand, informed by literature review. The background knowledge we gained through literature study (see chapter 2) guided the coding and reorganizing of our data to a more focused theme.

The process of data analysis was undertaken in parallel with the conduct of the empirical research and was made at every important step of observation. The overall focus was on understanding the pre-existing Ethiopian ART management system, its characteristics and work practices, how various partners surrounding the ART initiative interact, how these influence development and implementation attempts of a supporting IS, and, most important, what it seeks to make this IS work in practice in the given context. Primarily, using the data we collected we incrementally analyzed the requirements which led to the development and implementation of the prototype where we actively participated. As we were watchful, this process, in turn, vividly revealed to us not only the work practices in the ART clinics but also the challenges surrounding our improvement efforts especially the political ones. In time, we applied various approaches and strategies to penetrate the unfavorable conditions and make the system work. While analyzing the findings from these efforts, the literature review equipped us with theoretical perspectives which helped us to develop the theoretical framework guiding this research (see chapter 2).

Meanwhile, the meanings of the raw data and our analyses were progressively discussed among ourselves. Discussions on these were also made with various research informants including the Addis regional HIV/AIDS program manager and his IT team, some of the clinic staff, and with many research participants including our research advisor. Typically, findings were compared, for example, with those of the SNNPR implementer who has been exerting similar efforts in that region. These discussions helped to gain feedback to our analysis and to further enrich the understanding process, thus developing coherence in interpretations, and also understanding of contexts. After discussing on the meanings of the empirical material, we developed narratives of our concrete research activities (see chapters 6 and 7). For these descriptions, issues were selected with regard to the problems of ART management and the environment enveloping our efforts to support it with an IS. Some quotes were interpreted to reflect the political conditions surrounding these efforts as the wordings of the health workers who stated the quotes manifests so. Also, in addition to the clear quotes from informants interpreted to emphasize the problems in ART management, inferences were supported by the use of photographs which depict the poor data management system. Both of these pieces of evidence contributed to the interpretation of the challenges in the practices of health staff, and the politics hindering the provision of solutions to these problems.

In summary, a sort of cultivation approach characterizes the analysis process where inputs were coming from various sources such as discussions, and findings were incrementally communicated between ourselves and with other researchers. With certain concepts drawn from literature, the inductive and cyclic[#] characteristics of qualitative study were reflected in our analysis, thus making it dialectic rather

[#] Learn something (collect some data), make sense out of it (analyze), go back and see if the interpretation makes sense in the light of new experience (collect more data), then refine the interpretation (analyze more), and so on.

than linear (Agar 1980). We first analyzed our case to identify issues such as politics and then compared results with others. Finally, we related the overall result to the theoretical concepts and existing knowledge in the relevant domain from literature to draw more general inferences which are presented in chapter (8).

In chapter 2 we have reviewed relevant literatures and established the theoretical framework guiding this research. In this chapter (3) we have described the research methods. Now, before we discuss in detail the different phases that our action research needed to evolve through, let us provide consecutive discussions on the broader research background – HIV/AIDS and ART – in the next chapter (4) and also on our research context in chapter 5 where we navigate the specific research settings. Following these discussions we will present our concrete research activities in chapters 6 and 7 where the different phases of the action research are also described. The study will then be concluded by the *Analysis and Discussions*, and the *Conclusions* chapters (8 and 9).

4 HIV/AIDS and ART: The Research Background

4.1 Introduction

Before diving straight into the different facets of the actual research reported in this thesis, we discuss in this chapter the broader research context including background information on the HIV/AIDS (the human immunodeficiency virus that causes acquired immunodeficiency syndrome) epidemic and its antiretroviral treatment/therapy (ART). Following this, in the next chapter we discuss these issues in the specific context of Ethiopia where this research was conducted. The information, concepts and technical terminologies in terms of which this chapter is composed will be helpful to understand the discussions in the rest of the chapters. The detailed discussions about the nature of the disease and its antiretroviral treatment help to see the significance of ISs that support HIV/AIDS management. Most importantly, the discussions provide background information on some important issues around the efforts to introduce and make work such ISs.

Accordingly, the chapter is organized in the following manner. In section 4.2 we briefly present the global spread of HIV/AIDS and some of its major consequences. Section 4.3 continues to discuss some of the technical aspects surrounding HIV/AIDS including its nature and means of spread. After presenting the most important impacts of HIV/AIDS in section 4.4, a description of global responses against the epidemic is provided in section 4.5. The multiplicity of HIV/AIDS-related programs (including, PMTCT, TB, VCT, Home-Based Care, STI, and OI), and the multiple national and international stakeholders associated with these initiatives and the informational problems accompanying them are then discussed. This provides the context of our research, and its implication for supporting ISs. Then, with a brief technical explanation specifically on ART, section 4.6 particularly attends to the significance of ART in averting the impacts of AIDS but also how peculiar and challenging its administration is, and the urgency of supporting it management with an IS.

4.2 Global Spread and Consequences of HIV/AIDS

The scale of the AIDS crises now outstrips even the worst-case scenarios of a decade ago. Dozens of countries are already in the grip of serious HIV/AIDS epidemics, and many more are on the brink. Today, around the world, an estimated 12 000 people are newly infected with HIV everyday. In 2006 alone, AIDS claimed an estimated 2.9 million lives – more than in any previous year – and an estimated 4.3 million people were newly infected with the virus, 530 000 of them being children (see Table 4.1 for the year's summary). To make matters worse, more than 95% of these new infections are in low- and middle-income countries. Amongst adults 15 years and older, young people (15 to 24 years) accounted for 40% of new HIV infections. In fact, AIDS has become the leading cause of death among 15- to 24-year-olds. Globally, and in every region, more women than ever before are living with HIV (UNAIDS/WHO, 2006). The 17.7 million women living with HIV in 2006 represented an increase of over one million compared with 2004. More and more people are fearful of contracting AIDS. The future holds the frightening prospect of a much more widespread illness. The epidemic's full effect is obscured by fear, denial, limited treatment and a lack of public health resources.

World Health Organization | UNAIDS

Global summary of the HIV and AIDS epidemic, 2006

Number of people living with HIV in 2006	Total	39.5 million [34.1 – 47.1 million]
	Adults	37.2 million [32.1 – 44.5 million]
	Women	17.7 million [15.1 – 20.9 million]
	Children under 15 years	2.3 million [1.7 – 3.5 million]
People newly infected with HIV in 2006	Total	4.3 million [3.6 – 6.6 million]
	Adults	3.8 million [3.2 – 5.7 million]
	Children under 15 years	530 000 [410 000 – 660 000]
AIDS deaths in 2006	Total	2.9 million [2.5 – 3.5 million]
	Adults	2.6 million [2.2 – 3.0 million]
	Children under 15 years	380 000 [290 000 – 500 000]

Table 4.1: Global summary of the AIDS epidemic. Source: UNAIDS 2006 AIDS Epidemic Update, December 2006

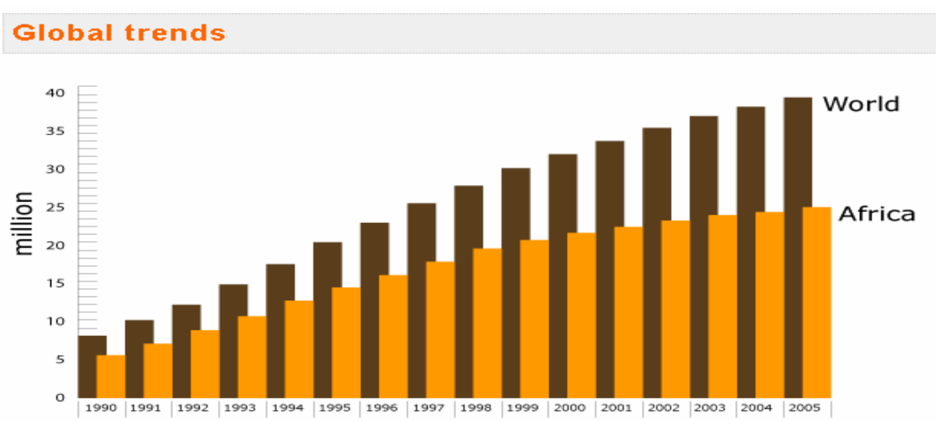


Figure 4.1: Global trends of people living with HIV. Source: (www.avert.org)

While new infections in 2006 remained roughly the same as in 2004 in Latin America, the Caribbean and North America, the number of people living with HIV generally increased in every region in the world in the past two years (see Table 4.2 and Figure 4.1). The most striking increase has occurred in East Asia, Eastern Europe, and Central Asia, where the increase was over 21% higher in this two year period. The 270 000 adults and children newly infected with HIV in Eastern Europe and Central Asia in 2006 showed an increase of almost 70% (over the 160 000 people) over 2004. In South and South-East Asia, the number of new HIV infections rose by 15% in 2004–2006, while in the Middle East and North Africa it grew by 12% (ibid; UNAIDS, 2006). This clearly emphasized the unprecedented scale of the epidemic.

> *"History will judge us harshly if we fail [to combine efforts and save people] now, and right now."* – Former South African President Nelson Mandela in his address to the 13th International AIDS conference.

HIV/AIDS marks a severe development crisis particularly in sub-Saharan Africa which continues to bear the brunt of the global epidemic. Declines in national HIV prevalence* are being observed in some sub-Saharan African countries, but such trends are currently neither strong nor widespread enough to diminish the epidemics' overall impact in this region. With almost 25 million (63% of all persons with HIV globally) cases, sub-Saharan Africa remains the hardest-hit and by far the worst affected region in the world, followed by South and Southeast Asia with 7.8 million infected. Two thirds (63%) of all adults and children with HIV globally live in sub-Saharan Africa, with its epicenter in southern Africa. One third (32%) of all people with HIV globally live in southern Africa and 34% of all deaths due to AIDS in 2006 occurred there. Almost three quarters (72%) of all adult and child deaths due to AIDS in 2006 occurred in sub-Saharan Africa – 2.1 million of the global total of 2.9 million (UNAIDS/WHO, 2006).

Overall, sub-Saharan Africa is home to shocking number of adults and children infected with HIV and the trend shows that the situation is worsening – the figure for 2006 being 1.1 million more than that of 2004. The number of children orphaned by AIDS in the region has kept increasing. While people of all ages are affected by HIV, significant numbers of those infected are in the 25-45 age group. This group is particularly important not only in terms of economic productivity but also as those who provide care, parents and providers. The loss of productive workers and increases in spending on health care and social services require difficult decisions about resource allocations across all governmental sectors (UNAIDS, 2005b). And, across all age groups, nearly 60% of all people living with HIV in the region

* When talking about HIV and AIDS figures, the terms 'incidence' and 'prevalence' are used. HIV 'incidence' is the number of new cases of HIV in the population during a certain time period. People who were already infected before that time period are not included in that figure, even if they are still alive. HIV 'prevalence' is given as a percentage of sample population.

are women (ibid). This group contributes to over 50% of food production in the region and typically carries out the most labor-intensive farming activities in addition to being usually responsible for preparing food at home. For every ten adult men living with HIV in the region, there are about 14 adult women who are infected with the virus. Still, women are more likely than men to be infected with the virus, and they are also more likely to be the ones caring for people living with HIV/AIDS (PLWHA) (UNAIDS, 2002).

	Adults and children living with HIV	Adults and children newly infected with HIV	Adult (15–49) prevalence (%)	Adult and child deaths due to AIDS
Sub-Saharan Africa				
2006	24.7 million [21.8–27.7 million]	2.8 million [2.4–3.2 million]	5.9% [5.2%–6.7%]	2.1 million [1.8–2.4 million]
2004	23.6 million [20.9–26.4 million]	2.6 million [2.2–2.9 million]	6.0% [5.3%–6.8%]	1.9 million [1.7–2.3 million]
Middle East and North Africa				
2006	460 000 [270 000–760 000]	68 000 [41 000–220 000]	0.2% [0.1%–0.3%]	36 000 [20 000–60 000]
2004	400 000 [230 000–650 000]	59 000 [34 000–170 000]	0.2% [0.1%–0.3%]	33 000 [18 000–55 000]
South and South-East Asia				
2006	7.8 million [5.2–12.0 million]	860 000 [550 000–2.3 million]	0.6% [0.4%–1.0%]	590 000 [390 000–850 000]
2004	7.2 million [4.8–11.2 million]	770 000 [480 000–2.1 million]	0.6% [0.4%–1.0%]	510 000 [330 000–740 000]
East Asia				
2006	750 000 [460 000–1.2 million]	100 000 [56 000–300 000]	0.1% [<0.2%]	43 000 [26 000–64 000]
2004	620 000 [380 000–1.0 million]	90 000 [50 000–270 000]	0.1% [<0.2%]	33 000 [20 000–49 000]
Oceania				
2006	81 000 [50 000–170 000]	7100 [3400–54 000]	0.4% [0.2%–0.9%]	4000 [2300–6600]
2004	72 000 [44 000–150 000]	8000 [3900–61 000]	0.3% [0.2%–0.8%]	2900 [1600–4600]
Latin America				
2006	1.7 million [1.3–2.5 million]	140 000 [100 000–410 000]	0.5% [0.4%–1.2%]	65 000 [51 000–84 000]
2004	1.5 million [1.2–2.2 million]	130 000 [100 000–320 000]	0.5% [0.4%–0.7%]	53 000 [41 000–69 000]
Caribbean				
2006	250 000 [190 000–320 000]	27 000 [20 000–41 000]	1.2% [0.9%–1.7%]	19 000 [14 000–25 000]
2004	240 000 [180 000–300 000]	25 000 [19 000–35 000]	1.1% [0.9%–1.5%]	21 000 [15 000–28 000]
Eastern Europe and Central Asia				
2006	1.7 million [1.2–2.6 million]	270 000 [170 000–820 000]	0.9% [0.6%–1.4%]	84 000 [58 000–120 000]
2004	1.4 million [950 000–2.1 million]	160 000 [110 000–470 000]	0.7% [0.5%–1.1%]	48 000 [34 000–66 000]
Western and Central Europe				
2006	740 000 [580 000–970 000]	22 000 [18 000–33 000]	0.3% [0.2%–0.4%]	12 000 [<15,000]
2004	700 000 [550 000–920 000]	22 000 [18 000–33 000]	0.3% [0.2%–0.4%]	12 000 [<15 000]
North America				
2006	1.4 million [880 000–2.2 million]	43 000 [34 000–65 000]	0.8% [0.6%–1.1%]	18 000 [11 000–26 000]
2004	1.2 million [710 000–1.9 million]	43 000 [34 000–65 000]	0.7% [0.4%–1.0%]	18 000 [11 000–26 000]
TOTAL				
2006	39.5 million [34.1–47.1 million]	4.3 million [3.6–6.6 million]	1.0% [0.9%–1.2%]	2.9 million [2.5–3.5 million]
2004	36.9 million [31.9–43.8 million]	3.9 million [3.3–5.8 million]	1.0% [0.8%–1.2%]	2.7 million [2.3–3.2 million]

Table 4.2: Regional HIV and AIDS statistics and features, 2004 and 2006. Source: UNAIDS 2006 AIDS Epidemic Update, December 2006.

Southern Africa is where the epidemic is the most severe in the world. The HIV epidemics in Mozambique and Zambia continue to grow and there is no evidence of a decline. Similar patterns are visible elsewhere. An estimated one in three (33%) adults in Swaziland was living with HIV in 2005—"the most intense epidemic in the world" (UNAIDS/WHO, 2006; Carroll, 2003). If a natural HIV prevalence limit does exist in these countries, it is considerably higher than previously thought. Startling as these prevalence levels are, they do not reflect the actual risk of acquiring HIV, especially in specific groups.

> ***Some sad consequences of HIV and AIDS***
>
> - *12 000 people are newly infected with HIV everyday.*
> - *4.3 million people were newly infected last year alone.*
> - *95% of these new infections were in low- and middle-income countries.*
> - *Hosting almost 25 million (63% of all persons with HIV globally) cases, sub-Saharan Africa remains the hardest-hit and by far the worst affected region in the world.*
> - *60% of all people living with HIV in sub-Saharan Africa are women.*
> - *About 40 million people are living with HIV/AIDS now.*
> - *In less than two decades, more than 65 million people have contracted HIV globally.*
> - *8,000 people are dying from AIDS every day.*
> - *Last year alone nearly 3 million people died of AIDS.*
> - *Children, young people, and women are particularly affected by the virus and the epidemic it causes.*
> - *More than 25 million people have died of AIDS since the first clinical evidence of HIV/AIDS was reported in 1981.*
> - *The epidemic continues to expand reducing world population estimates by 0.4 billion to 8.9 billion for 2050.*

In South Africa, which in terms of sheer numbers has one of the world's largest HIV epidemics, some 5.5 million people, including 240 000 children younger than 15 years, were living with HIV in 2005 (UNAIDS/WHO, 2006). HIV data gathered in the country's extensive antenatal clinic surveillance system suggest that HIV prevalence has not yet reached a plateau (Department of Health South Africa, 2006). It is not surprising, therefore, that in his address to the 13th International AIDS Conference held in Durban in July 2000, the first time that such a conference was held in a developing country or in Africa, the former South African President Nelson Mandela, who himself lost his son to AIDS, lamented: "*We were shocked to learn that within South Africa 1 in 2, that is half, of our young people will die of AIDS. The most frightening thing is that all of these infections, which statistics tell us about, and the attendant human suffering … could have been, can be, prevented.*" He closed the conference with a call for action to combine efforts and save people saying "*history will judge us harshly if we fail to do so now, and right now.*" (Sidley, 2000)

By and large, globally, the epidemic continued to expand, reducing world population estimates by 0.4 billion to 8.9 billion for 2050 (Schlagenhauf and Ashraf, 2003). In less than two decades, more than 65 million people have contracted HIV globally. Currently, the UN agency estimates that more than 39 million people are infected with HIV (UNAIDS/WHO, 2006). Without effective treatment and care, they too will join the ranks of the more-than-25 million people who have died of AIDS since the first clinical evidence of HIV/AIDS was reported in 1981. It is equally clear that the vast majority of people (including those living in countries with high national HIV prevalence) have not yet acquired the virus. Enabling them to protect themselves against HIV; and providing adequate, affordable and effective treatment and care to people already living with the virus, representing two of the biggest challenges facing humankind today (www.the-south-asian.com, UNAIDS, 2002). Not surprisingly, AIDS is now a prominent issue at international gatherings – North and South. It has been on the agenda of summits and decision-making forums of the G8 and G77 nations, the Organization of Africa Unity, the European Union, the Association of South-East Asian Nations, and the Caribbean Community Secretariat (CARICOM). Both the World Economic Forum and the World Social Forum have held key sessions on AIDS and its global implications.

What is this HIV/AIDS that is devastating the world so much? The next section attends to describe this subject which provides some information about the content of the IS we are seeking to develop.

4.3 HIV/AIDS – Nature and Transmission

AIDS is a disease caused by HIV which strikes at the heart of the immune system. The immune system is the body's defense against infections by microorganisms (such as very small bacteria or viruses) that get past the skin and mucous membranes and cause diseases. It produces special cells called antibodies to fight off or kill these microorganisms. A special weakness of the immune system is called an immunodeficiency. Human immunodeficiency virus (HIV) infects, and eventually progressively destroys a particular class of special cells in the immune system called lymphocytes and monocytes. These cells carry the CD4 antigen (key components of the immune system) on their surface (CD4+ lymphocytes). HIV recognizes the CD4 antigen and enters and infects CD4+ lymphocytes. The result is the killing of many CD4+ lymphocytes. This slowly leads to the incapacitation of an extremely important part of the individual's defenses and to a persistent, progressive and profound impairment of the immune system, making an individual susceptible to infections and conditions such as cancer. After that, infections recur and are never completely eradicated. In fact, they get worse, and the body is left without the means for defending itself like a city in ruins, without walls, that can be conquered by anyone (Hardon et al., 2006).

Once the infection progresses, the immune status of the individuals becomes depressed and they become vulnerable to a range of different illnesses, called opportunistic infections, the first of which is often tuberculosis. Many other conditions may also emerge, including pneumonia, some cancers, meningitis and fungal infections. HIV is thus the beginning stage of infection. When the immune system becomes very affected, the illness progresses to AIDS (acquired immunodeficiency syndrome) and the infected individual is said to have advanced to full-blown AIDS as the HIV has succeeded in crippling the whole immune system. AIDS kills because the individual's immune system is not able to fight infections. Blood tests, or the appearance of certain infections, indicate that the infection has progressed to AIDS. Almost all, if not all, HIV-infected people will ultimately develop HIV-related disease and AIDS. This progression depends on the type and strain of the virus and certain host characteristics. Factors that may cause a faster progression include age of less than 5 years, or over 40 years, other infections, and possibly genetic (hereditary) factors. HIV infects both the central and the peripheral nervous system early in the course of infection causing a variety of neurological and neuropsychiatric conditions.

HIV can be spread through sperm, blood, breast milk and vaginal secretions. Unprotected sex is the most common route of transmission. However, among particular risk groups, other methods of transmission may be dominant. Mother to child transmission (MTCT) of HIV – which can occur during pregnancy, labor, and delivery in addition to breast feeding (approximately 30%) – are also the major means of HIV infection in children. This highlights the need to on focus prevention, treatment and care strategies effectively on population groups that are most at risk of HIV infection. One terrifying thing about AIDS is the long period of latent infection that precedes the actual physical symptoms of full-blown AIDS. For 8-12 year olds, the infected carrier may harbor the deadly HIV in his/her body while having a disguised healthy look and feel. Unless the victim has undergone a test for the disease, he/she will never know that he/she faces the terminal illness – until the symptoms strike! It is this seemingly healthy, yet infected, segment of the population that is unwittingly spreading AIDS (Hardon et al., 2006).

4.4 Impacts of HIV/AIDS

Twenty six years after the world first became aware of AIDS, it is now quite clear that humanity is facing one of the most devastating epidemics in history – one that threatens development in major regions of the world. Since the 1960's, most countries have made impressive strides in human development. However, such achievements are being undermined as countries lose young, productive people to the epidemic, economies stumble, households fall into deeper poverty, and the costs of the epidemic mount. Despite this devastation, however, it is clear that the epidemic is still in its early stages. Countries that fail to bring the epidemic under control risk becoming locked in a vicious circle as worsening socioeconomic conditions render people, enterprises and communities even more vulnerable to the epidemic.

Granted, the most obvious and visible effect of the AIDS crisis on human welfare has been illness and increment of general and age-specific mortality rates. Nevertheless, the impact of the pandemic has certainly not been confined to the health sector. While the impact of the AIDS epidemic especially on middle- and low-income societies remains to be felt most strongly in the course of the next ten years and beyond, its social and economic consequences are already widely felt, not only in the health sector but in all walks of society – households, workplaces, education, industry, agriculture, transport, security, human resources and the economy in general. We now discuss some of the key impacts of HIV/AIDS.

The demographic impact

As mentioned previously, more than 65 million people have been infected with the virus since the epidemic began. HIV/AIDS is now by far the leading cause of death in sub-Saharan Africa, and one of the biggest global killers. The rapid increase in AIDS related mortality, particularly in low-income countries is eroding the gains made in reduced mortality and increased survival probabilities at all ages.

In many countries, AIDS is also erasing decades of progress made in extending life expectancies. For example, millions of adults in sub-Saharan Africa are dying from the epidemic while they are yet young or in early middle age. In the worst affected countries, AIDS has wiped out 50 years of development gains, measured in terms of improved life expectancy. Average life expectancy in Sub-Saharan Africa is now 47 years, when it could have been 62 without AIDS. Life expectancy is dropping to levels not seen since the 1960s and hard won gains in child survival are being reversed. Life expectancy at birth, for instance, in Botswana fell from 65 years in 1990-1995 to less than 40 years in 2000-2005 – a figure about 25 years lower than it would have been without AIDS, and a drop to a level not seen in that country since before 1950 (UN, 2004). We can see why the President, Festus Mogae, in an address to the UN assembly in June 2001, lamented at the situation saying: *"We are threatened with extinction. People are dying in chillingly high numbers. It is a crisis of the first magnitude"* (Farley, 2001). Worse still, losing 29 years, in Zimbabwe life expectancy became 40 instead of 69. Average life expectancy for women, who are particularly affected by Zimbabwe's AIDS epidemic, is 34 – the lowest anywhere in the world (WHO, 2006).

In short, AIDS mortality is resulting in population pyramids that have never been seen before in Africa. The death toll has kept rising. In 45 most affected countries, it is projected that, between 2000 and 2020, 68 million people will die earlier than they would have in the absence of AIDS. These projections are based on the assumption that prevention, treatment and care programs will have a modest effect on the growth and impact of the epidemic in most countries over the next two decades. The projected toll is greatest in sub-Saharan Africa, where 55 million additional deaths can be expected – 39% more deaths than would be expected in the absence of AIDS.

The Impact on Households

The toll of HIV/AIDS on household can be very severe. In many cases, the presence of AIDS means that the household will dissolve, as parents die and children are sent to relatives for care and upbringing. For example, in Zambia 65% of households in which the mother had died had dissolved. But much happens to a family before this dissolution occurs; HIV/AIDS strips the family of assets and income-earners, further impoverishing those already poor. A study of three countries (Burkina Faso, Rwanda and Uganda) has calculated that AIDS not only reverses efforts to reduce poverty, but will increase the percentage of people living in extreme poverty from 45% in 2000 to 51% in 2015 (UNAIDS, 2002).

Loss of income, additional care-related expenses, reduced ability of caregivers to work, and mounting medical fees and funeral expenses collectively push affected households deeper into poverty. According to a study in Cote d'Ivoire, health-care expenses rose by up to 400% when a family member had AIDS. Yet, the hardship does not end there (UNAIDS, 2002). The financial burden of death can be far greater than that of illness. Traditions in many parts of Ethiopia, for instance, require that relatives and community members gather (sometimes for several days) at the home of the deceased to mourn and support the bereaved who incur costs in different forms. Tapping into savings and taking on more debt are usually the first recourse by households that struggle to pay for medical treatment or funeral costs. As debts mount, precious assets such as livestock and even land are sold. Once households are stripped of their productive assets, the odds of them recovering and rebuilding their livelihoods grow ever slimmer.

The Impact on the Health Sector

In all affected countries, the HIV/AIDS epidemic is bringing additional pressure to bear on the health sector. In countries where per capita health expenditure is low, extending prevention and care for sexually transmitted infections, counseling and testing, prevention of mother-to-child transmission services, and HIV treatment and care strains health budgets and systems. As the epidemic matures, the demand for care of those living with HIV/AIDS rises, as does the toll on health workers. In sub-Saharan Africa, the annual direct medical costs of AIDS (excluding ART) have been estimated at about US$30 per capita, at a time when overall public health spending is less than US$10 for most African countries. Even in high-income countries, the pressure on health budgets and health insurance schemes is significant. At the turn of the century, the direct medical costs of treating HIV/AIDS patients in the European Union ranged from about US$3400 per person annually, in the early stages of symptomatic HIV infection, to more than US$50 000 in the later stages of AIDS. Health-care services face different levels of strain, depending on the number of people who seek services, the nature of the demands for health care, and the capacity to deliver the care. In the early stages, HIV-infected persons (often experiencing common bacterial infections) tend to use primary-health-care and outpatient services. As the HIV infections progresses to AIDS, however, there is an increase in total hospitalizations related to HIV/AIDS. It is estimated that people living with HIV/AIDS occupied half the beds in some health-care centers of a few countries.

Impact on Enterprises and Workplaces

HIV/AIDS dramatically affects labor, setting back economic activity and social progress. The vast majority of people living with HIV/AIDS worldwide are between the ages of 15 and 49 – in the prime of their working lives.

Productivity and profitability are core concerns for enterprises, large and small. AIDS weakens economic activity by squeezing productivity, adding costs, diverting productive resources, and depleting skills. In addition, as the impact on households grows more severe, market demand for products and services can shrink. The epidemic hits productivity mainly through increased absenteeism, organizational disruption, and the loss of skills and 'organizational memory'. Rising absenteeism tends to push visible costs up while forcing productivity down, putting profits at risk. Production cycles can be disrupted, equipment stands idle and temporary staff may need to be recruited and trained. A study in several southern African countries has estimated that the combined impact of

AIDS-related absenteeism, productivity declines, health-care expenditures, and recruitment and training expenses could cut profits by at least 6-8%. The impact on informal enterprises can be especially harsh (UNAIDS, 2002). When the lead entrepreneur is no longer able to work, there is a high risk that the entire enterprise will collapse.

Macroeconomic Impact

Through its impact on the labor force, households and enterprises, HIV/AIDS can act as a significant brake on economic growth and development. Reliable knowledge of the impact of HIV/AIDS on the national economy and its various sectors and participants is valuable for effective national strategic planning and necessary for strong advocacy. A range of studies agrees that the net effect of the epidemic on per capita gross domestic product (GDP) growth is negative and possibly substantial (UNAIDS, 2002). For those countries with national HIV/AIDS prevalence rates of 20%, annual GDP growth has been estimated to drop by an average of 2.6 percentage points. More recent calculations have suggested that the rate of economic growth has fallen by 2-4% in sub-Saharan Africa as a result of AIDS. Meanwhile, nationally focused studies have forecast that, by 2015, the economies of Botswana and Swaziland would grow by 2.5 and 1.1 percentage points less, respectively, than they would in the absence of the epidemic (UNAIDS, 2002). *AIDS in Ethiopia: 6th Report* observes that "the loss of young adults in their productive years of life will affect the country's overall economic output. The HIV epidemic will continue to tax the limited available health and social service delivery systems." (FMOH/NHAPCO, 2006a, p. 48). Long term scenarios developed for Mozambique indicate that AIDS would reduce gross domestic product and could discourage foreign and domestic investors.

In some countries the epidemic directly attacks at the heart of the economy. For instance, more than 85% of Ethiopians live in rural area and are the basis for significant amount (about half of the GDP and 60% of the exports nationally) of the country's economy. Yet, as K.Y. Amoako, Executive Secretary, Economic Commission for Africa explained, that is exactly where HIV/AIDS is attacking:

> *"Earlier, HIV/AIDS was viewed mainly as an urban phenomenon, and most of the responses are still concentrated in urban areas. However, we are now witnessing the epidemic's spread to the rural areas of our countries – the areas where the vast majority of our people live. HIV/AIDS exacerbates the problems of already vulnerable rural communities and agricultural production systems."* – (ECA, 2004, p. 5)

By the beginning of the next decade, South Africa, which represents about 40% of sub-Saharan Africa's economic output, faces a real gross domestic product of 17% lower than it would have been without AIDS. One study has forecast that South Africa's economy would grow 0.3-3.4% less annually in 2000-2015, than it would have been in the absence of the AIDS epidemic (UNAIDS, 2002).

More research is required to achieve greater precision in the modeling of macroeconomic impacts of the disease. Per capita calculations can disguise and underestimate the human impacts of AIDS. The epidemic kills people, as well as eroding economic activities (including subsistence agriculture) features strongly, measured economic output only scratches the surface of the total impact of HIV/AIDS on livelihoods, food security, community welfare and the destinies of societies. Despite these and other impacts and anticipated population implications, it has been very difficult to fully capture the magnitude of the implications of the pandemic on economic growth or development, particularly when the long term is considered. No African country, for example, has yet experienced the full implications of the pandemic and no model has yet fully captured the holistic impacts of the HIV/AIDS taking place at different levels from the individual to the household to the society. The epidemic comes in successive waves, with the first wave being HIV infection, followed several years later by a wave of opportunistic diseases, and later still by a wave of AIDS illness and then death (Barnett and Whiteside, 2002). The final wave affects societies and economies at various levels, from the family and community to the national and international levels. None of the highly affected countries have yet hit the peak of the third wave nor advanced very far into the fourth, and as one study put it (Bell et al., 2003):

> *"We don't know how severe the impacts of the third and fourth waves will be – little about this pandemic is linear and AIDS is a unique threat . . . What for example is the likely long-term damage—social, economic, psychological – wrought by the orphaning of millions of children? What we do know is that impacts will continue to be felt for years to come and the situation will get significantly worse before it gets better."*

While simultaneously weakening the underpinnings of the economy, as part of its multiple impacts, HIV/AIDS also leaves security at risk as it weakens many of the pillars of social cohesion on which stability and progress of any country depends. Security and order are important parts of creating an environment in which human development can flourish but the epidemic's impact on police forces and the military is of considerable concern in some high-prevalence countries. For example, in Ethiopia a 2004 study of police officers' wives found that about one-third were living with HIV (Garrett, 2005). A state less able to provide social services (be it education, health or justice) may unwittingly foster political alienation and weaken its own political legitimacy. Thus, through its impact on both State and community capacity, AIDS can contribute to social disruption and perhaps civil unrest.

In general, HIV/AIDS is acting as the single biggest barrier to the development of many countries including Ethiopia. As increasing number of people with HIV are becoming ill, the extent of the AIDS crisis is now becoming crystal clear in many countries. Along with other diseases, conflicts and droughts, AIDS pandemic is worsening matters further. In some countries, AIDS is undermining progress towards the Millennium Development Goals particularly those related to poverty reduction (IAVI, 2005; UNFPA, 2003). If the crisis is not addressed, untold suffering will continue to take its toll in these regions. Given the uniquely devastating impact of HIV/AIDS on the entire society, national policies and poverty reduction strategies need to be adjusted and expanded accordingly. Without this, AIDS will continue to erode human development achievements and deepen poverty. The expanding epidemic provides a compelling case for accelerating much-needed global reform in an effort to better support local responses. Huge global challenges still shape the context in which the world confronts the epidemic. Failure to control AIDS is an index of inequitable development and poor governance.

One way to reduce and reverse the impacts of the epidemic, as numerous studies have shown, is proved to be through the provision of ARV (antiretroviral) drugs (ARVs) to PLWHA – ART – in both industrialized (Hammer et al., 1997) and developing (Laurent et al., 2002) countries. In the absence of massively expanded ART efforts, it is expected that the AIDS death toll especially in sub-Saharan Africa will continue to rise. But before discussing how in particular ART helps to mitigate the problem, let us discuss in the following section about the different ways the world has been struggling against HIV/AIDS to avert its impacts, and the multiple stakeholders and organizations that emerged in the process. This provides the context within which ART, our broader application domain, is operating and helps to see the kind of information system that needs to be cultivated (Hanseth and Monteiro, 1995) to support the management of HIV/AIDS as a whole, and not just ART, our primary focus in this specific study.

4.5 Global Responses and the Accompanying Informational Challenges

In the recent years, the sense of common purpose in the worldwide struggle against HIV/AIDS has intensified. More than at any other time in the history of the epidemic, the need to translate local and national examples of success into a global movement has become strengthened. The political momentum to tackle AIDS has grown. Public opinion in many countries has been mobilized by the media, nongovernmental organizations, activists, doctors, economists and people living with HIV/AIDS. Communities and nations are progressively taking the lead in responding to the epidemic with increased political commitment, resources and institutional initiatives. But this new political resolve has not always been universal – an unacceptable number of governments and civil society institutions have been in the state of denial about the HIV/AIDS epidemic and hence were failing to act to prevent its further spread or alleviate its impacts, only to worsen the situation. Thus, by failing to act, governments and civil society have been turning their backs on the possibility of success against AIDS. Nevertheless, growing political engagement in the response to AIDS is grounded in two decades of AIDS activism, led by individuals and communities whose lives have been touched by the epidemic.

At the Millennium Summit of the United Nations in September 2000, 43 Heads of State and Government, from both countries heavily affected and those less so, referred to AIDS as one of the most pressing problems worldwide. Presidents and prime ministers, particularly those from Africa and the Caribbean, but also those in Asia and Western and Eastern Europe, are displaying a personal commitment to the fight against AIDS. Support for expanded AIDS responses has been voiced by religious leaders and groups of quite many faiths – from Catholic and Protestant bishops and the Patriarch of All Russia, to associations of Imams and networks of Buddhist monks in South-East Asia. Thus, there has been a sea change in the understanding of the resources that are needed for an effective global response and in how to generate those funds. For instance, as agreed at the UN General Assembly, it is now clear that AIDS-related spending need to rise to US$7-10 billion to meet the main prevention and care needs of low- and middle-income countries.

At the United Nations General Assembly Special Session on HIV/AIDS in June 2001, Nongovernmental and community-based organizations showed a sense of urgency. The Global Fund to Fight AIDS, Tuberculosis and Malaria has modeled a new way of working to drive political momentum locally, nationally and globally. From within the United Nations, Secretary General Kofi Annan has helped catalyze growing global engagement. In April 2001, at the African Summit on HIV/AIDS, Tuberculosis and Other Related Infectious Diseases, in Abuja, Nigeria, he issued a global call to action in the fight against AIDS. The personal priority he has given to AIDS has helped energize political and business leaders towards the challenge.

In June 2001, the membership of the United Nations met in a Special Session of the General Assembly to agree on a comprehensive and coordinated global response to the AIDS crisis. The members adopted a powerful Declaration of Commitment, and reaffirmed the pledge (made by world leaders in their Millennium Declaration) to halt and begin to reverse the spread of AIDS by 2015. The UN General Assembly Special Session on HIV/AIDS differed from the hundreds of meetings and summits held on

AIDS in the past 20 years in this crucial respect: it was a meeting of all States, acting as governments. As such, it yielded both a common mandate and a basis for political accountability. The Special Session's Declaration of Commitment, adopted unanimously, now serves as a bench-mark for global action. Its goals include the need to make treatment and care for people with HIV/AIDS as fundamental to the AIDS response as is prevention. The Declaration of Commitment also provides the world with a basis for effective political action and a yardstick of accountability. At international, regional and national gatherings since the Special Session, the Declaration of Commitment has served to define agendas and create a common platform for action.

Underpinning the renewed global resolve in tackling AIDS is a series of shifts in fundamental thinking about the epidemic. For example, it is realized that the HIV/AIDS epidemic is at an early stage of development and that its long-term evolution is still unclear. Despite the epidemic's manifest potential for explosive growth within a matter of years, its overall dynamic needs to be considered in a time frame of decades. Proven approaches to HIV prevention have been identified. It was also underscored that access to comprehensive care and treatment for HIV/AIDS is not an optional luxury in global responses. Access to care is a basic necessity in programming in every setting – from the wealthiest to the poorest – and needs to encompass the full continuum, including home-based care, treatment of opportunistic infections and ART. Hence, nearly twenty-five years of experience with HIV prevention and ten years of experience with effective ART have produced mountains of evidence about how to prevent and treat HIV.

Therefore, while inaction has proved to be a deadly mistake, the evidence has never been stronger that action against AIDS gets positive results. Where the momentum of action has been seized, there is mounting evidence of inroads being made against the epidemic. Examples of success come from settings where HIV prevalence is low and from those where the impact of HIV/AIDS is already substantial. There is growing evidence that early and sustained HIV prevention efforts by means of different initiatives can be effective. For example, Uganda's experience – fall of HIV prevalence from around 15% in the early 1990s to around 5% by 2001 which largely happened due to intensive preventive campaigns – is a living testimony that a widespread AIDS epidemic can be brought under control. The most populous country in Latin America, Brazil, is home to 620 000 people living with HIV, one third of all persons living with the virus in Latin America (UNAIDS, 2006). The country has provided an outstanding proof that a dual emphasis on prevention and treatment can keep an HIV epidemic under control, and success has been achieved on this front for the past several years (Okie, 2006). It is a leading example of the integration of comprehensive care and a renewed commitment to prevention. Alongside the familiar achievements of Brazil and Uganda, there are new hopeful signs of successes which underscore the fact that even a rampant HIV/AIDS epidemic can be brought under control on every continent.

There is growing evidence that prevention efforts are bearing fruit, including in some of the most heavily affected countries of sub-Saharan Africa, though much of the progress is still occurring in localized settings. Though there is no single or immediate tool to prevent new HIV infections, the major components of a successful HIV prevention program are now known. For instance, around 2 million children in Sub-Saharan Africa (representing more than 85% of all children living with HIV worldwide), the vast majority of whom were infected with HIV during pregnancy or through breastfeeding, were living with HIV at the end of 2006. Without appropriate interventions, this mother-to-child transmission (MTCT) is inevitable. In fact, there is a 20-45% chance that an HIV-positive mother will pass infection to her child. One such intervention, PMTCT (prevention of MTCT), significantly reduces the risk by means of supplying a woman with ARVs after her HIV status is known through testing. In fact, ARVs are able to cut mother-to-child HIV transmission by at least 50%.

In general, in historical terms, AIDS is bringing national and global responses that are little short of revolutionary. Only a decade ago, the challenge of engaging the attention of political leaders in the fight against AIDS appeared too great. Today, one sees examples of Heads of State worldwide displaying unmistakable personal commitment. The barriers to involving sectors out-side health are steadily being removed. And there is increasingly sophisticated understanding of the suffering caused by the epidemic and of the connections between HIV/AIDS and the achievement of national development goals. More and more, political leaders are personally overseeing the coordination of national activities, bolstering human and financial resources, and supporting effective decentralization as a means of expanding activities.

At the same time, this process of fighting against the HIV/AIDS pandemic has been giving rise to the emergence of many prevention and control as well as treatment, care and support organizations. For instance, in Uganda, there are over 600 HIV/AIDS-related national and international organizations. Similarly, in Ethiopia, they exceed 300 most of which are donor driven and operate on their own budget and information support mechanisms. This, in turn, gives rise to the proliferation of different pieces of ISs which are usually geared to entertaining primarily the interests of the parent organization.

Still, this in turn, has resulted in a wide range of problems including fragmentation within and across the different stakeholders and initiatives in the HIV/AIDS program. For example, from our study in Ethiopia, we found out that medicine consumption was counted both at the ART pharmacy and also reported from the ART clinic. This contributed not only to the duplication and magnification of workloads but also to poor quality reports. In fact, staff from both the ART clinic and the ART pharmacy told us there were frequent mismatches between reports which were supposed to be the same. It is with this situation at the backdrop that we saw the need to cultivate (Dahlbom, et al., 1996; Hanseth and Monteiro, 1998; and Braa and Hedberg, 2002) an Integrated HIV/AIDS Management System (IHAMS). Such an integrated approach can potentially support the management of HIV/AIDS as a whole, and not just that of ART which, of course, is our primary focus in this specific study. To that end, our initial focus was on the development and implementation of an expandable IS to support ART management in Ethiopia with an immediate view of linking up particularly with those initiatives (such as PMTCT, VCT, ART Pharmacy, STI, and OI) that are closest[#] to ART.

But what exactly is ART? That is the concern of the next section which intends to provide scientific background and some of the key technical issues relating to the broader[π] application domain of this study – antiretroviral treatment. We first discuss what ART is and some of its major impacts, its peculiarities and the challenges to administer the treatment which arguably is unlike the treatment of other diseases, issues around scaling up ART, and then go to describe the implications. Each of these descriptions is important to provide the content of the information systems we are seeking to develop.

4.6 HIV/AIDS Treatment – ART – Peculiarities and Challenges

Antiretroviral Treatment and Antiretroviral Drugs – The Averting Impacts

Alongside the various initiatives to prevent and control the epidemic, there is also the urgent need to treat the PLWHA. This is where ART comes into the picture, and concerns the administration of at least three different medications known as ARVs in order to suppress the replication of the virus. There are many kinds of ARVs, which attack the virus in different ways. For this reason, treatment today always

[#] They are where a patient can be referred from and to ART in relation especially with directly medical related aspects of HIV/AIDS.

[π] Our specific study context and application domain which is also the analytical focus of this thesis is **ART management** *in Ethiopia*.

involves a combination of ARVs*. All ARVs have different side-effects and these can have an impact both on how the medicines will be used and how patients take them. In some situations, several ARVs are combined in a single tablet, a fixed-dose combination (FDC), which ensures that patients always take multiple doses together. As a first-line treatment, ART can be delivered relatively cheaply. However, if drug-resistance develops and these medicines are no longer effective, second-line ARVs may be required, which are much more expensive than first-line medicines.

The effect that HIV has on an individual can be known by measuring the number of CD4 cells in the blood stream and the actual viral load, the latter, of course, is if the required equipment is available. The normal average CD4 count is about 1000 (900-1300) per ml. Once the CD4 count falls, on average 70-90 CD4 cells per year, the individual is likely to suffer from various different infections unless they are treated with ARVs. When the CD4 count falls below 200, treatment with ARVs is usually started. However, if there are AIDS-defining conditions – when patient manifests signs and symptoms of WHO Stage III and a CD4 count below 350 – treatment may also be started. People in these two categories – fulfilling the laboratory definition of AIDS – are referred to as "people in need of treatment" (WHO, 2002).

Although ARVs are not the ultimate weapon in the fight against HIV, they are very effective in controlling the virus, and can even reduce the level of the virus to a point where it is no longer possible to detect any HIV in the blood. ART just seeks to transform a uniformly fatal disease to what is now considered to be a complicated but manageable chronic disease. The successful use of ART suppresses the rapid viral replication of HIV while at the same time boosting the body's immune system, consequently slowing down disease progression and delaying mortality. *HAART* was the breakthrough in the industrialized world leading to the reduction of mortality. In the United States and Europe, for example, ARV use has reduced AIDS deaths by over 70 percent. In addition, several studies have shown that selected ARV treatment can dramatically (by half) reduce HIV transmission from an infected pregnant woman to her child. Thus, while ART is not a cure, it helps to prolong and enhance the quality of life of PLWHA and enable them to lead full and more productive lives (Hogg et al., 1998; Palella et al., 1998; Marins et al., 2003; Koenig, Leandre, and Farmer, 2004; Wools-Kaloustian et al.,

* Treatment with these combinations of drugs is also known as Highly Active Antiretroviral Therapy (HAART). There are currently three major classes of ARV drugs: nucleoside or nucleotide analogue reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PIs). Almost all of those who are currently on ART are on a regimen of three or more ARVs (Grierson et al., 2000). A combination of at least three drugs is necessary in order to overcome the viruses' drug resistance.

2005). There are no words powerful enough to explain the devastating impact of the pandemic on individuals unless they are helped with ART (see Figure 4.2).

Figure 4.2: How treatment may improve life

Top left: Joseph Jeune before treatment for HIV/AIDS /TB co-infection, March 2003,
Top right: Joseph Jeune having gained 20kg six months later after treatment for HIV/AIDS /TB co-infection, (David Walton/PIH)

Bottom left and right: Ravaged by opportunistic infections, Ana Maria Muhai was barely alive when she was first brought to a Sant'Egidio clinic in Maputo in 2002. Three weeks of ARV treatment brought her back to life and she started a new mission—advocating for more AIDS education.
Source:

http://www.who.int/3by5/treatmentworks/en/index.html and (WHO, 2005)

The benefits being gained from ART are dramatic. AIDS related deaths and illnesses in countries where ART has been available since the mid 90's have declined considerably. The experience of developed nations has proven that ART reduces disease burden and dependence, increases well-being and productivity and restores hope for individuals. There are several examples that illustrate the success of ART. The graph on Figure 4.3 shows the widening gap in AIDS associated death rates between Western Europe and Sub-Saharan Africa. The major factor for the gap is the inadequate use of ART in Africa. Countries that have scaled up ART treatment have benefited not only from reduced mortality, but also, reduced disease burden among their society, reflected by markedly reduced hospital admissions. Even more impressive is the rate of return to work of formerly HIV disabled patients. Brazil saved half a billion USD in four years after the scale-up of ART program (FMOH, 2005). The dramatic reversal of disease progression creates hope and reduces the fatalistic attitude of the HIV patients, health care providers and the society at large. The will to live then becomes a very powerful motivator for people to seek counseling and testing services and to follow behavior change messages. These positive ART related outcomes, including stigma reduction and increased community participation in prevention are the lessons learnt from countries with ART experience.

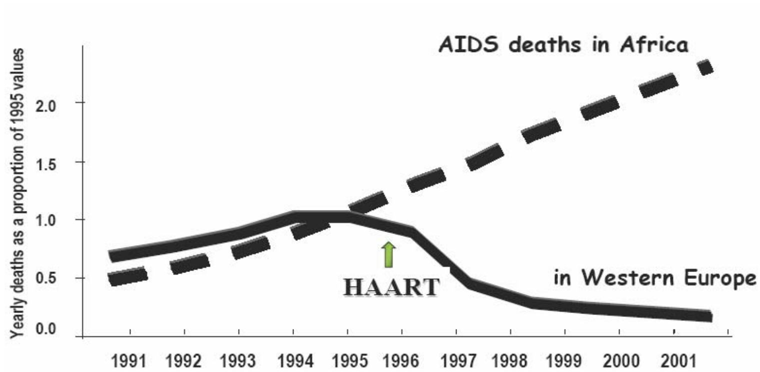


Figure 4.3: Widening mortality Gap of AIDS due to HAART. Source: (FMOH, 2005)

Through the expanded provision of ART, an estimated two million life years were gained since 2002 in low- and middle-income countries. In sub-Saharan Africa alone, some 790 000 life years have been gained, the vast majority of them in the past two years of ART scale-up (UNAIDS/WHO, 2006). The effect of the epidemic on economic growth would be reduced by 17% if the proportion of those in need of ARVs who are receiving them increased to 50%. In Ethiopia too, the number of AIDS deaths in 2009 is projected to be lower by over 50 000 than that in 2005 as a result of an expanded ART program (FMOH/NHAPCO, 2006a). As access to treatment is slowly expanding throughout the continent, millions of lives are being extended and hope is being given to people who previously had none.

A growing number of countries have shown that increasing access to treatment is both possible and effective. In Latin America, where wide-scale treatment provision began earlier, some 834 000 life years have been gained since 2002. Antiretroviral provision in Brazil, which has the most advanced national HIV/AIDS program in the developing world, is among the most comprehensive in the world, and is yielding positive results. Nationally, mother-to-child transmission of HIV declined substantially, from 16% in 1997 to less than 4% in 2002 (Dourado et al., 2006). AIDS mortality rates decreased by 50% between 1996 and 2002 – 100 000 deaths have been averted, while hospitalizations related to AIDS fell by 80% during the same period (Okie, 2006).

Interestingly, yet more encouraging as to the significance of ART in averting the impact of the AIDS pandemic are recent study findings (from rural Tororo, Uganda) which point to the fact that persons receiving ART had significantly less risk of transmitting HIV after two years on treatment, partly due to a strong reduction in viral load and less frequent unprotected sex. Because the risk of sexual transmission is closely associated with viral load (Quinn et al., 2000), reducing a person's viral load through ART could reduce the likelihood that he or she will transmit the virus to someone else. A recent study in Uganda calculated that the risk of sexual HIV transmission in HIV serodiscordant couples fell by 98% when the HIV infected partner was receiving ART (Bunnell et al., 2006). Being deprived of ART would then mean a great loss for a nation. For example, at current levels of HIV prevalence, young persons in Zambia face a 50% life time risk of dying of AIDS in the absence of treatment (Ministry of Health Zambia, 2005). Also, more recently, the increased availability of treatment, due to national and international initiatives, has more dramatically improved survival rates and lowered the incidence of opportunistic infections in people with AIDS (UNAIDS, 2005). Hence, societies which deny the facts about ART and fail to scale-up access to it will in a way be turning their backs to its possible benefits and to the successes that can be achieved against AIDS.

Why ART?

While ART is not a cure and the ultimate weapon in the fight against HIV, the successful use of it is very effective in many different ways including the following:

- *It transforms a uniformly fatal disease to a complicated but manageable chronic disease.*
- *It suppresses the rapid viral replication of HIV while at the same time boosting the body's immune system, consequently slowing down disease progression and delaying mortality.*
- *It controls the virus and reduces its level to a point where it is impossible to detect its presence in the blood stream.*
- *It significantly reduces the risk of transmitting HIV after two years on treatment partly due to a strong reduction in viral load (Bunnell et al., 2006)*
- *It dramatically (by at least 50%) reduces mother-to-child HIV transmission from an infected pregnant woman.*
- *It prolongs and enhances the quality of life of PLWHA and enables them to lead more productive lives – making HIV/AIDS a chronic disease, not a death sentence.*
- *It more dramatically improves survival rates and lowers the incidence of opportunistic infections in PLWHA.*
- *It reduces overall healthcare costs.*
- *ART – once very costly – is now much more affordable, even accessible for free in many countries.*

Scaling up ART

Since the introduction of ARVs in the 1990s brought new hopes to people living with HIV, considerable efforts have been made towards greatly improving access to ART in recent years, albeit from a very low starting level in many countries. In response to the epidemic and the need to ensure the availability of ARVs in resource-poor settings, a major focus of global advocacy efforts, a number of strategic partnerships and new organizations have been established and new initiatives launched. Meanwhile, the price of most first-line ARVs has fallen substantially due to the involvement of Indian generic pharmaceutical companies which have produced ARV formulations at prices that allow patients to be treated for less than US$ 1.00 per day. The first of these initiatives to improve ART availability was the Accelerating Access Initiative, a partnership established in 2000, involving UN organizations and a number of pharmaceutical companies which offered to make their products available at reduced prices.

> ***Some benefits already enjoyed from ART so far***
>
> - *Through the expanded provision of ART, an estimated two million life years were gained since 2002 in low- and middle-income countries.*
> - *In sub-Saharan Africa alone, some 790 000 life years have been gained, the vast majority of them in the past two years of antiretroviral treatment scale-up.*
> - *In the United States and Europe ARV use has reduced AIDS deaths by over 70 percent.*
> - *Other affluent countries have seen a 50 - 70% decline in HIV/AIDS deaths since the introduction of ART.*
> - *In Latin America, where wide-scale treatment provision began earlier, some 834 000 life years have been gained since 2002.*
> - *Brazil – being among the most comprehensive in the world and having the most advanced national HIV/AIDS program in the developing world – got mother-to-child transmission of HIV nationally declined substantially, from 16% in 1997 to less than 4% in 2002 (Dourado et al., 2006), and AIDS mortality rates decreased by 50% between 1996 and 2002 – 100 000 deaths have been averted, while AIDS-related hospitalizations fell by 80% during the same period (Okie, 2006).*
> - *The improvement in treatment access saved between 250,000 and 350,000 lives during 2005 alone.*

In 2001, the Global Fund to Fight AIDS, Tuberculosis and Malaria (the Global Fund) was established. Although essentially a financing organization, the Global Fund has assisted many countries, including Ethiopia, in their efforts to obtain ARVs. The Global Fund aims to provide ART to 1.8 million people over five years and to support many more people with voluntary counseling and testing for HIV, medical services and community care. In 2003, WHO launched the “3 by 5” initiative, which aimed to ensure that 3 million patients are on ART by the end of 2005 (WHO, 2005). Although this milestone was not reached[*], as the final report on the 3 by 5 initiative released in March 2006 pointed out, an estimated 1.3 million people (just 40% of the intended target but only about 20% of those estimated to be in need) in low- and middle-income countries, who would not otherwise have been treated, were initiated on the therapy and now have access to ART (UNAIDS/WHO, 2006). Thus, the substantial reduction in prices of ART and the establishment of these large donor organizations have led to the scaling up of ART in many countries in response to the global need for ARV therapy.

This provision of ART has particularly expanded dramatically in sub-Saharan Africa: out of an estimated 4.7 million who needed it, 810 000 were on treatment from the 3 by 5 initiative. More than

[*] Of the 152 countries targeted by the 3 by 5 initiative, only 18 managed to provide treatment to at least half of their needy people by the end of 2005. The list included Poland, Thailand and thirteen countries from the Americas and the Caribbean. Only three African nations - Botswana, Namibia and Uganda – met their 50% targets.

one million people (63% of all people now accessing ART in low-and middle- income countries) were receiving ART by June 2006, a tenfold increase since December 2003 (UNAIDS/WHO, 2006). Scale-up efforts have been especially strong in a few countries including Botswana, Kenya, Malawi, Namibia, Rwanda, South Africa, Uganda and Zambia. However, the sheer scale of need in this region means that a little less than one quarter (23%) of the estimated 4.6 million people in need of ART in this region are receiving it (UNAIDS/WHO, 2006) – the region still accounts for 70% of unmet treatment need in low- and middle-income countries.

Also in 2003, the United States Government established the President's Emergency Plan for AIDS Relief (PEPFAR). This initiative focuses on 15 high-burden countries including Ethiopia, and provides substantial resources, not only for ARVs, but also for systems support. The target of PEPFAR is to treat 2 million patients within 5 years. Also included in the list of initiatives are the Gates Foundation, Merck (the Merck Company Foundation/Merck & Co., Inc.), and Clinton foundation. By mid-2005, the WHO target had already been overtaken by an even more ambitious aim. In July 2005, the G8 group of industrialized countries committed to the goal of achieving 'as close as possible to universal access to treatment for all those who need it by 2010' – "all by 2010". (UNAIDS, 2006; G8 Gleneagles Summit, 2005).

ART Statistics for 2006 - Where are we?

- Percentage of people needing AIDS treatment in low- and middle-income countries who are actually receiving treatment 24%
- Sub-Saharan Africa 23%
- Asia 16%
- Eastern Europe and Central Asia.......13%
- Middle East and North Africa 5%

Source: UNAIDS 2006 AIDS Epidemic Update, December 2006

Achieving the all by "2010" target means putting many more people on treatment than the more than 6.8 million currently in need. This is because people who started treatment in previous years must continue to receive medication, and each year many hundreds of thousands of people progress to the stage of disease at which treatment is required. The World Health Organization does not plan to set any interim global targets until 2010, but it is encouraging individual countries to set their own goals. According to the most common definition, universal access to treatment is achieved when 80% of all people in urgent need of treatment are receiving it. Experience has shown that this level of coverage is seldom exceeded even in rich countries, for a variety of reasons including adverse reactions to drugs and personal choice. It has been estimated that, under this definition, universal access means at least 10 million people receiving treatment by the end of 2010. For this reason, some people use the phrase "10 by 10" instead of "all by 2010" (WHO, 2006; UNAIDS/WHO, 2005b) (see Figure 4.4).

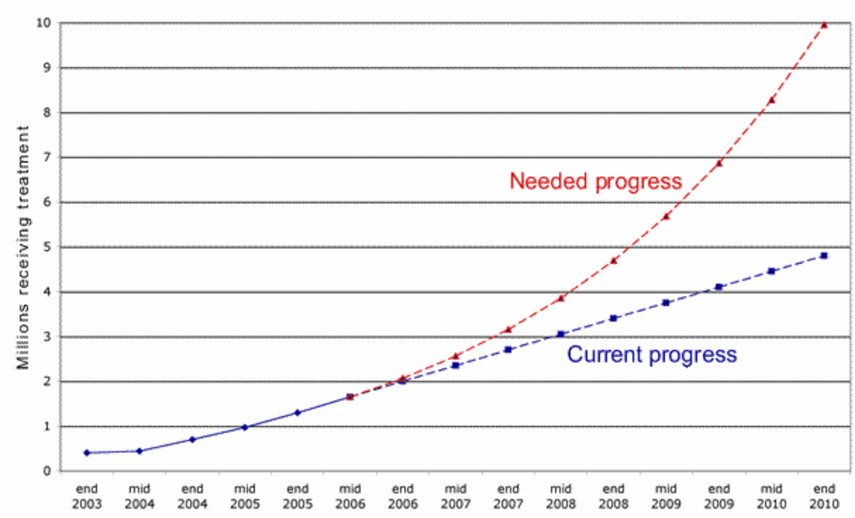


Figure 4.4: At the current rate, fewer than 5 million people will be receiving treatment by the end of 2010, instead of the 10 million target. Source: (www.avert.org)

> *"Lack of access to antiretroviral therapy (ART) is a global health emergency. To deliver ART to the millions who need it, we must change the way we think and change the way we act."* – Dr. LEE Jong-Wook, Director-General, World Health Organization

As of June 2006, of the 39.5 million PLWHA worldwide, an estimated 6.8 million of the people living with HIV in developing and transitional countries urgently needed life-saving ARVs. Of these only 1.65 million (24%) – about one in four – were accessing the drugs (see Table 4.3). Though shockingly small, this figure is a great improvement on figures (400 000 – only 7%) from 2003, when global efforts to expand access to ART began to increase significantly. Over the past year, the number of people receiving the treatment increased in these countries by about 300 000 every six months. At the UN General Assembly Meeting on HIV/AIDS on September 22nd 2003, the WHO, UNAIDS and the Global Fund declared the lack of access to HIV treatment a global health emergency. Since that meeting, much progress has been made. Many countries, including Ethiopia, have set targets for scaling-up treatment, and global organizations and funding bodies are rolling-out plans to increase ARV coverage. Never before in the history of the epidemic has so much money been available to finance treatment and care for people with HIV, and never before have ARVs been so cheaply and plentifully available. Still, every day, 8 000 people are dying from a disease which can be treated, but which all too often is not.

In any case, the improvement in treatment access saved between 250 000 and 350 000 lives during 2005 alone, and will save many more lives in the years to come. Nonetheless, with the expanded provision of ART, the challenges particularly in sub-Saharan Africa remain great. Health systems are weak. Worse yet, the target orientation of ART programs risks an emphasis on initiating people on ART at the expense of ensuring effective treatment and use of medicines. Those early treatment scaling successes had hidden challenges in resource-poor settings. One of these is the risk of treatment failure and the development of widespread ARV drug resistance unless all patients are given the continuing support they need to achieve the required adherence to ARVs.

Region	UNAIDS/WHO estimates		
	People receiving treatment in June 2006	**People needing treatment in 2005**	**Treatment coverage in June 2006**
Sub-Saharan Africa	1,040,000	4,600,000	23%
Latin America and the Caribbean	345,000	460,000	75%
East, South and South-East Asia	235,000	1,440,000	16%
Europe and Central Asia	24,000	190,000	13%
North Africa and the Middle East	4,000	75,000	5%
All developing and transitional countries	1,650,000	6,800,000	24%

Table 4.3: Regional treatment estimates for low- and middle-income countries only*. Source: (www.avert.org)

Adherence and Drug Resistance – Peculiarities and Challenges of ART

HIV/AIDS treatment – ART – is quite unique. Unlike the treatment of other diseases such as TB and malaria, once ART is started, the treatment has to be taken for life with a better than 95% adherence to achieve viral suppression; and this is extremely challenging as well as being costly. Rightly, then, the increasing availability of ARVs has prompted concerns about their proper use (Richard et al., 2004) especially relating to the levels of adherence needed to ensure positive treatment outcomes (Paterson et al., 2000) and to avoid drug resistance.

Simply put, adherence to an ARV treatment regimen involves the following elements: taking all the medicines (often 20 or more pills daily) which make up the ARV combination in the correct prescribed doses, at the right times (once, twice or three times a day), in the right way, uninterruptible and lifelong! (Carter, 2005) The best response to ART is seen when adherence is 100% (Fischl et al., 2000). Levels of

* The above table includes all countries except those of Western Europe and Australia, Bahamas, Bahrain, Brunei, Canada, Cyprus, Grenada, Israel, Japan, Kuwait, New Zealand, Qatar, Republic of Korea, Singapore, United Arab Emirates and United States of America. The total number of people needing treatment is comprised of those already receiving treatment plus those who should ideally start receiving treatment immediately because they have already reached the advanced stages of HIV infection. It does not include the majority of people living with HIV who have not yet reached the advanced stages of infection. The number of people receiving treatment includes those accessing it through the private sector.

adherence below 95% have been associated with poor suppression of HIV viral load and a lower increase in CD4 count (Carter, 2005). Just to leave you with a hint as to how demanding adhering to ART is: If a patient is of type taking treatment only once a day, 95% adherence means missing no more than one does in a month! Hence, while access to ARVs is advancing dramatically and many patients have been started on treatment, taking ARVs once, twice or three times a day; and strictly doing this at the right time throughout life is a challenging task for people who may be ill and who may also face multifaceted obstacles to use the drug regularly and rationally. For instance, even if enough ARVs were supplied to developing lands many obstacles would have to be overcome. For example, some drugs need to be taken with food and clean water but hundreds of thousands of people in some of these countries can eat only every other day. Moreover, many patients do not own a timepiece to take all pills at a certain time each day.

Therefore, many people with AIDS do not manage to achieve such high levels of adherence. ART is a life-long process. While conscientious treatment adherence is difficult under any circumstances, the unforgiving nature of HIV replication, the complexity of the ART regimens, and the associated short- and long-term toxicity of the medicines all pose particularly difficult challenges for patients. The ability to consistently take the medicines at exactly or approximately the same times each day depends on the individual's frame of mind as well as the support of family and community members. Administration of ARVs imposes constraints on the daily schedule and lifestyle and it can be difficult for individuals to adapt to these demands, especially on a long-term basis. Some studies of ART in developing countries show that resistance is already circulating among patients starting their first course of therapy (Mugyenyi, 2002). Before ART was scaled up, fear of stigma led many people to seek ARVs clandestinely on the black market, leading to poor monitoring regimes. Whatever the case, while experience of adherence to treatment for chronic diseases has great relevance, HIV/AIDS treatment, ART, is particularly challenging because it requires achieving exceptionally extremely high levels of adherence to prevent treatment failure and the generation of ARV-resistant virus (Paterson et al., 2000).

Some peculiarities of ART

- Uninterrupted once, twice, or three times a day regimes dosage.
- Treatment is lifetime and uninterruptible and hence patients need to be strictly followed up.
- Exceptionally very high and virtually perfect level of adherence (at least 95%) is required for an indefinite period of time, and hence patients' adherence has to be strictly monitored to avoid the development of drug-resistant virus.
- Treatment is extremely challenging and costly.

Drug-resistance is a well-recognized biological phenomenon occurring with infectious organisms including bacteria, viruses and parasites such as malaria. When an infectious organism is exposed to an antibiotic, an antiviral agent or an antiparasitic agent such as chloroquine, some of the organisms will be very sensitive to the agent while others will be partially resistant, due to genetic variation. If the course of therapy is interrupted, those organisms that were sensitive will have been killed, while the more resistant organisms will have survived and can replicate. If there are repeated interruptions in treatment, only drug-resistant organisms will survive. In the case of HIV, the problem is complicated and pronounced by the very rapid replication of the virus and the fact that it can go into a non-active state where it is not affected by ARVs. When the viral load is very high, as it is at the beginning of therapy, high adherence to ARVs is required (Carrieri et al., 2003). If an individual misses a few doses at this stage, the danger of the development of drug-resistant organisms is far higher than it would be after six months of regular treatment, by which time the person is likely to have a low viral load. Only if the required very high level of adherence is maintained for the duration of therapy and especially in the first six months can this development of drug-resistance be prevented (Paterson et al., 2000).

If an individual develops resistance to ARVs, two problems occur. Firstly, the first-line ARVs will no longer work and the individual will start to suffer from multiple opportunistic infections. Secondly, the individual may transmit the drug-resistant virus to their contacts and when those individuals go for treatment they will discover that their virus does not respond to the first-line therapy. Once a person develops resistance to first-line medicines, they will need to be changed to second-line ARVs. However, at present these products are substantially more expensive than the first-line ARVs and more difficult to use as well as having a different range of side-effects. Moreover, the decision to change a person from first-line to second-line therapy is a difficult one to make, especially if CD4 and viral load testing equipment is not available. At present, the cost of second-line therapy is about 10 times more than first-line therapy. The danger is that if too many patients progress to second-line therapy, the increased costs involved will limit access to treatment for many people who would benefit from first-line therapy. Therefore, every effort should be made to ensure the expected adherence to the first-line ARVs in order to prevent or delay the emergence of drug-resistance and enable individuals to be treated for many years with first-line ARVs.

Every effort should be made to ensure the expected adherence to the first-line ARVs in order to prevent or delay the emergence of drug-resistance and enable individuals to be treated for many years with first-line ARVs.

Drug-resistance is not the only cause of treatment failure. The natural history of HIV infection is very unpredictable and people respond to treatment regimes in different ways (O’Brien et al. 2000). Sub-optimal adherence itself is an important cause of failure. If people are interrupting their daily dosage regimes, they simply do not get enough of the medicines for effective treatment and they will generate drug-resistance. Inappropriate use of ARVs is a multifaceted problem increasing the likelihood of drug-resistance and contributing to direct treatment failure. Policies and programs that aim to provide increased or universal access to treatment face a key challenge – in order to succeed, these programs need to achieve the required exceptionally very high level of adherence for an indefinite period of time.

Really, then, although the roll-out of ARVs in many resource-poor countries has been a remarkable expression of international solidarity, starting patients on ARVs without ensuring full adherence through an adequate support system is likely to lead to treatment failure and the emergence of drug-resistant virus which can be transmitted to others. Drug-resistance is a potentially major threat to achieving universal access as it could mean that more and more people have to switch to the more expensive and difficult to manage second-line ARVs (Hardon et al., 2006). The major increase in program costs that this would entail would limit the total number of people with access to treatment. Harries et al. (2001) argued that adherence problems would constitute a perceived significant barrier to the delivery of ART in sub-Saharan Africa. They warned that unregulated access to ARVs in sub-Saharan Africa could lead to the rapid emergence of drug-resistant viral strains and individual treatment failure, curtailing future treatment options and leading to the transmission of drug-resistant strains of HIV.

To ensure that AIDS can continue to be treated, it is essential that effective adherence support should be an integral part of any treatment program. As treatment roll-out is increased to meet the global target of achieving universal access to ART by 2010 for all who need it, the need for effective adherence support mechanisms will intensify. Failure to tackle this will jeopardize the future of treatment programs, and may result in the failure of the immense global and national efforts to provide hope to people living with HIV through the provision of treatment to those most in need. Efforts to increase access to ARVs should go hand-in-hand with the efforts needed to ensure that every ART patient receives adequate adherence support. These key challenges in achieving and maintaining optimal adherence should encourage policy-makers, planners, funding organizations, AIDS doctors and patients, and all HIV/AIDS stakeholders to work together towards pointing to possible solutions to sustainable ART – optimal adherence on top of access to treatment.

Consequently, since it is proved that those who have access to ARV drugs and the care needed to maintain therapy can live for many years as far as they *regularly follow the treatment with the required* *adherence*, those patients who are lost, have dropped follow-up, or show poor adherence need to be tracked to ensure timely cure. However, the administration of this, as we will see in the case of Ethiopia in the next chapter, puts challenges not only on the patients but also on the healthcare workers and the healthcare system at large. In addition to the above aspects of the treatment, many other cases relating to the epidemic including the number of AIDS-deaths in a month should also be reported for national and international use, as part of ART management. There are now many new arrangements being made in developing countries working towards these ends. For example, in Ethiopia telephone and internet lines are being set up in many ART clinics to track dropped out patients (and the associated reasons) and do all the necessary HIV/AIDS-related reporting in time.

Efficiently tracking different medical variables of a patient including adherence level throughout the patients lifetime in such a way that it is easily presentable to a physician in a ready made and organized manner is, thus, a matter of at most importance in ART management to keep an ART program up and running without causing destructive side effects in the society including emergence of transmittable drug-resistant viruses. The benefits of such an efficient arrangement, however, are far from being limited to an individual patient and a medical doctor – it, clearly, extends to being societal. For example, unless clinics make sure that patients in a cohort are in good status with regards, for example, to adherence, regional and national ART initiatives will suffer and not be efficient, but, rather, become causes for devastation for the society at large.

Implications – Urgent Need for Suitable Information Systems

While the above discussion underscores the importance of regular follow-up and strict adherence to the treatment, what is often not given adequate emphasis is the role of information in supporting this process. Information can play a key role in HIV/AIDS and ART management in a variety of ways from the identification of those who need the treatment most, to monitoring the progress of the treatment, to ensure an active level of adherence, and to reduce the percentage of drop outs. Furthermore, the strong link that the ART initiative has with others such as Pharmacies, VCT and PMTCT dictates more integrated information which program managers seek. As Mamlin et al. (2006) put it:

> *"A worthy response to this pandemic will require coordinated, scalable, and flexible information systems."* (p. 1)

Nevertheless, the situation is not so as yet. And as discussed in chapter 1, there are very limited examples of information systems that can help effectively manage HIV/AIDS and its treatment. In many cases, as is the case in Ethiopia, ART is managed manually. However, given the challenges and particularities of ART we discussed above, such a paper-based system is far from satisfying the need ART management demands. RHINO (2004a) rightly observed:

> *"In most resource-constrained settings, patients are treated for acute conditions and are rarely followed-up over time. Consequently, the information systems most commonly found in clinical facilities consist of traditional paper-based medical records with limited utility for constructing a useful patient history. In contrast, the foundation of quality care and treatment for HIV/AIDS patients requires the ability to establish continuity of care… The key to continuity of care is some type of information system that can capture clinically relevant information on patients that can be easily retrieved at the patient's next contact with the clinical facility. From a program monitoring perspective, longitudinal data retrieved from these types of information system can provide key data useful to evaluate the performance of a program offering clinical services. … … ART tracking is complex and requires a longitudinal medical record that tracks patient status, treatment (and adherence), laboratory, opportunistic infections, TB status … and treatment response" (p. 1, 2, 12, 36, emphasis ours)*

Further, one of the most important factors associated with adherence to ART is the issue of clinical setting (Reiter et al., 2003). The effect that a clinic setting and service provision has on adherence should not be underestimated. Studies have, for example, shown that such clinic characteristics as lengthy delays between appointments and long waiting times of patients impact on both attendance at clinic and adherence (Nemecheck and Tritle, 1998; Hradon et al., 2006). From the study they conducted in Botswana, Tanzania and Uganda, Hardon et al. (2006) reported that they have found lengthy waiting times to be a major factor for patient's non-adherence. They reported that these patients had to travel long distances and then had to wait for a long time, sometimes for 10 hours (average 5 hours). We have observed the same thing in the clinics we have been in Ethiopia. In addition to the impact of this on adherence, the long waiting times strain the relationship between staff and patients (Hardon et al., 2006). Chesney (2000) also found that dissatisfaction with the health services is a predictor of non-adherence. In administering ARVs, efforts should be made to minimize waiting times. In many settings it should have been possible to provide patients with appointment times so that they do not have to wait all day (Hardon et al., 2006). But this is not practically possible with paper based systems especially when dealing with large number of patients.

For example, in one of the biggest (more than 12 000 patients) clinics where we have been in Ethiopia, doctors and data clerks told us that the number of patients that they serve greatly varies from day to day. Sometimes all patients are treated and doctors remain idle. In other cases, however, patients who have come from long distances are sometimes sent home untreated after waiting for long times because it was the end of the day and doctors were exhausted. This, as they told us and we observed, was not always necessarily because of the mere patient load of the clinic. It was, rather, because patient's appointments were not evenly distributed throughout the working days. This, in turn, was due to the fact that the patients' next visit date is not filled up on the card but they were simply informed verbally. In this regard, a doctor said:

> *"Since we have too many patients in our clinic, it has been extremely difficult for the clerks to go through all the patients' cards to find out who is coming tomorrow or so. Also when wanting to give appointment for a patient we don't remember by heart for how many patients we have already given appointments so far on a particular date. So, as we are not using it anyway, we stopped filling up the next visit date and started going this way."*

Clearly, as ART keeps being scaled up in many regions in the world, efficiently managing it without being aided by a supporting information system becomes extremely difficulty and with severe effects.

Yet, how these information support systems can be appropriately designed and implemented is a pressing and, unfortunately, ignored issue in the context of ART. Further, the challenges to introduce and make such systems work were not exposed. Exploring and trying to address these challenges, specifically through the design, development, implementation and use of a scalable patient-based ART management system, is a key focus of this thesis. Addressing these multiple and interconnected challenges, clubbed under the pragmatic theoretical framework of "making it work," is the primary aim of this thesis. The theoretical basis of "making it work" is outlined in chapter 2, while the empirical descriptions follow in chapters 6 and 7.

After having discussed the broader research background, HIV/AIDS and ART, the next chapter presents these issues in the specific context of Ethiopia where the study was conducted.

5 Research Settings

5.1 Introduction

In this chapter, we provide descriptions of the research settings more broadly of Ethiopia, the country in which this study is carried out, and more specifically of our research sites in the capital (Addis Ababa). Of primary importance are the discussions on the situation of HIV/AIDS in general and in particular of, ART management in Ethiopia, our specific study context. The descriptions in here will be useful as they provide an overview of the research situation, the settings in which the system (IHAMS-ART) is developed and implemented. The situation analysis, the various action research interventions we carried out to address the problems identified during the situation analysis, and our findings will be presented in the subsequent three chapters (6, 7 and 8).

In view of that, the chapter is organized as follows. Section 5.2 begins with brief discussions on the settings of Ethiopia with an attempt to show the implications of the issues under discussion on our system development and implementation efforts. Provided in section 5.3 is a brief description of the context of one of the eleven regions in the country, Addis Ababa, our main study site. Out of the various programs in the Ethiopian healthcare system, section 5.4 discusses the HIV/AIDS program with a focus on its management problems. Following this, section 5.5 presents the situation of ART in Ethiopia including its potential impacts in averting the impacts of AIDS in the country. Out of the multiple research sites where we have been (see chapter 3), descriptions of three of our principal pilot sites, ART clinics[*], in Addis Ababa are also provided in this section. Finally, section 5.6 wraps up the chapter by discussing the situation of ART management in Ethiopia, the specific study context and analytical focus of this thesis, and also the application domain for the design, development and implementation of IHAMS-ART.

5.2 Ethiopia: Summary of Country Profile

To situate the study in its broader socio-economic and cultural context, in this section we provide brief background information about Ethiopia.

[*] We visited ten ART clinics in Ethiopia: Nine clinics from Addis Ababa and one from SNNPR.

Background Information and Geographic Features

The Federal Democratic Republic of Ethiopia is a country located at the Horn of Africa approximately between latitude 43^0N and 15^0N and longitude 33^0N and 48^0E (MOH, 2002b; The World Factbook, 2004). Covering an area of approximately 1.3 million square kilometers, Ethiopia is a land locked country bordered by Sudan on the West, Somali and Djibouti on the East, Eritrea on the North and Kenya on the South (see Figure 5.1). The country is one of the least developed in the African region and is best known in the Western media for its periodic drought, famine, and protracted civil war. Ethiopia is the oldest independent country in Africa and one of the oldest in the world. It is the only country in Africa that has never been colonized. The three main colors of its flag (Green, Yellow and Red) have also been adopted by other African countries upon independence (The World Factbook, 2004). Ethiopia has historically been an empire and in 1974, Emperor Haile Selassie was deposed by a Marxists military junta after 34 years of reign. In 1991, this was overthrown by a coalition of guerilla groups lead by EPRDF, the current ruling political party, which resulted in the establishment of formal democratic institutions (Freedom House, 2005).

Figure 5.1: Map showing Ethiopia and its neighboring countries.

Ethiopia is a country with varied geographical diversity with topographic features ranging from the highest peak at Ras Dashen (4,500m above sea level) to the Afar Depression (110m below sea level). More than half of the country lies above 1,500 meters. Broadly, there are three climatic zones: the hot lowland (kola), the Weyna Dega and cool temperature highlands (Dega). Mean annual temperature ranges from 10-16^0c in the Dega, 16-29^0c in the Weyna Dega and 23-33^0c in the kola. In general, the highlands receive more rain than the lowlands. But irregularity of rainfall is a characteristic of the climate in, which often exposed the country to recurrent droughts and famines. The diverse topography has resulted in inaccessibility of roads and other infrastructures. Many of these geographical conditions have contributed to making the epidemiology of malaria and problem of malnutrition more variable and unstable than in any other country in Africa (The World Factbook, 2004; MOH, 2002b).

Administrative and Political Structures

Administratively, the country is divided into 9 ethnically-based regional states: Amhara, Benishangule-Gumuz, Gambella, Harari people, Oromia, Somali, Tigray and the Southern Nations and Nationalities Peoples Region (SNNPR); and two administrative cities – Addis Ababa and Dire Dawa (see Figure 5.2). Each region has its own parliament and is responsible for legislative and administrative functions except for foreign affairs and defense.

The politics of Ethiopia takes place in a framework of a federal parliamentary republic, whereby the Prime Minister is the head of government. The political system is divided into an executive, a legislative and a judicial branch. The chief of state is a President and is elected every six years by the House of People's Representatives. The head of government is designated by the party in power following legislative elections. The government endorses the policy of ethnic federalism.

Ethiopia
- *11 Regions*
- *1. 3 million km^2*
- *About 75 million people*
- *85% rural*

Selected Basic Indicators
[*Italicized: UNDP figures.* Others: FMOH Ethiopia (NHAPCO/FMOH, 2004b)]
- *GDP per capita (US$)* *90*
- *Population living < $1 and $2/day* *26%, 81%*
- Life expectancy (years) 50
- *Per capita health expenditure (US$)* *1.4*

Access to basic health care 46%

Figure 5.2: Administrative and political divisions

This federal system allows the Ethiopian government to administer the different regions which have the power to raise and spend their own revenues. The nine ethnically-based administrative states are further subdivided into 68 zones, and the two chartered cities: Addis Ababa and Dire Dawa, are also subdivided into 550 woredas (to mean district and also called kifle ketema or sub-city in Addis) and 6 special woredas. The federal government interferes in the affairs of the regional states to contribute its share when necessary. This interference, as we will discuss in chapter 7, had a detrimental effect on our implementation efforts.

The 1995's Ethiopian constitution has a number of unique features. The role of the federal government is limited to directing the country's fiscal, defense and foreign affairs and articulating economic and social policies. Decentralization is also made based on ethnicity, granting the regional states the status of a nation, and giving rights of self-determination up to secession. The government has also devolved power to regional and local governments and courts. The regional states have their respective autonomous governments. State governments are empowered to design and operate region specific programs and polices in the management of natural resources, health services and maintenance of internal law and order (*www.wikipedia.org).* This regional autonomy, as we will discuss in chapters 6-8, had a profound positive significance on our system development and implementation efforts, though it was at times interfered by the federal involvement.

Socio-demographic and Economic Status

Making it sub-Sahara's second most populous country after Nigeria, the total population of Ethiopia is estimated to be about 75 million[*], 49.8% females and 50.2% males (The World Factbook, 2004). The average annual population growth rate is 2.7%, and the population density is 52.2 persons per square km. The population is expected to reach 106 million by the year 2020. The average household size is 4.8. The age structure of the population is typical of many developing countries, with 43.5% of the population under the age of 15 years, 51.9% between the ages of 15 and 59 years and only 4.6% of the whole population are aged 60 years and above. The largest proportion of women (24%) is in the reproductive age (15-49 years). The main characteristic of the Ethiopian population, therefore, is its youthfulness, with children (0-14 years) and youth (15-24) together accounting for almost 64% of the total (The World Factbook, 2004).

The Ethiopian population is very diversified with respect to language, religion, background and traits, methods of gaining a livelihood, and other cultural differences (Encyclopædia Britannica, 2006). The main religions are Islam, Ethiopian Orthodox, and Animists. The country's population includes Semitic, Cushitic (Hamitic), Omotic and Niotic peoples. The population comprises of more than 80 ethnic groups speaking about 83 languages and several dialects. The ethnic groups of Oromo, Amhara, Tigre and Sidama are the largest in number in that order. Among those, Amharic, Oromiffa, Tigrinya and Somali are spoken by the majority of the population (The World Factbook, 2004). Amharic is the official language of Ethiopia. It has been the language of primary school instruction for a long time but

[*] The latest national census has been going at the time of the writing of this thesis. Different literatures we referred to in this thesis use different estimates sometimes for the same year.

it has now been replaced in many areas by local languages. English is the medium of instruction in secondary schools, colleges and universities. Official government documents are available both in Amharic and English. In the health sector, most of the data capturing and reporting formats, including those used in HIV/AIDS and ART management, are prepared in English.

Although Ethiopia is endowed with natural resources, it still remains to be one of the poorest nations in the world. All the socio-economic indicators are the lowest by any standard. Ethiopia’s economy is highly dependent on agriculture through which about 85% of the populations earn their livelihoods, and the overwhelming majority of the total population lives in rural areas. The agriculture sector respectively accounts for half of the GDP and about 60% of the exports nationally. Coffee, hide, and skin are key agricultural products (MOH, 2002b; The World Factbook, 2004). Yet, the agriculture sector repeatedly suffers from and remains to be vulnerable to frequent droughts, and poor and traditional cultivation practices. These problems of drought along with under nourishment places further pressure on the health services of the country. High donor dependency is an outcome of the country’s attempts to address this vulnerability. Still, as a development strategy, the government adopted Agricultural Development Led Industrialization (ADLI) with a long-term development framework for economic transformation. On the other hand, the share of industry has never exceeded 15% of the GDP. It is based primarily on the processing of agricultural products. Similarly, the structure of export reflects heavy reliance on some primary agricultural commodities especially coffee (accounting for about 37.2 % of export earning). Primary subsistence crop included maize, sorghum, wheat, barley, millet teff (grown only in Ethiopia) and inset (*www.ethiopia.ottawa.on.ca/*).

The population of Ethiopia below poverty line is about 50% and the GDP per capita is about $100 (FMFFA/ADC, 2004). Since World War II, Ethiopia has often been economically and politically dependent of the major world powers and in 2001 the country qualified for debt relief from the Highly Indebted Poor Countries (HIPC). (Freedom House, 2005; Encyclopædia Britannica, 2006). The population that is provided with safe drinking water is only 24% as compared to the world average of 81%. This is even lower than that of other low-income countries such as Mozambique (60%) and Rwanda (41%) (MOH, 2004). The decentralization of basic service delivery responsibilities first to regions and more recently to local governments since the mid-1990's and the rise of spending on poverty reduction has contributed to making important gains on human development indicators (World Bank, 2006).

Ethiopia has its own alphabet, Ethiopic, and uses the Julian calendar of 13 months – 12 of which consisting of 30 days each and the 13th month having five or six days at the end of the year. The Ethiopian calendar (E.C.) is seven years and about eight months behind that of Gregorian. Furthermore, the country is three hours ahead of Greenwich Mean Time. Time remains constant throughout the year in Ethiopia. The Ethiopian day is calculated in a manner similar to that in many equatorial countries, where day and night are always the same length: counting starts at Western 6:00 a.m. and 6:00 p.m. Western 7:00 a.m., therefore, is one o'clock, noon is six, 6:00 p.m. is twelve o'clock, and so on. The first day of the Ethiopian new year, 1 "Meskaram", for years between 1901 and 2099 (inclusive), is usually September 11 (Gregorian), but falls on September 12 (Gregorian), in years before the Gregorian leap year (*www.wikipedia.org/*). Ethiopia entered to its third new Millennium, the year 2000, on 12 September, 2007. As we will discuss in chapter 7, this different dating system had implications in our development and implementation work.

The National Healthcare System and Health Status

In addition to the public health problems resulting from the topographic, climatic, and agricultural conditions of the country, widespread poverty along with the generally low income levels of the population, inadequate access to water and sanitation facilities, a high rate of migration, and poor access to health services contribute to the high burden of ill health in the country. This situation is further aggravated by a combination of rapid population growth, poor economic performance and low educational levels which have constrained Ethiopia's socio-economic development (MOH, 2002b).

As a result, Ethiopia has an extremely poor health status relative to other comparable low-income countries. The major health problems that account for about 60-80% of the registered morbidity of the country are due to preventable infections diseases, communicable diseases, nutritional deficiency diseases, and infant mortality (MOH, 2002b; Awala, 2003; The World Factbook, 2004). For example, according to the 2004/2005 national health indicators (see Table 5.1), the infant mortality rate in the country is 96.8 per 1000 live births. As discussed in section 5.4 HIV/AIDS has become a unique challenge. Diarrhea, tuberculosis, malaria, and maternal and prenatal complications are also other public health burdens. Acute upper respiratory infections and skin diseases are amongst the top leading illnesses in the country. Outbreaks of meningitis, measles and cholera are common during droughts (WHO, 2004). Health service providers attribute the high incidence of diseases to poverty, hunger, and poor sanitation. In addressing such serious problems, healthcare services are rendered through the framework of the four sectors, public, private, NGO and traditional healers. Yet, the health system is underdeveloped and only able to provide health services to about half of the population. Population coverage in terms of health workers remains poor (see Table 5.1). Ethiopia faces serious human resource constraints in the health sector that hampers the equitable distribution of health services (The World Bank Group, 2005). As compared to the WHO standard of 1:10 000 (ratio of physician to people served), the Ethiopian average is 1:25 958 indicating the significant overburdening of physicians. Moreover, most health institutions and physicians were concentrated in urban areas of the country. There is also inter-regional variation in the distribution of physicians. For example, in Somali a physician serves 72,764 people and in Addis Ababa 13, 164.

The overall level of health service coverage is estimated to be approximately 45 percent. The actual coverage estimates for the individual programs are very low. One of the major reasons for the poor coverage of health services in Ethiopia is the limited physical access of the population to health facilities. Apart from the physical and cultural barriers that affect health services utilization, the pattern of resources allocation has left most of the rural population without appropriate health care. Most of rural population of Ethiopia has limited access to health care with a small hospital network (0.2 beds per 1 000 population) and geographical constraints (more than 50% of the population lives more than 10 km from the nearest health facility, usually in regions with poor transportation infrastructure). Also it is estimated that only 75 percent of urban households are within ten kilometers of a health facility.

Generally, the responsibility of health policy and regulation is that of the Federal Ministry of Health (FMOH or simply MOH), while responsibility for management of health service delivery, including that of HIV/AIDS, falls to the respective Regional Health Bureaus (RHBs). The roles and responsibilities of FMOH and RHBs are defined by the national and regional constitutions. The managerial set up of the Ethiopian health services has historically been centralized until a new Health Policy and Health Sector Strategy was adopted in the mid-1990s by the government which involves decentralizing the health system and strengthening the regional, zonal and district health departments.

According to the recent health policy of the government, emphasis is given to improve access of all segments of the population to a basic package of quality primary health care services, via a decentralized state system of governance. To this end, the first Health Sector Development Programme (HSDP I) introduced, in 2000, a four tier system for health service delivery. This is characterized by Primary Health Care (PHC) units, comprising of one health center and five satellite health posts, and then the district hospital, zonal hospital and specialized referral hospital. A PHC unit has been planned to serve 25 000 people, while a district and a zonal hospital are each expected to serve 250 000 and 1,000,000 people respectively (MOH, 2002a). Consequently, the decentralization process gives the primary responsibility of managing the PHC services to the woreda. However, in practice it is often seen that there are hardly any health centers having five health posts under it, and available health posts are often unable to provide the required services due to lack of medical facilities and staff. To strengthen the health sector development plan, the MOH has recently published a five year (2005-2009) plan of expanding the PHC care coverage through constructing and equipping of 563 new health centers and upgrading 2167 existing health stations to health centers.

Total Population	73,043,510
Rural Population Proportion (%)	84.5
PHS Coverage (%)	72.1
PHS Coverage (%) *	82.9
EPI Coverage (%)**	70.1
Health Service Utilization (%)	0.3
Contraceptive Prevalence Rate (%)	25.2
Antenatal Coverage (%)	42.1
Infant Mortality Rate (per 1000)	96.8
Under 5 Mortality Rate (per 1000)	140.1
Total Fertility Rate (per woman)	5.9
Life Expectancy Female (years)	55.4
Life Expectancy Male (years)	54.1
Number of Facilities	
Hospitals	131
Health Centers	600
Health stations	1,662
Health Posts	4,211
Private Clinics	1,578
Pharmacies	276
Drug Shops	381
Rural Drug Vendors	1,787
Human Resources (at Service)	
Physicians	2,453
Health Officers	776
Nurses	18,809
Health Assistants	6,363
Para Medicals	6,259

Table 5.1: Basic health indicators, 2004/2005. Source: (FMOH/NHAPCO, 2006b)

ICT and the Healthcare System

Computers were introduced into Ethiopia in the early 1960's by some bigger organizations in the country. The Ethiopian Science and Technology Commission and Ethiopian Telecommunications Corporation have contributed significantly to introduce ICTs and create public awareness. It also played a leading role in enabling the imports of IT products based on the context of the country. Later, national ICT policy was developed which describes the development of a national ICT infrastructure as one of the national strategic components to make changes and improve the determinants of national performance. As of July 2003, the Ethiopian Information Communication Technology Development Authority (EICTDA) was established with the objective of utilizing ICT for socio-economic development (Federal Negarit Gazeta, 2003).

EICTDA designed various projects to develop the ICT infrastructure at the three tiers of the government system (Federal, Region and Woreda). Out of these, the Woreda-Net and the Content and Application Development Projects are the major ones. The Woreda net project is aimed to develop ICT infrastructure in 571 woredas of the country (EICTDA, 2004). The Content and Application Project is also working in identifying the prioritized sector organizations' content to develop shareable applications and to utilize the established infrastructure. One of these prioritized sectors is the health sector. The Ministry of Health (MOH) is a member of a steering committee in EICTDA to utilize the established Woreda-Net infrastructure for the health sector. The MOH has identified four content areas including HIS (health information systems) to develop applications that will be a shared resource at various healthcare levels. Since 2002, there are some efforts and initiatives which are ongoing to implement HIS in collaboration with different governmental and international agencies to make the best use of ICT. However, these efforts are not only yet satisfactory as discussed below but also are largely uncoordinated as we have found out in the case of HIV/AIDS and ART management (see sections 5.4 and 5.6).

Health Management Information Systems (HMIS)

The HMIS in Ethiopia is also in a poor status. At the national level, the HMIS has been established for receiving summarized data, including that of HIV/AIDS, from all the Regional Health Bureaus in each quarter of a year. At the end of each year, the report is issued in a MOH publication which includes health and health related indicators (MOH, 2002b; Awala, 2003). The major concerns regarding the current HMIS refer to certain gaps in coverage, particularly drug-related and financial management indicators. Lack of timeliness and completeness of reporting as is the case in ART reports remains a weakness of the HMIS, and such delays contribute to the failure (at all levels) to use data as the basis for timely informed decision-making. In addition, parallel reporting mechanisms persist, with program-based and donor-supported initiatives resulting in multiple reporting formats and an increased administrative workload (MOH, 2002b; WHO, 1999). Moreover, HIS in Ethiopia is unevenly developed with great differences between Addis Ababa and other regions. In Addis, an integrated HIS database application called District Health Information System (DHIS) for Addis Ababa is implemented by the Health Information System Program (HISP), in the framework of which we conducted this specific research, and is working in all sub-cities, hospitals, and health centers. As the city also benefits from modern infrastructural and human resources facilitating the information exchange it remains in big contrast to other regions where much still has to be done (Braa et al., 2006).

This situation has also contributed to getting our ART system first implemented in the city than elsewhere.

After this brief summary of issues at the national level, we provide some further details specifically about the Addis Ababa region where most of our research sites are found.

5.3 The Addis Ababa Region

Addis Ababa is located at $90^{0}03^{0}$ latitude and $38^{0}42^{0}$E longitude. It has been serving as the capital city since the Menelik regime in 1890. Recently, the Ethiopian constitution article 49 has declared Addis Ababa to be the capital city of the Federal state. The city is the seat of large organizations and government offices including the Federal Government. The office of the MOH is also found in the city. Addis Ababa hosts many international offices including the office of the African Union and United Nations Economic Commission for Africa (UNECA).

Administrative and Political Structure

The structure of the organs of power of the city include; the city government, 10 administrative sub-cities and 100 Kebeles (www.addisababacity.gov.et/). A Kebele is a third administrative level at grass root community level. The city is divided into 10 sub-city administrations that is equal to a district or Woreda (in Ethiopia) each comprising of 250 000-300 000 people.

Geography and Socio-demographic Profile

The total projected population of Addis Ababa is 2 973 000 (1 428 000 male and 1 545 000), and estimated to become more than 3.7 million in 2014. The population would still be growing by more than 2% per year in 2014 from both natural increase and migration. Unemployment is high and incomes are low in Addis Ababa. A recent report indicated that 60 percent of households earn less than 40 USD per month (AACGHB, 1999). Addis Ababa covers 540 square kilometers, and its altitude ranges from 2 000 to 2 500 meters above sea level, and is dominated by the 3 000 meters high Entoto Mountains immediately to the north. The city is situated roughly at the center of the country, around which lie all the country's other administrative districts. Thus, geographically, Addis stands at the very heart of Ethiopia. Socially, there is a representation of the different ethnic groups in the capital. In addition, the large numbers of foreign residents, from all parts of the world, contribute to the city's vibrant cosmopolitan atmosphere. The city enjoys connections with all Ethiopia's economic zones. Many manufacturing plants are located in and around Addis Ababa, making it the center of commerce and industry for the country. As the largest city of Ethiopia and economic center of the country, Addis Ababa is by far well developed in terms of modern technology (e.g. internet, mobile phone), roads and transportation, and other facilities as compared to other regions. In addition to its being our region of residence, these features of Addis facilitated our research processes as we could, for example, make use of them to easily access the research sites and communicate with our different respondents.

Health Service Status

According to the Ethiopian national health indicators, there are 15 public hospitals in the city of which 5 are owned by the regional health bureau and 5 by the Federal level. These different ownerships of hospitals were problematic when it comes to our implementation effort as discussed in chapter 7. In addition, there are 15 private general hospitals, 7 specialized hospitals, 28 health centers, and 46 health posts in the region. Including the ART clinics, there are also 456 higher, medium, lower, and specialized clinics of which 6 are run by the city administration, 28 by NGOs and 56 by other government organizations, 46 by factories and 320 by private owners. In addition to these, there are about 180 retail drug outlets and 46 health posts (30 run by the sub-city administration and 16 by NGOs). Moreover, the city has about several NGOs working on different health activities. As indicated by national health indicators, a better health facility and health worker distribution is seen in this region as compared to the other regions of the country. Yet, communicable diseases that could be prevented through interactions of primary health care activities are the main causes of morbidity and mortality in Addis are. TB and nutritional deficiencies also assume greater importance in the region. Addis is severely affected by HIV/AIDS (see section 2.4)

The Regional Health Bureau and Some Characters in Our Research

Addis Ababa City Government Health Bureau (AACGHB) was established in 1985 E.C. The bureau is authorized to organize, co-ordinate and regulate the overall public health activities in the city. It is also responsible for the provision of both curative and preventive health care activities of the city including those of HIV/AIDS and ART. In relation with our system development and implementation efforts, we maintained a sustained contact with the bureau staff particularly with the Disease Prevention, Control and Health Programs Department head (who also was the regional HIV/AIDS program manager) and with the IT team. We established contact with these people by means of a HISP researcher who had been working in the region around DHIS. At the beginning of our research, we found the regional program manager to have experienced many system failure stories and undelivered promises in his search of a program specific information system to support HIV/AIDS management. He granted us permission to use some of the ART clinics under his supervision and develop an IS that supports ART management as he could not find one that satisfied his need so far. He (with the head of the bureau) also later facilitated the now ongoing implementation of our system in all (67) clinics under the bureau as per the MOU (see chapters 3, 6 and7). The IT team of the bureau has also been providing us feedback and strong support throughout the process especially after learning the urgency of system needs in the region and the strength of our system to satisfy this need. Moreover, after being on the field with us for a sustained period of time, they have been somehow collecting feedback about the system from the clinic staff (including clerks, doctors and clinic head) and providing positive feedback to the program manager which helped us a lot to gain support and legitimacy (see detailed stories in chapters 6 and 7).

> *"Our cemeteries are filled beyond capacity. Parents are dying from HIV/AIDS or burying their children; a generation of fathers and mothers is being lost leaving the grandparents to grieve and raising the next generation. I cannot understate the terrible nature of the crisis that is enveloping our societies. As bad as it is today, the reality is that it is getting worse."* – HE Girma Wolde Giorgis, President, Federal Republic of Ethiopia

5.4 HIV/AIDS in Ethiopia

Having discussed various issues that impacted the national socio-economic status, this section attends to the HIV/AIDS side of Ethiopia which became a pressing health issue, and also a serious threat to the development of the entire country at large (FMFFA/ADC, 2004). The discussion provides the basis for our system development and implementation efforts.

Spread and Status

The first evidence of HIV in Ethiopia was discovered from stored sera collected in 1984. Two years later, the first two AIDS cases were reported in 1986 (FMOH/NHAPCO, 2006a). Nearly after 25 years since then, the disease has spread at an alarming rate, due to such factors as socio-economic vulnerabilities, cultural practices and gender disparity. Thus, Ethiopia is among the countries most heavily affected by the HIV/AIDS epidemic with the third largest population of HIV-infected persons living in Africa, and contributing approximately 4% of the world's total AIDS load (GAP, 2003). The spread of HIV/AIDS in Ethiopia was initially localized in major urban areas located along major roads and commercial routes. The current surveillance report indicates a steady rise in HIV infection rate in the rural setting while the trend in the urban areas seems to be stabilizing (MOH, 2004). Without effective intervention, a potential devastating epidemic is a threat to rural areas, where the majority of

Ethiopians live (85%) and upon which the economy of the country heavily relies. The Ethiopian Demographic and Health Survey (DHS) 2000 document that the rural population had markedly lower knowledge and awareness about HIV/AIDS as compared to urban population.

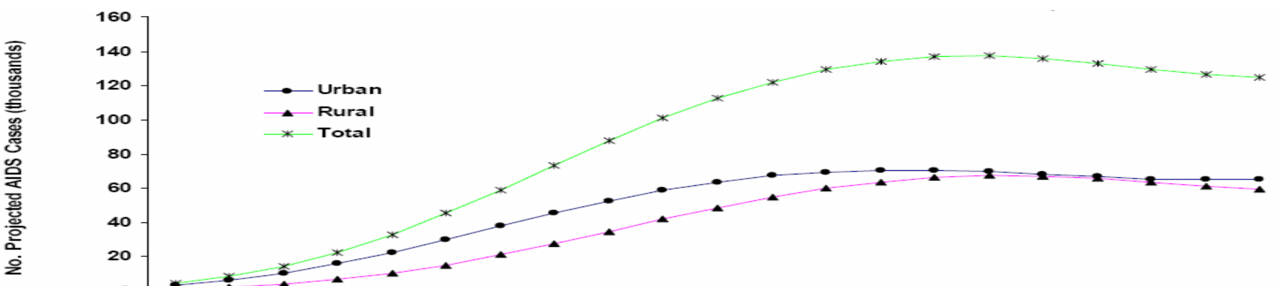
Figure 5.3: People living with HIV/AIDS by region (total=1 319 795), 2005. Source: (FMOH/NHAPCO, 2006b)

Based on the 2005 sentinel surveillance findings, the report titled "*AIDS in Ethiopia*"* estimates that the cumulative number of PLWHA to be about 1.32 million (45% male and 55% female) including 134 586 children under age 14 (see Figure 5.3). This reflects a prevalence rate of 3.5% (3% among males and 4% among females) for the total estimated population of about 73 million in the country. The estimated number of new adult AIDS cases was 137 499 (see Figure 5.4). The number of new HIV infections was 128 922 including 30 338 HIV-positive births, suggesting that 353 new cases were being added to the pool of positive cases per day (FMOH/NHAPCO, 2006a). Females accounted for 53.2% of these new infections. While there were more men living with HIV/AIDS than women in the age group 30+ years, there were more women than men in the age group 15-29.

A number of complex underlying factors contributed to the spread of the pandemic in Ethiopia. The major mode of HIV transmission is unprotected heterosexual intercourse which accounts for approximately 87% of all HIV infections. Another 8-10% of infections occur due to transmission from infected mother to her fetus/child during pregnancy and breast-feeding. HIV can be both a cause and a symptom of poverty. Given the high rates of unemployment and poverty at the household level,

* The current AIDS in Ethiopia report is the 6th in the "AIDS in Ethiopia" series – published by The Federal Ministry of Health of Ethiopia. The present edition (September, 2006) reports the 2005 antenatal based site-level surveillance findings and estimates the HIV and AIDS status in the country.

increasing numbers of women turn to selling sex for survival which further spreads the virus. Ethiopia has also been affected by significant social disruptions such as wars (troop movements), further fueling the epidemic. Illiteracy, stigma and discrimination of those infected by HIV, population movement including rural to urban migration, and harmful cultural and traditional practices are reported to be among the major factors that help drive the epidemic in the country (FMOH/NHAPCO, 2006a; HAPCO/FMOH, 2004). In particular, the widespread and large numbers of commercial sex workers in Addis Ababa has aggravated the spread of the virus in the city more than in any other region in the country (AACGHB, 1999).



	90	91	92	93	94	95	96	97	98	99	00	01	02	03	04	05	06	07	08	09	10
Urban	3	6	10	16	23	30	38	46	53	59	64	67	70	71	71	70	68	67	66	65	65
Rural	1	2	4	7	10	15	21	28	35	42	49	55	60	64	66	68	67	66	64	62	59
Total	5	9	15	23	33	45	59	73	88	101	113	122	129	134	137	137	136	133	129	126	125

Figure 5.4 Annual Estimated and Projected New AIDS Cases, 1990-2010. Source: (FMOH/NHAPCO, 2006a)

National adult HIV prevalence in 2005 was more than five times higher in urban (10.5%) than in rural (1.9%) areas. Overall, prevalence remains high in Addis Ababa where it has remained at 14%–16% since the mid-1990s while in other urban areas where it has stayed between 11% and 13% in the same period (Hladik et al., 2006). Figure 5.5 shows the regional prevalence for 2005. In rural areas, where about 85% of the country’s population lives, prevalence among women attending antenatal clinics there rose from 1.9% in 2000 to 2.6% in 2003 and 2.2% in 2005 (Hladik et al., 2006; NHAPCO/FMOH, 2004b; FMOH/NHAPCO, 2006a). According to the 2005 DHS, 1.4% of adults (15–49 years) were living with HIV in 2005, with prevalence among adult women double that of adult men. Infection levels were much higher in urban areas (5.5% among adults) than in rural areas (0.7%) (Central Statistical Agency and ORC Macro, 2006).

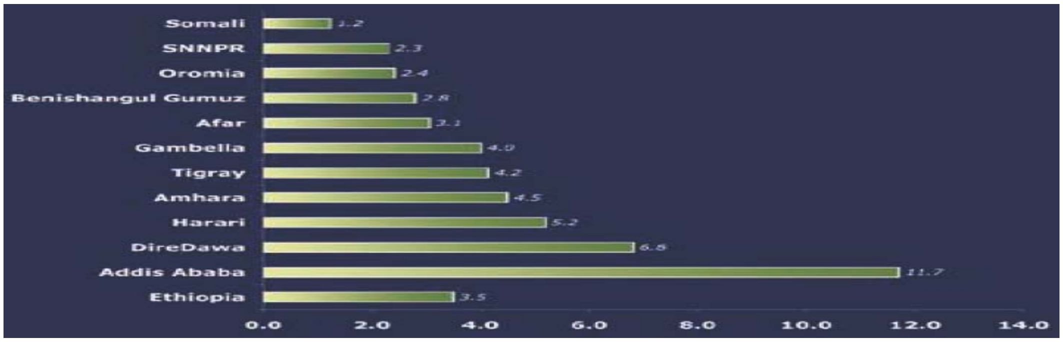
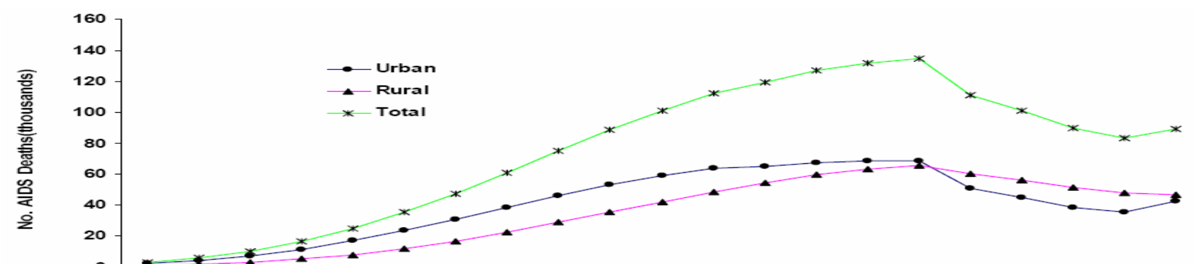


Figure 5.5: Regional HIV prevalence, 2005. Source: (NHAPCO/FMOH, 2006).

Some Consequences and Impacts

It is estimated that in 2005 there were 134 450 (368 a day) AIDS-related deaths in the country including 20 929 children 0-14 years (83.6% under age five). Females accounted for 54.5% of AIDS-related deaths. AIDS-related deaths have been increasing until it started to decline in 2005 (see Figure 5.6) due to the impact of ART (see section 5.5).



	90	91	92	93	94	95	96	97	98	99	00	01	02	03	04	05	06	07	08	09	10
Urban	2	4	7	11	17	24	31	39	46	53	59	64	65	68	69	69	51	45	38	36	43
Rural	1	2	3	5	8	12	17	22	29	35	42	49	54	59	63	66	60	56	51	48	47
Total	3	6	10	16	25	35	47	61	75	88	101	112	119	127	132	134	111	101	90	83	89

Year

Figure 5.6: Estimated and Projected Number of AIDS Deaths, 1990-2010. Source: (FMOH/NHAPCO, 2006a)

The total number of AIDS orphans aged 0-17 years in 2005 was reported to have reached 4, 885,337. Out of these, 744 100 were AIDS orphans, 250 295 of them being dual orphans. This growth of the number of orphans due to AIDS is worsening the social and economic situation of children. The burden of their care falls on grandparents, older siblings, and the community at large. The magnitude of the problem and the general level of poverty have weakened social cohesion and traditional coping mechanisms. Providing care and support to orphans has overwhelmed traditional coping capacity, leaving many children without their basic social education needs and rights unattended which in turn worsens their vulnerability. The total number of AIDS orphans is projected to increase though ART is expected to lessen the rate (see section 5.5).

Figure 5.7: Total Population Size and Population Lost to HIV/AIDS, 2000-2010. Source: (FMOH/NHAPCO, 2006a)

Like elsewhere in sub-Saharan Africa, the demographic impact of AIDS in Ethiopia is also considerable. Figure 5.7 shows the impact on the total population size. The cumulative number of AIDS deaths is projected to reach 1.9 million by 2010 if present trends continue. In particular, adult (15-49) deaths due to AIDS increased till 2005 when they accounted for 35% of young adult deaths, though they have from then on started to dramatically decline up to 2009 due to the impact of ART (see section 5.5). Also, AIDS has a severe impact on life expectancy in Ethiopia. It has already likely reduced life expectancy by five years in 2005 (FMOH/NHAPCO, 2006a) after which it started to decline again due to ART (see section 5.5). In any case, HIV/AIDS has already claimed the lives of too many Ethiopians. No wonder then HE Girma Wolde Giorgis, President, Federal Republic of Ethiopia said:

> *"Our* cemeteries *are filled beyond capacity. Parents are dying from HIV/AIDS or burying their children; a generation of fathers and mothers is being lost leaving the grandparents to grieve and raising the next generation. I cannot understate the terrible nature of the crisis that is enveloping our societies. As bad as it is today, the reality is that it is getting worse"* (ECA, 2004, p. v).

In addition to morbidity and mortality, the HIV/AIDS pandemic has adversely impacted the country's development in other different ways. For example, as HIV/AIDS is gradually but steadily spreading into the rural areas where 85% of the Ethiopian population lives, it is significantly affecting the agricultural sector which accounts for half of the GDP and about 60% of the exports nationally, and is already suffering from multiple other problems. Likewise, the epidemic is affecting all other sectors. Family and communities have also all been considerably affected. In short, the disease has multi-sectoral nature. On the whole, the impact of the pandemic on the country is so gross that NHAPCO/UNDP (2003) stated:

> *"In our country, Ethiopia, HIV/AIDS … is a major factor limiting the realization of the Millennium Development Goals (MDGs). The epidemic dampens our hopes of alleviating poverty and hunger, achieving universal education and promoting gender equality. Because of HIV/AIDS,*

> *mortality and morbidity rates are rising and the epidemic is altering the structure and function of the social sectors by straining and limiting the output of services, while increasing the demand and complexity of services required"* (p. v).

Table 5.2 provides the major AIDS indicators of the country for 2005-2007.

	2005	2006	2007	2010
Adult HIV Prevalence (%)				
Total	3.5	3.3	3.2	2.8
Urban	10.5	10.1	9.8	9.3
Rural	1.9	1.8	1.7	1.4
HIV-Pos Population	1,319,795	1,306,891	1,319,902	1,439,769
HIV-Pos Pregnant Women	105,675	102,781	101,741	105,159
HIV-Pos Births	30,338	26,364	23,003	19,073
New HIV Infections	128,922	129,907	132,154	144,737
New AIDS Cases	137,499	135,666	132,744	124,512
AIDS Deaths	134,450	111,200	101,180	89,225
ART Needs	277,757	274,364	287,881	351,001
AIDS Orphans	744,088	822,687	889,308	965,967
Non AIDS Orphans	4,141,249	4,189,114	4,228,311	4,260,217
Propotion of TB Cases Caused by AIDS	32%	31%	30%	30%
Proportion of 15 - 49 year olds Dying of AIDS	34%	30%	27%	24%
Decreases in Expectation of Life Due to AIDS	5 Years	4.2 Years	3.9 Years	2.8 Years
Population Increase	2,060,824	2,145,126	2,213,764	2,145,126

Table 5.2: Major HIV indicators for 2005-2007. Source: (FMOH/NHAPCO, 2006b)

In summary, despite enormous efforts, the burden of the problem has reached a stage beyond which the health sector can solely manage. Having devastating figures of PLWHA along with the prospect of an alarming growth rate (FMOH/NHAPCO, 2006a), fighting HIV/AIDS is now an urgent national priority. Despite all the challenges, the government has been working towards containing the epidemic, and hence the achievements so far are encouraging. The next subsection discusses what has been done as recognition of these seemingly never-ending challenges.

Reactions – Federal and International Aid Responses and Achievements

The government of Ethiopia has been steadfast in its response to the epidemic. As soon as the first evidence of HIV in Ethiopia was discovered in 1984, the government initiated the response by establishing a National HIV/AIDS Task Force (NTF) within the MOH in 1985, even prior to the first laboratory diagnosis and confirmation of the virus and report of the first two AIDS cases in 1986. This response focused on analyzing the situation, developing operational guidelines for prevention, and assessing the capacity required to arrest the spread of HIV infection. In 1987-89 Short and Medium Term Plan were drawn out to respond to the budding epidemic realizing the potentially enormous devastating impacts. In 1987, the National AIDS Control Program (NACP) was established at a Department level at the MOH (FMOH/NHAPCO, 2006a; FMOH/NHAPCO, 2006b; NHAPCO/UNDP, 2003; NHAPCO/FMOH, 2004a).

Two medium-term prevention and control plans were designed and implemented in 1989 and 1996 respectively. Activities were carried out in relation to HIV surveillance, patient care and expansion of HIV screening laboratories in different health institutions. This response, however, was not a strong enough response to the gravity of the problem. Initially the public at community level were only minimally involved, and coordination and integration across sectors was not adequately established. As a result of the continued high rates of infection, the Government approved a HIV/AIDS Policy formulated by MOH and adopted by the Council of Ministers in August 1998. This provided an enabling environment for a multi-sector response to prevent and control the epidemic. The policy supplemented several policies such as facilitating the development of policies, for example, on the supply and use of antiretroviral (ARV) drugs.

Some sad consequences of HIV and AIDS in Ethiopia

- *353 people are being newly infected with the virus everyday.*
- *128 922 were infected in 2005 alone.*
- *The cumulative number of people living with HIV/AIDS grew to be about 1.32 million.*
- *368 people are dying from AIDS everyday.*
- *In 2005 alone 134 450 people died of AIDS.*
- *There were 744 100 AIDS orphans in 2005.*
- *Deaths due to AIDS brought down life expectancy gains from 53 to 46 in 2001.*
- *HIV/AIDS has already likely reduced life expectancy by five years in 2005.*
- *If the current death trend continues, the projected life expectancy gain 59 years in 2014 will be reduced to 50 years.*
- *The cumulative number of AIDS deaths is projected to reach 1.9 million by 2010 if present trends continue.*

Still, the Government was aware of the threat of the epidemic and decided to take a series of measures to meet the challenges and reduce the spread of the disease. In 2000, the government issued a comprehensive national HIV/AIDS policy, the strategic framework and the establishment of a multi-sectoral and broad based National AIDS Council (NAC) under the chairmanship of the country's president. A National HIV/AIDS Prevention and Control Secretariat (NACS) accountable to the Prime Minister's Office was also established to coordinate the national multi-sectoral response to HIV/AIDS. Similar structures with similar constituencies were also established in the regions and at lower administrative levels (*www.who.int/countries/eth/*). The legalization of the current HIV/AIDS Prevention and Control Office (HAPCO), which evolved from NACS after 2 years of functioning, by proclamation in June 2002, and the launching of multi-sectoral HIV/AIDS control and prevention programs were some of the major steps forward in the battle against HIV/AIDS. HAPCO has now become an autonomous body, a national authority with a broad based multi-sectoral mandate. And, in addition to the national HAPCO (NHAPCO), there are regional HAPCOs (called RHAPCO) such as AAHAPCO and OHAPCO for Addis Ababa and Oromia regions respectively.

HAPCO had developed and implemented a five years (2000-2004) national strategic framework as part of the national response to HIV/AIDS. The Government of Ethiopia, in partnership with and with support from international donors, formulated Ethiopia's Multi-Sectoral HIV/AIDS Control Project (EMSAP), to implement and make the framework operational. EMSAP is in its third year of implementation. To date, many of the intervention areas described in the Strategic Framework have been implemented and a number of accomplishments have been recorded. Government bodies, NGOs, religious bodies and local communities are being made to fully understand how this epidemic strains and hinders advances in development. Since Ethiopia's developmental crisis requires a multi-sectoral response, all sectors and institutions are involved in fighting AIDS as part of their daily efforts to alleviate future devastating impacts. In August 2003, the publication of the mainstreaming guideline introduced new ways of approaching the epidemic via a multi-sector response. The document guided people to assess the impacts of AIDS on their respective sectors, and tried to assist in mitigating these impacts. HAPCO and the UNDP's HIV/AIDS Unit realized the effects of HIV/AIDS on advances in development, and the challenges associated with the concepts and the "how to" of mainstreaming HIV/AIDS related efforts into all sectors. The work of UNDP's HIV/AIDS Unit has largely been focused on targeting HIV/AIDS in a development mind frame. Both agencies united to produce a set of tangible tools that will provide sectors with the capacity to achieve "AIDS competence" (FMOH/NHAPCO, 2006a; FMOH/NHAPCO, 2006b; NHAPCO/UNDP, 2003; NHAPCO/FMOH, 2004a).

Granted, there still remains a high level of misconceptions (especially local ones), for example, about the transmission of HIV from one person to another like "eating uncooked egg laid by a chicken that has swallowed condom could transmit HIV" and "eating raw meat prepared by an HIV-infected person could transmit the virus" (FMOH/NHAPCO, 2006a). By and large, however, there are many encouraging achievements obtained form the above responses being made against the epidemic. The behavioral trends (2000 vs. 2005) from survey among the general Ethiopian population reveal high levels (98% of the study population) of awareness about HIV/AIDS and change in behavior. Specifically, prevalence went from 7.8% to 3.9% among men 15-19; from 20.8 % to 13.4% among men 20-24; from 4.0% to 1.0% among women 15-19; and from 16.5% to 3.1% among women 20-24.

The survey also revealed increases in condom use at last higher risk sex from 30.3% to 51.7% among men 15-49 and from 13.4% to 23.6% among women 15-49 (FMOH/NHAPCO, 2006a).

Also, there has been increasing political commitment and the society as a whole has been mobilized. Bilateral and multilateral organizations have significantly increased their technical and financial support with the United States President's Emergency Plan for AIDS Relief (PEPFAR), Global Fund, and the World Bank's MAP program being the major donors. These resources have facilitated large scale social mobilization and expansion of HIV/AIDS prevention and treatment services. As a result, the health sector response has been strengthened and is now taking important steps with respect to control, treatment and care services. This includes the rapid and massive scale-up of ART, PMTCT, and VCT services and the massive involvements of communities in the provision of social care and support and other activities. The number of centers providing VCT, ART, and PMTCT services have grown to 658, 132, and 173 respectively. The number of people using these services has also increased over the years (FMOH/NHAPCO, 2006a).

However, much remains to be done. Although the overall HIV prevalence in Ethiopia is low because of the large population, the absolute number of persons infected (and affected) by HIV is significant. The urban epidemic is at unacceptably high prevalence level of 10.5%. ART has been accessed by only13% of those who need it; and only 0.8% of HIV infections among births to HIV positive mothers were averted in 2005/6 through PMTCT programs. Universal provision of prevention, care, and treatment to the estimated 1.32 million PLWHA (278 000 of which requiring ART) and 744 100 AIDS orphans poses substantial challenges to the public health system of one of the poorest countries in the world. The loss of young adults in their productive years of life will affect the country's overall economic output. The HIV epidemic will continue to tax the limited available health and social service delivery systems. Universal access will be challenged by the fact that 50% of the PLWHA live in rural areas where access to communication and health care infrastructures is poor. FMOH/HAPCO (2006) sums up the overall situation as:

> *"Given the magnitude of the problem, it will take us a number of years to see significant declines in HIV prevalence and incidence reductions with consorted and sustained efforts. Although there are advances in the availability, accessibility and utilization of HIV/AIDS prevention, care, support and treatment services; improvements in the management of the epidemic and the increasing resource availability, we still face a situation unlikely to give us respite in the near future"* (p. vii).

HIV/AIDS Management in Ethiopia

Having devastating figures of HIV and AIDS in Ethiopia along with the prospect of an alarming growth rate, it is not surprising that there exist a number of stakeholder initiatives towards alleviating the already existing problems as well as preventing and controlling the epidemic. The HIV/AIDS system in this country comprises of a multiplicity of programs such as ART, PMTCT, STI, OI, TB, VCT, Home-Based Care, and ART pharmacy. A number of agencies – government, non-government, several social service providers, missionary organizations, international and also private – are in different ways, trying to provide support services to the implementation of these different programs. In fact, including HAPCO and WHO, there are more than 300 HIV/AIDS-related organizations in the country most of which are donor driven.

However, by and large, the different agencies involved in HIV/AIDS management often operate with their own budgets, reporting systems, manpower, and are minimally coordinated with each other in their efforts including those relating to the integration of their supporting ISs, and hence contributing to the proliferation of a plethora of IS. This means that the HIV/AIDS system runs in a compartmentalized institutional setting which is characterized by a lack of interface across the different programs. This compartmentalized health care provision underlies many of the weaknesses of the management of the HIV/AIDS program. Great challenges exist both within and across programs. For instance, it is a common experience that an HIV positive individual whose status is confirmed from VCT receives support (such as for nutritional support) from many similar providers where he/she is referred to unintentionally. Furthermore, as we have experienced from our attempt to develop and implement an IS to support HIV/AIDS management, gaining entry into the country's HIV/AIDS program and making such a system work is a task surrounded by various challenges including the political situation created from the stakeholders (see chapters 6 and 7).

The theme of this thesis is thus, firstly, to critically analyze the problems in the Ethiopian HIV/AIDS management in the following two chapters (6 and 7) particularly by making use of the ART program. And secondly, to propose pragmatic approaches and strategies (chapter 8) as to how to infiltrate the political situation and address other challenges encountered so as to effectively introduce and make work a scalable IS to support the management of the disease and its treatment with a vision of integrating the different initiatives. With that in view, let us specifically discuss the situation of ART and its management in Ethiopia in the succeeding two sections.

5.5 ART in Ethiopia

Some expected impacts of ART in Ethiopia (FMOH/NHAPCO, 2006)

- *The rate of increase of AIDS-orphans from 2005-2010 is expected to lessen because of ART.*
- *By the year 2010, there will be 13% fewer AIDS- orphans than it would be without ART.*
- *The number of AIDS deaths in 2009 is projected to be lower by over 50, 000 than that in 2005 mainly due to the expanding ART program.*
- *By the year 2010, there will be 41% fewer AIDS deaths compared to a projection without ART.*
- *Young adult deaths due to AIDS, which accounted to the deaths of 35% of young adults, are expected to dramatically decline up to 2009 due to ART.*
- *Reduction in life expectancy is projected to decline during 2005 -2010 due to ART*

History, Scaling up, and Status

The introduction of ARV treatment in Ethiopia dates back 9 years ago when very few patients in Addis Ababa received drugs from relatives living abroad or through the informal market at very high prices (FMOH, 2004). Following intensive advocacy campaign from associations of PLWHA and other organizations, and appreciation of the gravity of the problem, the government adopted the policy of ARV drug supply and use in July 2003. This paved the way for more initiatives which facilitated access to low cost and free ARV drugs. In effect, some hospitals were made to provide ART services to approximately 13 500 patients at minimal monthly costs depending on the regimen used. The first free ART was initiated in January 2004 at Humera Hospital in Tigray region by MSF-Holland.

In a move to make ARV treatment more accessible, their Excellencies the President and the Prime Minister of The Federal Democratic Republic of Ethiopia launched the free ART rollout program for Ethiopia on 24 January 2005. This materialized the government's commitment towards embracing the Global "3 by 5" initiative which, translated to the Ethiopian context, was meant to have 122 000 patients on ART by the end of 2005, though that milestone was not realized.

Forty-nine public health facilities were selected to provide free ARV treatment in 2005. These facilities included 17 public hospitals that were already providing low cost ARVs[#]. Consideration was also given to four other hospitals in Addis Ababa (some of which were our research sites) as they receive many referrals from all regions and all have well-established VCT services. Some private hospitals were selected and included in the first cohort. Hospitals that have already started treating paying patients were made to continue to deliver these services. It was anticipated that a number of patients would move to the free program. Other patients would continue with the fee based system, especially patients

[#] Currently, 10 ARV drugs are in use in the country. Out of which 7 of them are first-line and 3 are second-line.

accessing treatment through workplace interventions. Only about 20 of the 49 hospitals could start free ART in March/April 2005.

Though not achieved again, it was envisaged that the number of new patients who would benefit from free ARV treatment would increase, allowing reaching a target of about 41 000 and 100 000 new eligible patients on free ART at the end of 2005 and 2006 respectively. The availability of financial resources through funds such as the Global Fund and the US Government supported Ethiopian AIDS Emergency Plan (ETAEP) were hoped to help the country achieve its targets. Under the contribution of the Global Fund 2 and 4, sufficient funds are allocated for the procurement of 320 000 PLWHA on ART by 2010. The application for Global Round 6 currently being formulated focuses on expansion of PMTCT and pediatric ART and accelerated access to HIV/AIDS care in the rural areas.

Even so, a major concern is how to sustain a life long supply of free ARV for all those on treatment. Since the ART program is supported by donors, a complete dependence on donors' commitment was seen unadvisable. In order to address this issue, national leaders and policy makers have recommended various approaches to assure sustainability. These resource mobilization and cost saving strategies include establishing cost sharing with income sliding scale, encouraging workplace ART initiatives, approaching local groups and persons in the Diaspora for support, promoting public-private partnerships and most importantly promoting local production of ARVs.

At the end of 2005 the number of PLWHA in need of ART was 277 757[*] including 43,055 (15.5%) children aged 0-14 years (FMOH/NHAPCO, 2006a). Out of the 1.32 million PLWHA, as of January 2007, only 111 926 were enrolled in the HIV care[#] since 2003 (www.etharc.org). Out of these, only 67 235 have ever started the actual ART since then. Still out of these, only 53 720 were on ART as of January 2007, indicating drop outs or people having died during the course of treatment. Estimation and projection show that the total number of people requiring ART will increase by around 73 000 in 2010 from its level in 2005 (FMOH/NHAPCO, 2006a). Figure 5.8 shows the projected annual ART needs for the next three years. At present ART is being provided only to 13% of those in need of it, and only 0.8% of HIV transmissions from mother to child were averted through the PMTCT program (FMOH/NHAPCO, 2006a). More than 300 000 people are expected to need ART by 2008 and the MOH plans to make free ARV available to just half of them at the end of the year.

[*] We could not find published data after 2005.
[#] Before patients become eligible for ART, they may remain in the HIV care being treated for other cases such as opportunistic infections.

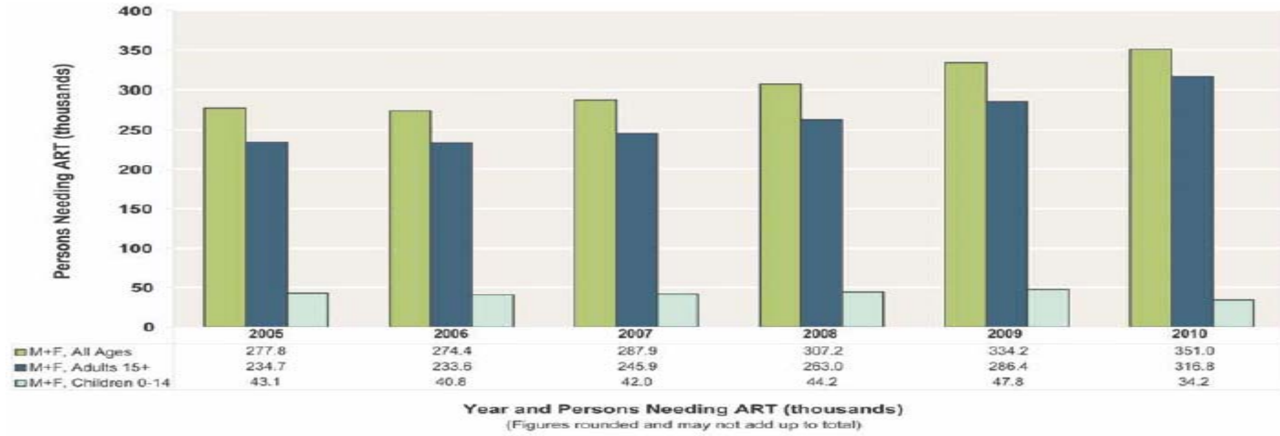


Figure 5.8: Projected Annual number of Patients Needing ART, By Sex and Age Group, Ethiopia, 2005-2010. Source: (FMOH/NHAPCO, 2006b)

Justifications and Expected Potential Impacts

In Ethiopia, like in most developing countries, which are faced with multiple competing demands of scarce resources, some may question whether the high financial investments on ART are justifiable especially in the face of problems with intense magnitude such as malaria, Tuberculosis and famine (ARC et al., 2005). Arguments against such a view are that HIV/AIDS is affecting every sector of the Ethiopian society including economic. At the macro-level, agriculture, education, health, and business and industry sectors are all adversely impacted by the disease. Families and communities are likewise affected. The MOH estimates that the annual mortality rate of the young adult (15-49) population range will increase from a projected 180 000 without AIDS to over 350 000 with the AIDS epidemic in 2008 (if ART is not considered) (NHAPCO/FMOH, 2004b). Behind these numbers is increased absenteeism in the workplace, reduction of productivity, reduced family income, and increased family expenditure on health care and burial rituals. In a resource poor country such as Ethiopia, the economic impact of AIDS related illnesses and deaths is so severe.

Given these multiple impacts of AIDS across the Ethiopian society and the potential of ART to reduce the burden, the justification for pursuing this agenda is unarguable. In contrast to Ethiopia, AIDS-related deaths and illness in countries where ART has been available since the mid 1990s have considerably declined. The experience of developed nations as well as that of developing countries such as Brazil and Uganda has proven that ART prolongs lives and impacts mortality; reduces disease burden, fatalistic attitudes, and dependence; promotes increased voluntary HIV testing and provide a rationale for making healthy living choices; and restores mental and physical functions to improve the well-being and quality of life of PLWHA so that they become productive individuals. These, in turn, can help offset some of the consequences of the HIV/AIDS pandemic. The declaration of ART as a human rights issue and support for universal access to ART from world leaders through several donor-led initiatives also encourages the national ART program. No wonder, the Government of Ethiopia elected to introduce and scale up the ART program expecting the following major potential impacts.

Potential Impacts on AIDS Deaths

If the FMOH's ART rollout plan is successfully implemented, the number of AIDS deaths is expected to start to decline from 2005 onwards as depicted on Figure 5.9. For example, the number of AIDS deaths in 2009 alone is projected to be lower by over 50 000 than that in 2005 "mainly due to the expanding ART program" (FMOH/NHAPCO, 2006, p. 24). Also, in particular adult (15-49) deaths due to AIDS which increased till 2005 when they accounted for 35% of young adult deaths, are expected to dramatically decline up to 2009, "the main reason for the decline [being] the anticipated universal ART coverage as per the MOH's plan" (FMOH/NHAPCO, 2006a, p. 41). Overall, by the year 2010, there will be 41% fewer AIDS deaths compared to a projection without an ART program (FMOH/NHAPCO, 2006a).

Figure 5.9: Potential Effect of Anti-retroviral Treatment (ART) on AIDS Deaths, Ethiopia 2000-2010. Source: (FMOH/NHAPCO, 2006b)

Potential Impacts on AIDS Orphans

The total number of AIDS orphans in Ethiopia is projected to increase until 2010. But "the rate of increase is expected to lessen due to the impact of the planned ART services" (FMOH/NHAPCO, 2006a, p. 25). The massive scale-up of ART is expected to decrease the number of AIDS orphans by preventing the death of HIV-infected parents as shown on Figure 5.10. The estimated number of AIDS orphans will be 13% lower with universal ART access by 2010 (FMOH/NHAPCO, 2006a).

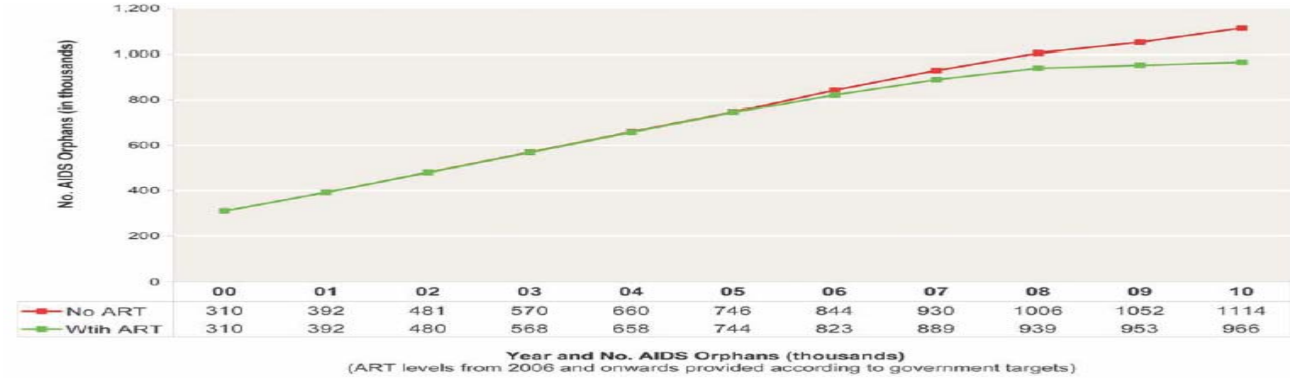


Figure 5.10: Potential Effect of Antiretroviral Treatment (ART) on the Number of AIDS Orphans, Ethiopia 2000-2010. Source: (FMOH/NHAPCO, 2006b)

Potential Impacts on HIV Prevalence

Odd as it may seem, the prevalence of HIV in Ethiopia is expected to increase from 2.8% without ART to 3.1% with ART in 2010 (see Figure 5.11). But does it mean that ART literarily contributes to an increase in the number of PLWHA? Far from it! The prevalence increases merely because PLWHA who take ART survive longer (FMOH/NHAPCO, 2006a).

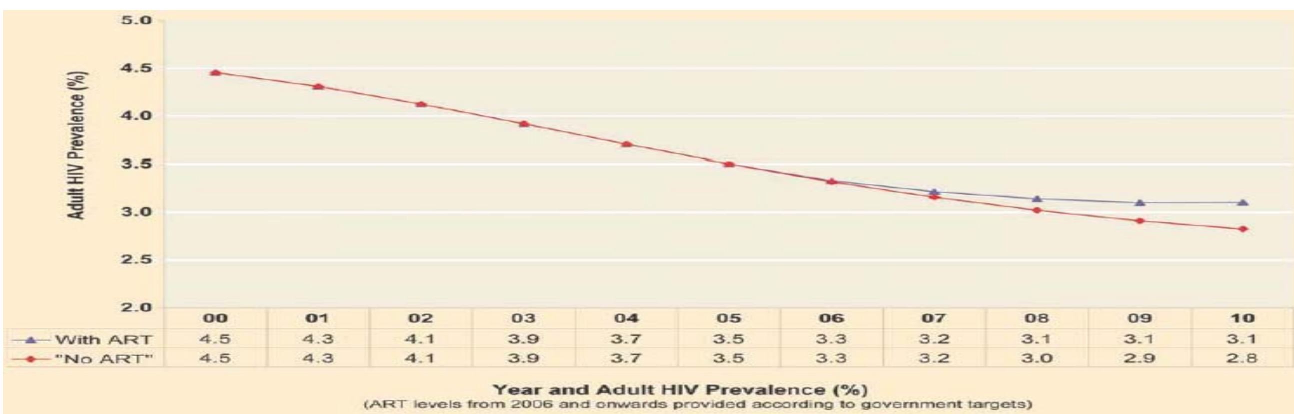


Figure 5.11: Potential Effect of Antiretroviral Treatment (ART) on Adult (15 - 49) HIV Prevalence, Ethiopia 2000-2010. Source: (FMOH/NHAPCO, 2006b)

Potential Impacts on Life Expectancy

AIDS's severe impact on life expectancy in Ethiopia is also avertable. Reduction in life expectancy is projected to decline during 2005 -2010 because of the anticipated universal ART coverage the ministry plans (see Figure 5.12).

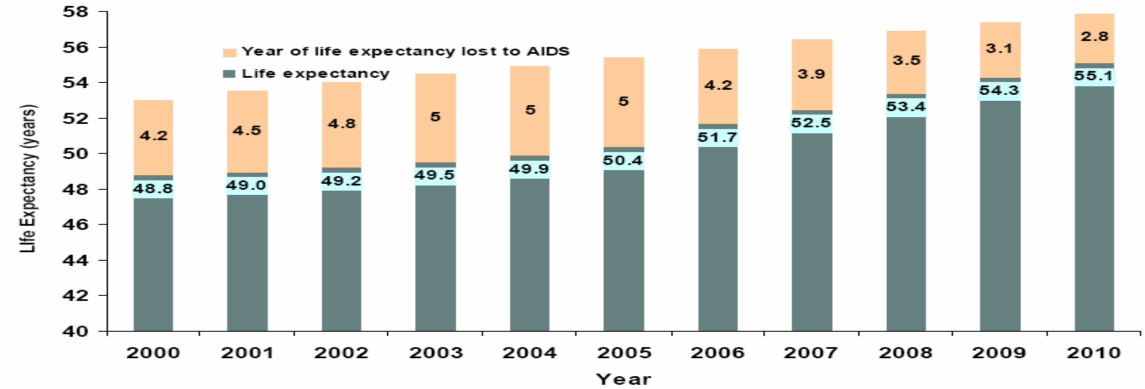


Figure 5.12: Estimated and Projected Life Expectancy at Birth, 2000-2010. Source: (FMOH/NHAPCO, 2006a)

There are thus indeed cost-effective arguments strongly justifying the need to invest in ART in Ethiopia. Consequently, as of January 2007 there were 233 ART clinics operating in the country (see Table 5.3), with ambitious plans underway to scale them up in terms of treating more patients, for example through including new treatment centers in the government health facilities. Some of these clinics were our research sites.

Region	ART Uptake by Regional Distribution as of End of Tahsas 30, 1999							
	Ever Enrolled	Ever Started	Currently on ART	New Enrolled	New Started	ART Sites HP	HC	Total
Tigray	8404	4826	3888	548	349	11	12	23
Afar	761	475	375	74	53	2	2	4
Amhara	24327	16074	12634	2331	1590	17	24	41
Oromia	19984	10392	8639	2001	947	28	15	43
Somali	596	404	279	25	28	2	0	2
SNNPR	8475	4641	3979	726	391	16	34	50
Benishangul Gumuz	1147	601	547	164	57	2	2	4
Harari	1686	1000	819	107	49	3	0	3
Gambela	601	266	275	55	30	1	0	1
Dire Dawa	2151	1330	1037	261	78	1	2	3
Addis Ababa (Public)	34524	21008	16902	1933	1023	9	*24	33
Private	3410	2211	1589	33	38	13	0	13
Uniformed	5860	4007	2757	344	229	12	1	13
Total	**111926**	**67235**	**53720**	**8602**	**4862**	**117**	**116**	**233**

*NB: * includes 2 NGO clinics.*

Table 5.3: Regional ART Uptake Report as of January 2007. Source: Ethiopian AIDS resource centre website – http://www.etharc.org

Our Research Sites in Addis Ababa

As mentioned in chapter 3, we have visited different initiatives under the Ethiopian HIV/AIDS management including PMTCT and VCT centers. However, here we focus on our ART sites since our intervention efforts mainly revolved around ART management.

Out of the 233 ART clinics in the country, we have been in ten of them for our research – nine clinics from Addis Ababa and one from the SNNPR. To have been in 10 clinics sufficed to conduct the study. In fact, it is significant since a uniform ART guideline as well as monitoring and evaluation (including standardized data capturing and reporting formats) is used nationally. However, we have discovered differences even in this context (see chapter 6). In addition, as discussed in the *Research Methods* chapter (3), the study is complemented by comparison of findings from similar research efforts made in other regions (see chapters 6-8). Furthermore, as discussed below, the representativeness of the sites we selected in Addis helped us to see the general situation of ART management in the country thus contributing to the relative generalizability of our findings.

Out of the ten ART clinics where we have been, we provide below brief descriptions of three of our primary pilot sites in Addis Ababa. These sites are the ones located at Zewditu Memorial Hospital, Menelik Memorial Hospital, and Gandhi Memorial Hospital. Two of them (Zewditu and Menelik) were initially used to carefully study the ART workflow from different angles thereby offsetting the existing lack of proper documentation. After the development of the system is over, the nature of one (Menelik) was particularly used to test the system with real data and verify the correctness of the logic of the system. Some characteristics of the other clinic, Gandhi, was used to make an intensive walkthrough of the system with the regional health bureau's IT team when the system was just about to be regionally accepted. As mentioned in chapter 3, due to our residence base in Addis Ababa, we were able to easily access the clinics frequently.

1. Zewditu Memorial Hospital

Zewditu Memorial Hospital (ZMH) was first established by Swedish missionaries in the compound of the present National Palace in 1934 as an important commemorative plaque for Empress Zewditu. Afterwards, it was moved out to its current location behind the palace after constructing better facilities. Since its establishment, the hospital has been rendering healthcare services in its several departments for a large number of inpatients and outpatients who have come not only from Addis Ababa but also from the surrounding urban centers and rural areas.

In July 2003, VCT and then both pediatric and adult ART services were first started in Ethiopia at ZMH. The hospital also provides PMTCT services. As the first ART clinic in the country, Zewditu is considered as a model by other clinics, a point stressed to us by staff from regional health bureau and various clinics where we were conducting field work. They also called it "an island." In the next chapter, we will discuss why they felt so. For now, suffice it to tell that the clinic has been providing ART service to all patients from all the regions of the country especially till March 2005, and, in effect, the number of patients kept tremendously increasing through time. When the free ART service was started in March 2005, Zewditu had to transfer out about 1 000 (stable) patients down to health facilities so as to admit more new patients. Still, Zewditu remains to be the biggest ART site in the county in terms of patient number (see Table 5.4[*]). As we could learn from the slides prepared by the head of the clinic, among the total number of bedridden[#] patients at the beginning of their ART, 75% is said to have started working as of July 2006, thus implying the positive impact of ART and the progress of patients in this clinic. Unlike any other site in the country, the large number of patients in the clinic called for 5 medical doctors, 2 adherence counselor nurses, 3 volunteer nurses, 1 pharmacist, 1 lab technician, 1 pediatric ART physician with 2 nurses, 6 case manager nurses, but only 1 data clerk. Huge amount of patients' backlog data is accumulated in the clinic – more than 12 000 patients were registered each with multiple ART follow-up records of many variables. The hospital has still kept admitting more patients. Considering its unique features, situations and place in the country, the government of Ethiopia is now taking steps towards making Zewditu a national ART Research Center.

Zewditu was the first clinic we started working with. When we first came to visit Zewditu, its huge amount of data used to be managed by a single data clerk. The clinic has been suffering from a manual data capturing and processing system. In addition to the large number of patients and the immensity of their monthly follow-up data which were all kept only on papers, the clinic's room was small in size and difficult to work in. The undesirable situation of the clinic has affected health workers at different levels. In the next chapter, we will discuss how problematic the situation in this clinic has been before we intervened. Once we introduced our system, however, many of these situations have improved (see chapter 7). The clinic staff, including the clinic head who also is a medical doctor, told us that they had been having a hard time dealing with the data, that they were desperately looking for a supporting information system, and that they had experienced many system failure stories and unfulfilled promises of systems from different stakeholders. Hence, by the time we entered the clinic, it was a challenge for us to get the clinic staff work with us and reveal the workflow to us because of this already developed mistrust.

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[*] We provided data of only the biggest hospitals in the country which are all found in the Addis region. Almost all the other sites, be them in hospitals or health facilities in the Addis and other regions, serve less than a thousand patients.

[#] Patients can be in either of the three functional status when they start ART namely: bedridden, ambulatory or working.

After the regional HIV/AIDS program manager gave us permission to use this clinic (which we selected) as a pilot site for our work, we have continued contact with the clinic staff in an effort to address their problems. That this clinic is relatively near to our working place and area of residence, it was fairly easier for us to follow it up. At the beginning of our research, we used to stay full time in the clinic for a sustained period observing, interviewing and discussing with the clinic staff in addition to communicating with them via phone when not physically with them. We spent much of our research time in this clinic from studying the ART workflow to system development and implementation and to supervising data entry and verifying reports as well as providing other necessary supports. The complex situations in this clinic particularly gave us a representative picture of the overall ART management of the country.

2. Menelik Memorial Hospital

Menelik Memorial Hospital (MMH) is the first Ethiopian Government hospital which was established in 1910 and name after Emperor Menilek II with the assistance of several foreign doctors. Some of them, including several German specialists, had come to Ethiopia to treat the Emperor, who was then mortally ill. The establishment was located on the site of the earlier Russian Red Cross hospital, which had ceased functioning a few years earlier. Since then, it has rendered healthcare services mostly for the residents of Addis Ababa. It is especially known for eye treatment as it has a number of eye specialists.

Name Of Sites	Ever Enrolled in HIV Care at the end of The Month	Total of patients Started ART In The Facility	Total patients Currently On ART
Alert	5,921	4,248	3,356
Zewditu	**12,434**	**7,284**	**4,741**
Yekatit	2,966	1,772	1,595
St Peter	2,616	1,591	1,055
St Paul	3,952	2,999	2,410
Black Lion	3,658	2,514	1,855
Menelik	**2,331**	**1,473**	**1,143**
Ras Desta	974	561	330
Gandhi	**396**	**97**	**92**

Table 5.4: Patient loads (as of May, 2007) of the 9 public hospitals in Addis Ababa including our primary research sites. Source: Slides from AACGHB.

Starting ART in December 2005 and hosting about 2 331 patients, Menelik represents an average size clinics in the country. It functions with 1 doctor and 1 data clerk. It is one of the first clinics we asked the regional program manager grant us access to and is near both to our living and working places. Like the case in Zewditu, the data clerk in this clinic had been searching for an IS to support his work, though failed to do. Our working with this clerk forced us to make some changes in our development work about which we were originally misinformed by a staff from Zewditu on a matter which significantly affected the nature of the system. Though neater than Zewditu, we found several problems in data management in this clinic too, some of which even being considerably affecting report qualities. The clerk complained about the difficulty of manual data capturing and reporting while he was employed with a promise of immediately working on a computer system.

Our use and sustained visits of this clinic especially in parallel with Zewditu helped us to grasp more accurate picture of the work while at the same time compensating the lack of proper documentation about the ART workflow. Most importantly, after we finished developing the system, that this clinic is of average size and that there were much less number of patient registrations and individual patient's monthly follow-up records to be captured than those of Zewditu, made it easier for us to use it to do data entry quicker. This paved the way to verify reports and confirm the correctness of the logic of the system to the clinic staff and to the regional health bureau. It was primarily the nearly 100% accuracy and matching of the reports from the system with the corresponding manual reports confirmed in this clinic that boosted the confidence of Zewditu's staff and that of the regional health bureau's IT team on the system. Although lately interrupted due to financial constraints, considerable amount of data from this clinic was secured electronically.

3. <u>Gandhi Memorial Hospital (GMH)</u>

After the visit of Mahatma Gandhi, a prominent hospital in the centre of Addis Ababa has been named "The Gandhi Memorial Hospital". It was constructed in the early sixties by the Indian community and dedicated to the local government. The hospital is best known in the country for its maternity ward. Starting ART recently in September 2006 and hosting only about 396 patients (the smallest of all hospitals in the capital), Gandhi ranks among the smaller clinics in the county. It functions with a doctor, a nurse, and a data clerk. The government is working towards making this site a national PMTCT Centre because of its maternity ward.

Established relatively recently and evidently learning from the experiences of the other clinics, the data management at Gandhi was in a much better situation than that of the others clinics where we have been. Contributing to this betterment was a well coded registration number assigned by an ART stakeholder (JHU) to all Pre-ART and ART patients which was very useful for us in our efforts to help this clinic. However, as we will discuss the complaints of the clerk from the clinic in detail in the next two chapters, this feature and its smaller size did not make it problem free and did not exempt it from needing a supporting system. In fact, we found the clerk entering data into a system delivered to her by a supporting stakeholder which she called “incomplete”.

We started working with this clinic much latter in our study. At the end of the development work and after the system was tested with some data both at Zewditu and Menelik, the IT team of the regional health bureau wanted to make a serious ‘walkthrough’ of the system. During this time, they wanted to evaluate each and every feature of the system with one month real patient data by continuously observing with us all the processes from data entry to the generation and accuracy of all the outputs of the system including the reports. We felt that doing data entry of all one month’s registrations and the multiple follow-ups of every patient and tracing where discrepancies lied in case they happen would take us quite a time. Hence, since we knew that Gandhi is a small clinic with the aforementioned positive features, we selected it for the walkthrough which the IT team agreed. We still continued contact with the clinic but we particularly spent more than a month with the IT team and the clinic staff during this process. From the walkthrough process we obtained insights to make some amendments to the system and further cultivate it which we found very useful when adopting the system in other clinics. Most importantly, Gandhi is especially the place where the IT team acknowledged not only the efficiency and accuracy of the system but also the problem of continuing with the paper system. The overall process, including their evaluation and witness to the regional program manager about both the paper work and our system, led to the formal acceptance of the system by the regional health bureau for its implementation in all the clinics in the region. After entry data for a sustained period of time, we could deliver electronic data of much higher quality than we did elsewhere, obviously because of the clinic’s small size and use of registration numbers.

In general, that we selected clinics of different size and age and with particular characteristics which had special significance for the different processes of our work, we believe, helped us to have a representative picture of the ART work in the country. Table 5.5 below summarizes the characteristics and significances of each of the three clinics.

Site	Basic characteristics	Specific significances in the research
Zewditu	▪ Is the first established ART clinic in the country ▪ Is a model clinic ▪ Is the largest of all the clinics in the county in terms of patients number ▪ Is hoped to be a national ART Research Centre ▪ Poor quality data and worst data management abounds ("is an island") ▪ Suffered from many system failure stories and undelivered promises	▪ Is the first clinic we started working with ▪ Provided us with the deepest knowledge about the ART work and the problems that come with patients number in the absence of a supporting system ▪ The experience of our system working here helped us to motivate other clinics which viewed the clinic as a model.
Menelik	▪ Is an average size clinic ▪ Has a neater data handling and management than that of Zewditu	▪ Helped us to grasp more accurate picture of the ART work and to change the nature of the system from ▪ Data entry here helped us to verify reports which boosted the confidence of the bureau's staff in the system.
Gandhi	▪ Ranks among the smaller clinics in the country ▪ Was in a much better situation than elsewhere we have been with respect to data handling	▪ Helped to make some amendments in the system which was found useful when taken to the other clinics ▪ Its smaller size was very suitably used for an exhaustive system walkthrough with the regional health bureau's IT team ▪ Was a site which most convinced the IT team about the problems of the manual system and the efficiency of our system thus leading us to a formal regional implementation

Table 5.5: Characteristics and significance of some research sites.

Now, after having discussed the situation of HIV/AIDS and ART more broadly in Ethiopia, we describe the issue of ART Management with respect to our specific thesis focus of information support.

5.6 ART Management in Ethiopia: The Specific Study Context, Application Domain, and Analytical Focus

Recognizing the devastating impacts of HIV/AIDS on its population and the positive impacts of ART, the Ethiopian government has responded to the epidemic as a national emergency and found it imperative to launch and steadfastly support the ART initiative. As Global Fund and ETAEP funds have been accessible, it has prepared the groundwork to establish an integrated National ART Program to deliver free ARV through one standard of care across the nation. The ART program is now being driven by a sense of urgency to save lives given that an estimated 278 000 persons require the treatment. The MOH is at the forefront of this effort, coordinating and facilitating the work of various donors, implementing partners and NGOs. ART training programs, drug supply management services, and HMIS have been developed. The Ministry has been working towards the provision of safe and effective ART services. In this effort, with support from national and international partners, it has developed ART policies. Based on these policies and the recommendations of the United Nations

General Assembly Special Session on HIV/AIDS (UNGASS), the government is now rapidly scaling up its ART program.

However, the implementation of safe and effective ART was foreseen to be a serious challenge in such a resource constrained country, where there is little experience in managing this type of complex treatment program. As a result, in 2003, the FMOH, DACA (Drug Administration & Control Authority) and HAPCO developed a National Program Implementation Guideline at all levels of the society highlighting the requirements for an ART program. This guideline is based on sound scientific and ethical standards and seeks to promote sustainability and equitable access to treatment (FMOH, 2005). Its primary goal is to support the development of a standardized ART program nationwide. This implementation guideline, which addresses public health approaches to ART, is guided by the national HIV/AIDS policy and the policy on supply and use of ARV drugs. Guidelines on ARV, PMTCT, OI, STI, VCT and infection prevention served to standardize the national approach to ART. The target audiences of this guideline included health providers and program managers in the public and private sectors. In line with this, the government provided ART training to teams of healthcare providers, and patients started receiving ARVs. Several challenges have already been identified including the need to strengthen the overall program oversight structure and to integrate program monitoring and evaluation. The guideline was meant to help foster a flexible response and address these issues, and to prepare for rapid scale up of ART.

The National ART Program is based on guiding principles which include the following: ART, which is a comprehensive service, will be an integral part of the HIV continuum of care; treatment and clinical procedures will conform with national ARV treatment guidelines which are based on international standards and best practices; the National ART Program will strengthen the national health care system; efforts will be made to ensure sustainability; only one National ART Implementation Guideline will be followed; and national and international networking will be ensured.

Program Management and Coordination

The ART program is implemented at different levels including national, regional, and facility. Program management and coordination has been in effect at all organizational levels and integrated into the existing health care systems. Figure 5.13 provides a schematic representation of the ART implementation structure. The key functions and organizations, and the information flow are described below.

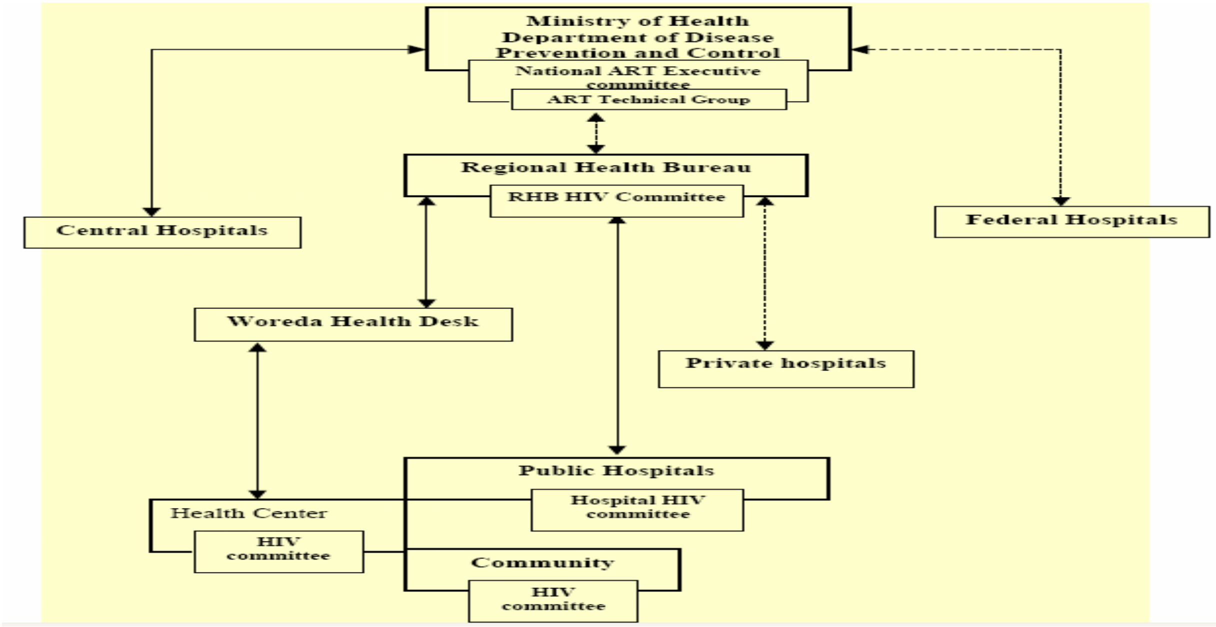


Figure 5.13: ART Management and Coordination Structure of Ethiopia. Source: (FMOH, 2005)

National Level

At the national level, the MOH oversees the overall ART program by providing technical assistance to RHBs. Its primary focus is to integrate, coordinate, and standardize delivery of ART. The MOH is also responsible for monitoring and evaluation (M&E), advocacy and operational research. It is supported by *the ART Technical Working Group* whose members include HAPCO**.** The technical group invites additional bilateral and non-governmental agencies when appropriate. Its responsibilities include determining criteria for expansion of ART program, reviewing ART program monitoring and evaluating data, reviewing the appropriateness of technology transfer and application, overseeing the activities of National ART training and technical support network. In our effort to support ART management with an IS, gaining entry to the national level has been impossible so far.

Regional Level

RHBs assist in implementing the ART program by providing technical and budgetary support to the healthcare facilities and the districts. The RHB manages and coordinates all ART activities at the district and facility levels including reporting data to MOH and integrating all ART activities into the national program. It is supported by the *Regional HIV/AIDS Committee* the members of which include RHAPCO. Its responsibilities include reviewing M&E reports from hospitals in the region and establishing link with national task force. In our implementation effort, we succeeded to gain entry to Ethiopian HIV/AIDS program through regional health bureau in Addis.

Facility Level

The facilities' primary role is to provide ART services. They are charged with patient care monitoring, and data collection, analysis, action, and reporting to RHB. It has also the responsibility of properly referring PLWHA to local community support groups such as for nutritional support. They are supported by the *Hospital and Health Center HIV/AIDS Committee* whose members include physicians and nurses. The committee's responsibilities include reviewing ART clinical monitoring data, acting without delay on emergent corrective measures, submitting M&E to regional ART task force via appropriate channel, assuring integration of ART with other services, establishing referral system to and from the community, and assisting in analyzing and reporting community care data. As mentioned above our efforts revolved mainly at facility levels for which we visited several of them.

Program Requirements

Successful implementation of ART program requires appropriate measurements and monitoring. The FMOH acknowledges that this entails developing and applying standardized health management information system (HMIS). *"The HMIS must support the monitoring of program implementation, the documentation of patient care and outcomes, … and performance"* (FMOH, 2005, p. 12). Thus, in order to have a unified national ART program, tools and reports were standardized. Regions, likewise, assured that reporting materials, tools and systems follow national standards in support of the national HMIS system. Although we could discover the opposite from our study (see chapter 7), MOH, as the responsible body, is expected to lay down mechanisms to eliminate uncoordinated individual operations (FMOH, 2005).

Furthermore, the skill, competency and capacity of health care providers are directly proportional to the degree they are supported as they deal with a complex chronic illness. Accordingly, ART clinics are provided with support staff and clinical tools. Also, to obviate writing, clinical

Critical requirements the Ethiopian Government acknowledged to be fulfilled for the effectiveness of the management of the National ART Program *(FMOH, 2005)*

- *"Electronic HMIS, standardized clinical records, hospital specific identifier …, unique patient numbers." (p. 24).*
- *"The HMIS must support the monitoring of [ART] program implementation, the documentation of patient care and outcomes, … and performance" (p. 12).*
- *"Systems that enable patient tracking … and allow patient follow-up are essential for safe care and continuity of care. At a minimum, there must be a medical record system. … This system should also allow for timely information exchange between disciplines on the patient flow tract. This system is the foundation, not only for patient care but also for monitoring and evaluation and patient referrals." (p. 20)*
- *"The monitoring of processes and evaluation of performances and outcomes are dependent on the identification of broad data elements that when collated and analyzed will generate diverse reports. …Customer tailored databases will satisfy the needs of managers with oversight responsibilities." (p. 25, 26, 27)*

documentations were more or less simplified with standardized checklists. The Ministry believes that *"ART ready facility should … have clinical tools adapted to local situations that cover comprehensive HIV care"* (FMOH, 2005, p. 9). Clinical process monitoring and reporting are expected of each facility providing ART. In addition, facilities are expected to develop an M&E system capable of informing a full evaluation of including ART. Above all these, concerning a system that should back these requirements of the ART program the FMOH (2005, p. 20) declared:

> *"Systems that enable patient tracking, clarify patient flow and allow patient follow-up are essential for safe care and continuity of care. At a minimum, there must be a medical record system. Pertinent information must be documented by all disciplines (physicians, nurses and pharmacists) that provide direct patient care. This system should also allow for timely information exchange between disciplines on the patient flow tract. This system is the foundation, not only for patient care but also for monitoring and evaluation and patient referrals."*

On top of this, communication within and outside the program is admitted to facilitate coordination and integration as well as helping to disseminate information on the continuum of care (FMOH, 2005).

Strategic Information

As an expanded version of the traditional monitoring and evaluation, surveillance, operational research and HMIS are critical in the planning and follow-up of program implementation. Planned and systematic data gathering, analysis and interpretation are essential for the purpose of monitoring clinical care and patient outcome improvement, logistical appropriateness, program cost-effectiveness, and performance measures and improvement. Hence data gathering is made clinically oriented and facility based. For example, although the list is far from being exhaustive, the following patient specific data which would provide useful information for clinical monitoring are gathered at the ART clinics: *patient demographics; patient lab data; patient clinical status and progress including drug adherence and drug resistance, weight gain, functional score (whether bedridden, ambulatory, or working), trends in CD4 and viral load (VL), occurrence of OIs, rate of hospitalization, death, adverse drug reactions, ratio of first to second line regimen, and ARV selection and changes.*

The Ministry believes that, at a minimum, management of strategic information requires trained staff who will collect and analyze data; and standardized tools including data collection forms, *"paper based and/or electronic HMIS, standardized clinical records, hospital specific identifier …, unique patient numbers. Legislation will be required so that everyone has one national health care identification number."* Also, *"health care information confidentiality must be assured. The confidentiality of data gathered for the purpose of M&E must be protected"* (FMOH, 2005, p. 24, 25) On the other hand, operational research, at a minimum, will look at the following critical ART program success defining issues: *adherence, drug resistance, drug regimen cost-effectiveness, minimum treatment safety monitoring package, and use and availability of ARVs.* Acknowledging that a wide range of information about individual patients has to be efficiently collected and analyzed at the facility level for the effectiveness of the national ART initiative and the overall HIV/AIDS program at large, the FMOH underscored the importance of patient based ART IS as follows:

> *"The monitoring of processes and evaluation of performances and outcomes are* ***dependent on the identification of broad data elements that when collated and analyzed will generate diverse reports. A variety of decision-makers, national and international, will need these reports in a timely manner for well-informed implementation planning and follow up decisions. Strategic Information must be patient centered and clinically oriented.*** *Customer tailored databases will satisfy the needs of managers with oversight responsibilities … The process of data management involves: clinical documentation by physicians, nurses and pharmacists; data entry by data clerks; aggregation and data analysis [by] data managers; [and] reporting by program coordinator (paper and electronic based). Information will be collected at all care sites (hospitals, health centers, clinics) … Data collected locally should be aggregated, analyzed and interpreted for intervention and action-plan both locally and centrally and then distributed to all stakeholders on a need to know basis in order to protect health information confidentiality ... Reports required by different organizations will be passed up the national M&E reporting channels. Note that reporting is bi-directional [see Figure 5.14 below]. M&E data, whether analyzed or raw must be utilized and reported to the section responsible for corrective action. … Report on indicators will be prepared by the program coordinators at each region, reported to the RHB, presented to the Regional HIV Steering Committee and then to the MOH and HAPCO [see Figure 5.13 below]."* (FMOH, 2005, p. 25, 26, and 27; ***emphasis ours)***

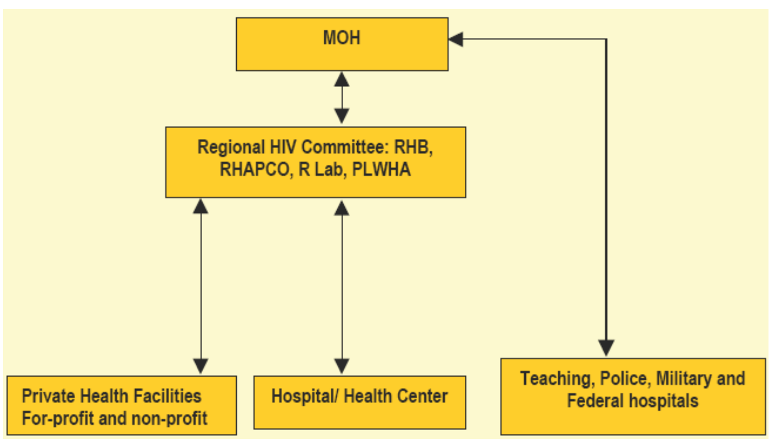


Figure 5.14 Report/Information flow of health related indicators. Source: (FMOH, 2005)

ART Stakeholders and Informational Performances

Including the Center for Disease Control and Prevention, Atlanta (CDC) and John Snow International (JSI), there are many national and international partners which make up national and regional HIV/AIDS task forces. In addition, there are specific task forces assigned to support ART management at regional levels. These task forces are comprised of several members, for example in Addis Ababa region, members include JHU/TSEHAI, AAHAPCO, DACA, Clinton HIV/AIDS Initiative, FHI Ethiopia, RPM Plus, AMREF, NHAPCO, and FMOH (AACGHB, 2006). Each of these members is supposed to play distinct roles around ART management in the region in connection with the above mentioned ART related issues. Nevertheless, those which are particularly responsible to provide informational support especially at facility levels, as the regional health bureau's staff related to us (see chapters 6 and 7), are not performing as expected.

For example, with the support of CDC, JHU/TSEHAI (Johns Hopkins University/Technical Support for the Ethiopian HIV/AIDS ART Initiative) was responsible to provide technical support including for information systems in the Addis region. However, though it has been in the region for several years, little has been achieved and this was lamented upon by the regional health bureau's IT team. The problems cited by the staff include delays and incomplete system deliveries by external agencies, and their inadequate knowledge of the region needs. Addis region is not an exception, and similar ineffective involvement was also noted of other American Universities in the remaining regions (such as Colombia University in Oromia region). The allocation of ART clinics in Ethiopia to American universities created difficulty in our attempt to scale up IHAMS-ART to the different regions of the country. Worst yet, these universities have especially been aggravating the political atmosphere surrounding our effort to fill the informational gap. These issues are further elaborated in chapters 6 and 7.

What is Missing – Seeking Urgent Attention?

While the government's vision of ART management, for example as described in the guideline, is elegant, the information system to support the management of this treatment has been sadly lacking at all levels of the management, despite the abundance of stakeholders around ART management. The immensity of the problems which resulted from the absence of such a system was especially pronounced at the facility level where exceptionally large amount of data have to be collected and analyzed. However, the lack a supporting IS poses a challenge at all levels, and even makes the effectiveness of the national ART program questionable since it is virtually impossible to measure the performance and progress of the national ART program without being aided by a supporting IS (see chapter 6).

As we have seen in section 5.4, the impact of HIV/AIDS on Ethiopia is insurmountable[π]. But we have also seen, in chapter 4, how significant the impact of ART in averting HIV/AIDS on the global society at large[*] and, in particular, its *potential* multiple impacts on the Ethiopian population including economic ones as discussed in section 5.5 above[#]. However, without effective management, we argue, the national ART program will certainly not attain its expected impacts. In fact, inefficiently managed ART will remain to be more of a danger than beneficial especially as seen from the point of view of the development of drug resistance which, if left unchecked, has an absolute potential to erupt and escalate into one of the largest global catastrophes. Central to the efficiency of the country's ART management, as the government underscored, is an "*electronic* …patient tracking …medical record system" –"*the foundation, not only for patient care, but also for monitoring and evaluation*" (FMOH, 2005), though it was missing for a long time.

While lack of a supporting information system is acknowledged to be at the heart of the inefficient ART management and hence an obvious case seeking urgent attention, the multiple challenges in introducing and making work such a system, which are far from being trivial, remained unexplored and hence rarely exposed. The next chapter (6) specifically discusses the political facet of the challenges, the specific focus of this thesis, we have been experiencing while endeavoring to gain entry into the country's HIV/AIDS program and to introduce and make the system work; and the tactics we adopted to infiltrate this political barrier to that end. While attempting to introduce the system after gaining entry, we also carried out a thorough situation analysis of the country's HIV/AIDS and ART management. Thus, the chapter also in detail discusses what problems, particularly at the facility level of ART management, which resulted from the absence of a supporting system, we identified the clinics to have been going through. After these descriptions of the political challenges and the situation analysis in the next chapter, the subsequent chapter (7) presents our action research interventions in relation with the problems identified during the analysis, and also the accompanying challenges.

[π] For quick reference, see the box entitled "Some sad consequences of HIV and AIDS in Ethiopia" under section 5.4 of this chapter.
[*] For quick reference, see Figure 4.2 and 4.3; and boxes entitled "Why ART?" and "Some benefits already enjoyed from ART so far" under section 4.6 in chapter 4.
[#] For quick reference, see the box entitled "Some expected impacts of ART in Ethiopia" under section 5.5 of this chapter.

6 Concrete Research Activities: Gaining Entry and Situation Analysis

6.1 Introduction

The descriptions of our concrete research activities are broadly divided into two parts, each in one chapter. This chapter focuses on the descriptions of the various challenges and the corresponding specific strategies we adopted to gain entry into the Ethiopian HIV/AIDS management so as to start the development and implementation of an HIS* that would support the management of ART in the country. The chapter also includes descriptions on the conduct of the situation analysis, representing the first phase of the action research cycle – the diagnosis phase. After these discussions on gaining entry and the situation analysis, the subsequent action research interventions carried out with respect to improving the information management of the existing ART initiative will be described in the next chapter.

Accordingly, the chapter is organized as follows. Section 6.2 begins with a discussion around the difficulties we experienced, with a focus on the political challenges, and how we penetrated them to gain entry into the country's HIV/AIDS program. Section 6.3 continues to discuss the findings from the situation analysis once we gained entry. The situation analysis particularly considers the information handling processes (data collection, processing, analysis, and reporting) of the pre-existing ART system of the country.

6.2 Gaining Entry

A key challenge that we had to deal with during the action research effort concerned the politics of gaining entry into the Ethiopia HIV/AIDS management to initiate the process, and then also for its subsequent scaling. We particularly focus in this section on how the political conditions created difficulties in gaining entry and how we tried to deal with them.

Even before formally gaining permission for carrying out the research, we started to do a preliminary investigation of the HIV/AIDS program particularly the ART initiative by making visits to one of the

* Out of the two systems in our project (see chapter 3), this chapter concerns IHAMS-ART, unless otherwise stated.

ART clinics in Zewditu Memorial Hospital (ZMH) in the capital region of Addis Ababa. For this, we went along with a local HISP researcher (see Figure 6.1) who had been previously working with some of the health personnel in this region. We studied the workings of the ART program by means of observations and discussions with a clerk, and the clinic head who was also the medical doctor (see Figures 6.2 and 6.3).

As we increased the number of visits and with it our understanding of the needs and requirements of the initiative, we decided to formalize the work with the regional health bureau from then on. This was especially required because, as we kept on repeatedly visiting them, we felt that the clinic people were not comfortable to tell us everything we wanted without formal permission. For this, we had to meet the Disease Prevention, Control and Health Programs Department head (who also was the regional HIV/AIDS program manager) at the Addis Ababa City Government Health Bureau (AACGHB). We told him that we wanted to study and contribute to the region's ART program describing to him who we were, and explaining to him our pre- existing familiarity with the working of the ART clinics. This program manager was initially unhappy when learning that we had visited the clinic without his knowledge and permission, and told us that we need an ethical clearance and a proposal in order to proceed further.

Figure 6.1: Learning from a data clerk (left) during a visit to a clinic with a local HISP researcher (right)

Figure 6.2: Discussion with a clerk

Figure 6.3: Discussion with a clinic head

However, since we met him with the HISP researcher (Figure 6.4) with whom he had worked earlier over the last 3 years under the HISP initiative in the region, he had a degree of trust in us which enabled us further access to the clinic. Nevertheless, there were still challenges to be addressed in getting him to accept our efforts as a real project, and not just see it as a student inspired academic exercise. We thus needed to work further to persuade him to allow us to work in a full blown project mode with his formal support. There were various issues which the program manager was seriously concerned about, which we first needed to understand and then slowly start to address.

Figure 6.4: Approaching the regional program manager with a local HISP researcher

For instance, although it was not explicitly stated by the program manager or others at the very beginning of our study, we were able to detect the prevalence of a strong political undercurrent in the various discussions. We began to better understand these issues much later in the process, though they have been there throughout. For example, as the program manager related to us during discussions right after being on the phone for about half an hour[*], in February 2006, around the time when we begun our work, he had been requested by his senior from the HIV/AIDS Secretariat at the Federal Ministry of Health (FMOH), to stop our efforts since it was said that an ART system had already been developed abroad under the supervision of the federal ministry and it will be implemented nationally in a month's time.

> *"… He [The HIV/AIDS Secretariat at the Ministry] has just told me that a system from Geneva sponsored by WHO is already secured and a person is assigned to train and introduce the systems both at the regional and national levels in a month time. … So I think you should stop [working on ART] … I suggest you work on OI. …"* – The regional HIV/AIDS program manager to the research team

> *"… No, I am just wondering why you people do duplicate effort bypassing the ministry while there is already a system, as far as I am told. …"* – A federal ministry official to us in an international conference

[*] We were there with the program manager asking him to grant us permission to formally continue our project.

Moreover, although there was actually no working system on the ground in the region, some people in power whom we met, for example in the different workshops and conferences, kept telling us that there was already a working system. For example, after we made a presentation and demonstration of the earliest version of our system (IHAMS-ART) during an international conference (see Figure 6.5), we were told by a federal ministry official:

Figure 6.5: Presentation and demonstration of an earlier version of the system (IHAMS-ART) during an international conference

> *… No, I am just wondering why you people do duplicate effort bypassing the ministry while there is already a system, as far as I am told. …*

We invited the regional manager who was also present in the meeting to comment on this question, and he replied:

"The region has been waiting for the promised system from the federal ministry for quite a long time. Now… that the work has become extremely unmanageable for us to do manually, we have decided to look for solutions ourselves. Patients' number is becoming out of hand. …" – The regional HIV/AIDS program manager in an international conference

> *The region has been waiting for the promised system from the federal ministry for quite a long time. Now that we are autonomous and that the work has become extremely unmanageable for us to do manually, we have decided to look for solutions ourselves. Patients' number is becoming out of hand. … This system is developed under the region's supervision by HISP-Ethiopia at the Addis Ababa University. This is not an individual's work. The bureau has always been following up the work throughout. We found these guys to be the first to appear and practically solve our problems. They are here right on time, when we need them most. … This is by no means duplication. It, instead, widens the opportunity from which the ministry can choose a national system.*

"I don't want to be involved in this dirty software politics." – An Official from an American University

When the IT team of the bureau invited an official from an American University to attend a meeting where some ART software, including ours, was to be evaluated, she rejected the invitation saying:

I don't want to be involved in this dirty software politics.

Since the program manager, a medical doctor by training, did not have previous experience working with IS implementation issues, he was concerned about detailed functional issues of the system. For example, when he was told that the system did not search by CD4 at an early stage of the prototype, he said "If the system doesn't search based on CD4, then what is the system for?" We had to slowly reassure him that this was an early prototype and that gradually additional functionalities would be incorporated. His concerns about functionality reflected the political conditions which were prevalent, and he did not want some of the adversaries to point out the shortcomings of the system as a basis to reject the system. He stated to us in a subsequent discussion:

> *"… At every corner they put hidden ditches for you to make wrong decisions and fall into. …"* – The regional HIV/AIDS program manager to the research team and the professor

… At every corner they put hidden ditches for you to make wrong decisions and fall into. …

Due to this fear of being driven into the wrong direction, giving us access into the area was not easy for the program manager. In fact, even after he let us start the work, he always sought a witness of others (such as clerks, and his own IT team) at every step of the process of our work to ensure that things were moving in the proper direction. Furthermore, as he was still waiting for the promised system from the federal level, he was keen that we do not "duplicate effort." Also, since he had experienced and heard about several system failure stories and undelivered promises of information systems to support ART management, he tended to be ultra cautious with us.

> *"Systems which are promised do not necessarily mean they will come, and furthermore there is no guarantee that they will fulfill the requirements and succeed."* – The research team to the regional HIV/AIDS program manager

These various complexities contributed to the difficulties of us gaining entry, and we needed to find different ways to convince the program manager to grant us access, and build his trust in us to secure his necessary support. For example, we had to repeatedly visit the regional health bureau and update him on our progress.

By making use of our various discussions with him, amongst other things, we exchanged with him our understandings, views, and concerns around the HIV/AIDS program and the ART initiative. A key concern which he expressed was the need to coordinate the various (uncoordinated) interventions being carried out within the framework of the national HIV/AIDS program. For example, he described how a patient under ART, when he/she returned home, was expected to go to the nearby NGO to obtain home-based care. However, because of the lack of coordination, the same patient could go to multiple NGOs to obtain the same services. This was causing a severe drain to their very scarce resources. Another need expressed by the program manager was for a patient specific system to follow how a patient is taking treatment over time, and to be able to analyze cohort patterns and the prevalence of drop outs. He felt the existing reporting system (of aggregate numbers on patients counseled and referred), while maybe useful for the HMIS department, was completely inadequate to support his very specific program based needs.

> *"Let the best system win."* – The regional HIV/AIDS program manager to the research team and the professor

We also explicitly cautioned the program manager that "systems which are promised do not necessarily mean they will come, and furthermore there is no guarantee that they will fulfill the requirements and succeed." In addition, we argued that our developing a system will not be duplicating efforts as it will, rather, provide the region a wider chance and opportunity to choose a system that best suits the needs and requirements. Moreover, we told him that unlike many of the previous systems which failed, ours is going to be based upon team work and be developed by local people which apart from being a matter of national pride will also help to establish strong support mechanisms. Sometimes we needed to show up for the meetings in a group including our professor, local HISP researchers, one of the medical doctors mentioned in the research methods chapter (3), and other members of the global HISP team. This mix of expertise – technical, public health, and HIS – and the global dimension of the team also helped to boost the confidence of the program manager. At one point, he said he "was tired of waiting for the mythical system being promised by the American donors for the last 2 years, and which showed little signs of appearing." He said more than 3 system demonstrations were scheduled by the Americans before and in January 2006, but in the last moment were always cancelled. His private inference was that maybe there was no system, and anyway, when that system does (and if) come, he will be happy to evaluate it and see how it fits into his scheme of things for regional program management.

As mentioned previously, since this program manager had worked with the HISP team earlier, he had experienced the successful introduction and scaling of the HMIS software (called DHIS) to all the facilities in the region, and was thus well aware of the potential and capacity of the HISP team. Also, given the fact that the HISP team was locally based in the national university (Addis Ababa University), he felt it would be easier to coordinate with us to develop the system than with an American donor. Moreover, as it was apparent from his reply at the conference (referred to earlier), the autonomy available to the regions enabled the program manager to move by himself without waiting for the approval from the federal ministry. Given these considerations, he decided that it would be worthwhile to give the HISP team a chance to try and develop such a system, and see how that shapes up. His approach was quite simple and logical: "let the best system win", which translated into the view that if and when the American system would come, it would be evaluated and compared with the HISP system, and the region will adopt that one which was more suitable to their needs.

***Challenge*: Penetrating the politics and gaining entry in to the HIV/AIDS program**
Tactics Adopted: • Making use of previously established links with the bureau. • Making use of the reputation of HISP and its potential and capacity. • Emphasizing that the HISP team is locally based at the national university in the capital region – a matter of national pride. • Promising close, long term and continuous support. • Emphasizing the broad mix of the team composition – technical and public health – and its global dimension. • Exploiting the "windows of opportunities" created through political hesitancies such as system failure stories, undelivered promises, and the regional autonomy provided by the federal structure. • Selecting ZMH as a pilot, which was politically very visible being the largest clinic in the country. • Promising through IHAMS an integrated vision of information systems support, with a clearly presented plan and schedule of deliverables. • Playing the politically charged "Free and Open Source Software" card. • Repeated visits and observations to the health bureau and the clinic, and discussions and presentations to the program manager. This made our efforts grounded in the local reality. • Providing the program manager with an exit strategy of "let the best system win", and convincing him that there is no risk as it is a zero cost experiment. • Emphasizing the advantages to be enjoyed from the technologies we would adopt – for example, that the code could be modified, could be used both as web based and stand alone, proposed link to GIS etc. • Emphasizing the superiority of our design – for example, patient specific; modular structure; would meet existing reporting needs and incorporate other important functionalities; and, could be slowly expanded from the initial ART system to an integrated HIV/AIDS management system (IHAMS) that would ultimately include the other program interventions like VCT, PMTCT, ART Pharmacy, and Home Based Care.

Table 6.1: Tactics adopted to gain entry into the Ethiopian HIV/AIDS program

From the HISP side, based on our initial investigations, we presented the logical design of the system which: was patient specific, would meet existing reporting needs, and incorporate other important functionalities. Furthermore, the system could slowly be expanded from the initial ART system to an integrated HIV/AIDS management system (IHAMS) that would eventually include the other program interventions like, VCT, PMTCT, ART Pharmacies, and Home Based Care[*]. We presented to him our

[*] The Debo project in progress (see chapter 3) which we latter started was started with the motive to achieve the IHAMS vision (see the details in chapter 7).

IHAMS vision and the schedule depicting the timing of the deliverables, the first of which was the ART system prototype. Furthermore, we proposed the use of a Free and Open Source Software (FOSS) platform for the development of the system. Further, the cost of the research team for the health bureau was zero, implying the total cost of this experiment from the perspective of the program manager was zero. He thus decided to go ahead with this experiment, and called (even before giving us a formal letter) one of the ART clinics at ZMH, and accorded permission to us to start the development processes. The selection of ZMH as the pilot was proposed by us as we had already established initial links with the clinic staff and it would be easier for us to operate. Furthermore, since the ZMH was very large in terms of ART patient numbers, it was agreed that it would be representative, and systems developed here would be scaleable to other clinics in the country. The program manager also gave us the ART data capturing and reporting formats along with the necessary explanations which we could not find before this.

In Table 6.1, we have summarized the various tactics adopted by us to gain entry.

After this section where we have described the poltical dynamics around the gaining entry, we elaborate on our approach to conducting the situation analysis, and also to bearing the various socio-technical challenges we faced.

6.3 Situation Analysis

In this section, we briefly present the situation analysis we carried out of the Ethiopian HIV/AIDS and ART management. We start by first describing how we built our own capacity in the unfamiliar domain of HIV/AIDA and ART management to better equip us to carry out the situation analysis.

6.3.1 Building Our Own Capacity

Having gained entry, we had to build our own capacity in various facets of the problem domain including understanding the structure of the HIV/AIDS program, various public health issues such as the terminologies used, and the technical issues around the software. The professor as well as one of the medical doctors referred to in chapter 3 helped us see the ART initiative in the context of the overall HIV/AIDS program and existing interconnections. This inspired us to develop an initial vision of the IHAMS. The inputs from the medical doctors were very useful in understanding the medical terminologies used in the various ART data capturing and reporting formats and registers. Furthermore, this helped us to understand the information and analysis needs from the perspective of medical doctors. Without these inputs, we would have been hard pressed to effectively conduct the situation analysis, especially in the absence of useful documentation.

We initially built our technical capacity with the support of a Vietnamese student who was also enrolled in the Oslo Masters program with us. We learnt the technologies we adopted for the development work from him while we were at the same time actually developing the system. As compared to our pervious lecture based methods of learning in our Ethiopian school life, we found his approach of “learning by doing” to be very effective and rapid.

Our capacity building processes took place simultaneously with the development of the prototype through the conduct of observations; document analysis; discussions with the staff at the ZMH and with the program manager, and internally within the HISP team especially with the help of one of the medical doctors. Two weeks after having gained entry, we demonstrated the first version of the prototype to the program manager, which gave him the confidence to give us permission to deploy and test the system with real data from the ZMH. Further suggestions for improvements were given to us, which we gradually incorporated. Once deployed, the ART prototype served as an effective means to elicit discussions with the staff about their requirements (Figure 6.6), which helped us to make further improvements.

Figure 6.6: Eliciting requirements using the prototype

As we did not have previous experience around information systems implementation, working with the professor and the local HISP members was particularly helpful to develop social relationships with important health workers at different levels. For example, the way they approached and interacted with these people at the beginning of our project was important lessons we took forward at the later stages where we needed to intensive socio-political challenges.

Figure 6:7 below depicts the progress of the basic research activities carried out by us part of which is described in the next two subsections while the remaining part will be brought into the picture in the appropriate place in the next chapter where we will discuss the action research interventions we carried out in our research to address the problems identified below.

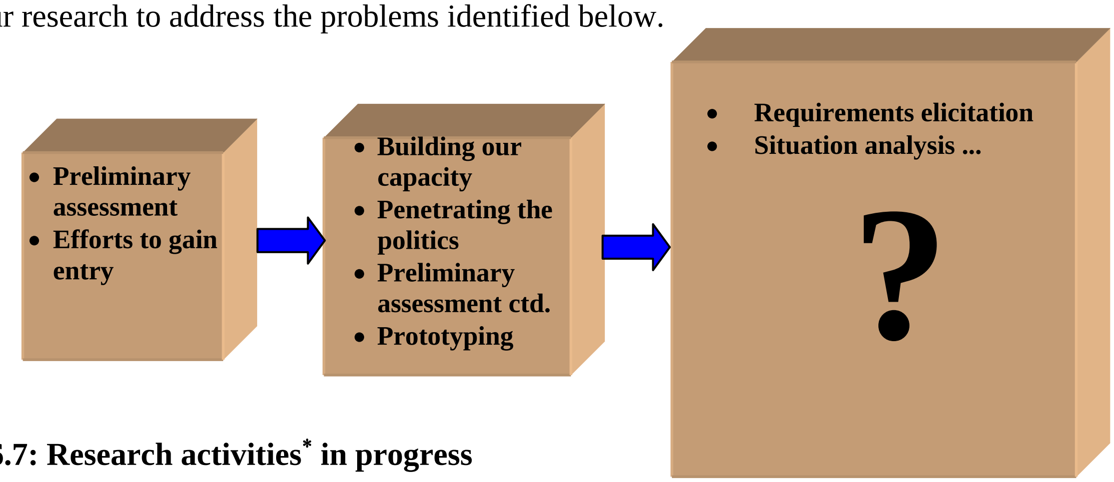


Figure 6.7: Research activities* in progress

6.3.2 How the ART Clinics Work – Requirements Elicitation

In this subsection, we describe the workflow in the ART clinics with a focus on data capturing, processing and reporting. This is first depicted in Figure 6.8 below, and then briefly described.

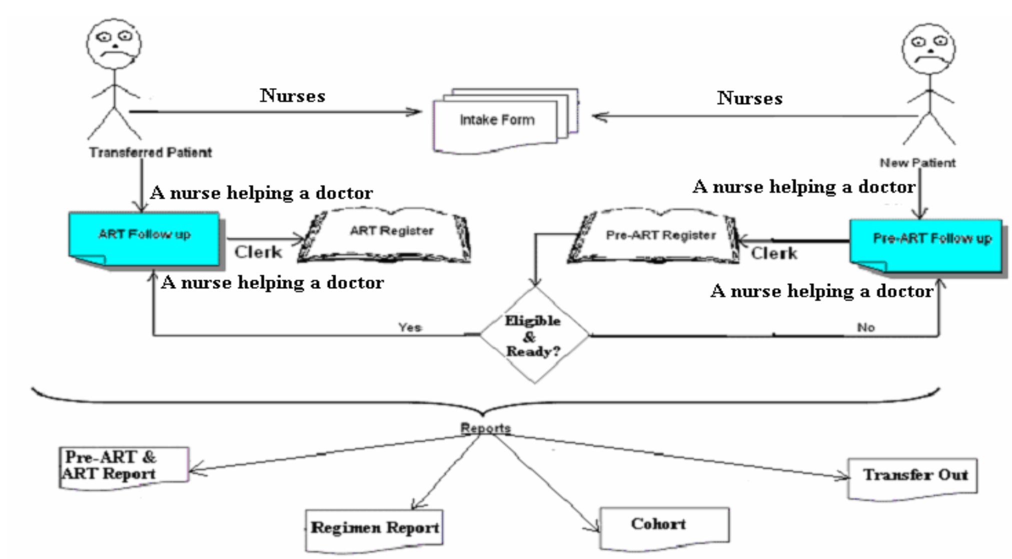


Figure 6.8: ART Work-flow made simple

* Activities in a group occurred largely in parallel. The remaining activities in the last group in question will be discussed in the next chapter.

Once a patient is referred to a particular ART clinic from different entry points (such as VCT and TB), a number of forms are used for capturing patient data and reporting. First of all, if the patient is a new case, his/her referral and other important letters are attached with the patient's hospital card. Second, a 7 page (containing about 305 data elements) form called ARV Clinic Patient Record/Intake form is filled up by the data entry clerk and the nurses (Figure 6:9). In addition to demographic information, this form contains many details about the patient's past medical life including the opportunistic illness he/she may have had.

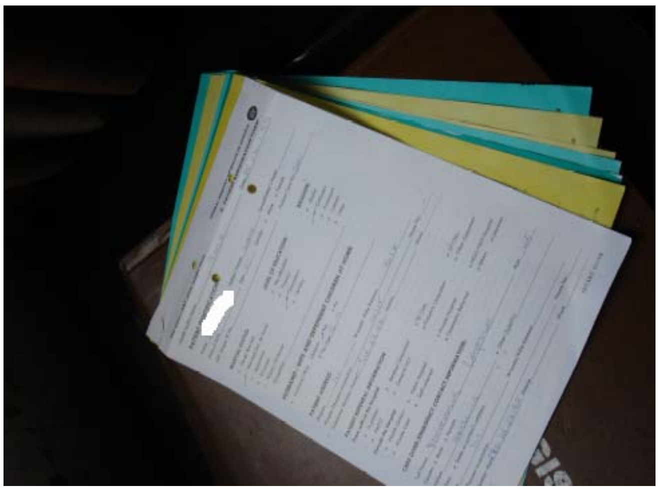


Figure 6.9: Pages of an intake form filled[*]

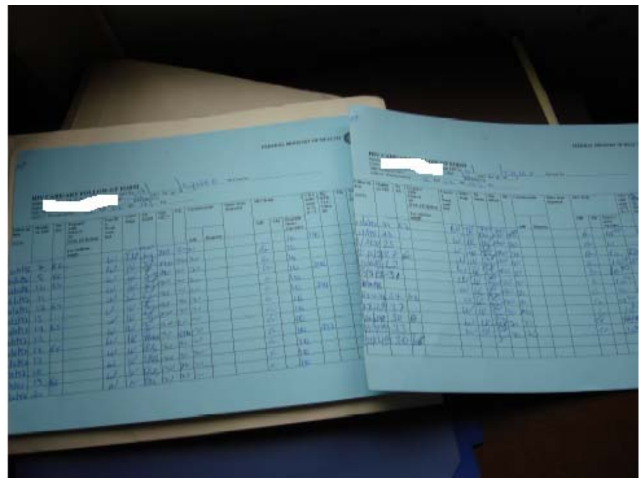


Figure 6.10: Multiple follow-up forms for a patient

Third, a form called HIV care/ART Follow-up Form, having 23 columns and about 115 data elements, is filled by a nurse while the doctor is treating the patient. This form, on which different data values (such as weight, CD4, and regimen) pertaining to the progress of the patient are captured, has 18 rows which are to be used 18 times, each time the patient visits the clinic (usually monthly)[#], after which another similar form is issued. A patient can in effect have multiple follow-up forms in the same clinic (Figure 6.10). The intake form and all the follow-up cards are attached with the patient's hospital card (Figure 6.11), and the file is placed on the shelf (Figure 6.12) based on the status of the patient – active, dead, lost, dropped out, transferred out etc.

[*] Patient's name and/or unique identifiers (if any) are deliberately removed if pictures were directly taken from formats containing real data.

[#] In an ART clinic both Pre-ART and ART services are provided. When a new patient is referred to an ART clinic he/she may remain as a Pre-ART patient taking treatment, for example drugs for opportunistic infections, until he/she becomes eligible (fulfilling the laboratory definition of AIDS) to start the actual ART and take ARV drugs. However, the HIV care/ART Follow-up form is used to capture both Pre-ART and ART data which makes comprehending the patient's ART progress from the form difficult for a doctor.

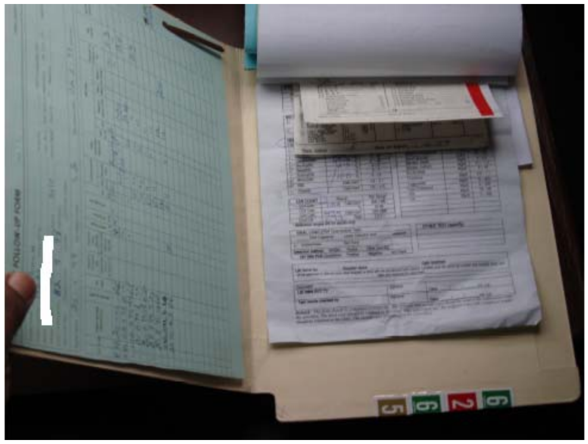


Figure 6.11: A patient's file

Figure 6.12: How file section is congested with files – only partial view

Figure 6.13: Part of a page of a Pre-ART register

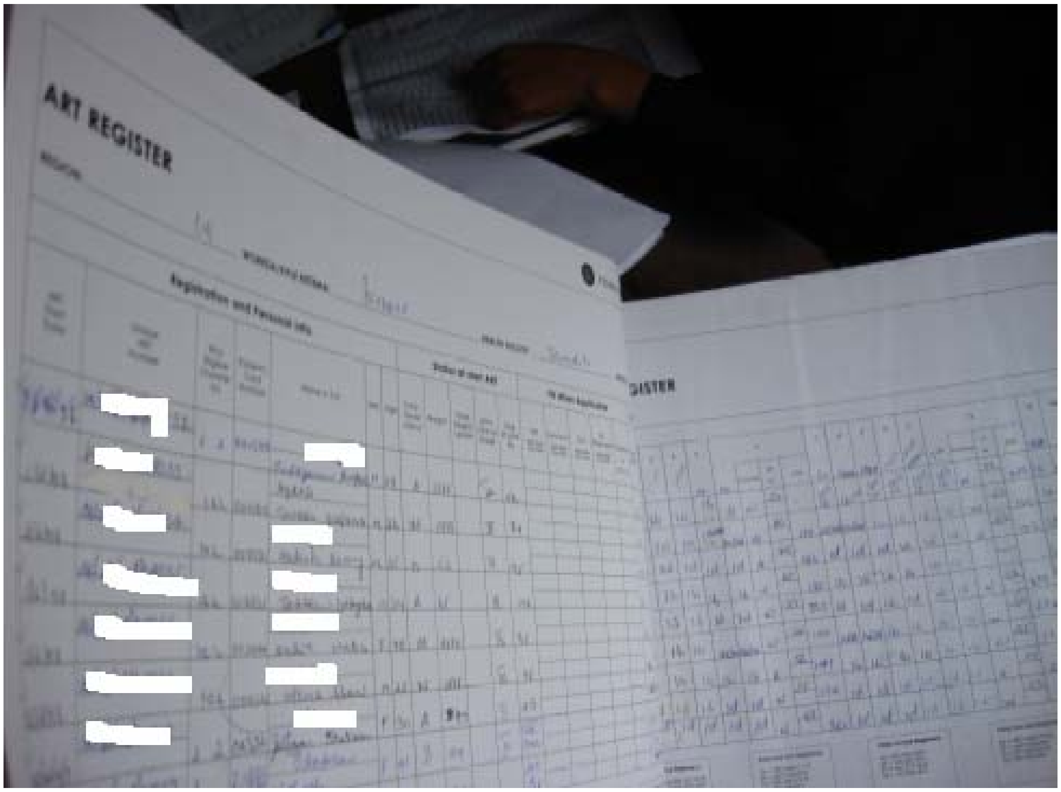


Figure 6.14: Part of the two pages of an ART register*

Every time a patient comes to the clinic (usually based on appointment), his/her follow-up form has to be searched before seeing the doctor. After the treatment, the clerk copies the records from the follow-up form into either the Pre-ART Register (if the patient is not yet eligible to start taking the actual ARV drugs) or into the ART Register (having 26 and 55 columns respectively) depending on the nature of the case (see Figures 6.13 and 6.14). This compilation is done to make the counting and analysis processes easier since most of the key data is available in two registers rather than a multitude of forms. Also, to avoid making counting mistakes, the clerks underlined the registers at the end of a month before starting registrations for the next month. There was also no clear way in the registers to distinguish between different kinds of patients, and we found that the clerks invented their own distinguishing marks. For example, clerks used red ink to underline the records of transferred in patients and to help them differentiate the status (such as dead, lost or drop out) of a patient during counting, though they were not always consistent when doing so (see Figures 6.15 and 6.16). These local improvisations no doubt were prone to serious errors such as of double counting. Further, we observed that forms were repeatedly edited making them rather untidy (see Figure 6.17).

* An ART patient's record needs at least two pages of a register. Each register can hold information for about 1000 patients, and there were about 20 registers in one of the clinics where we have been.

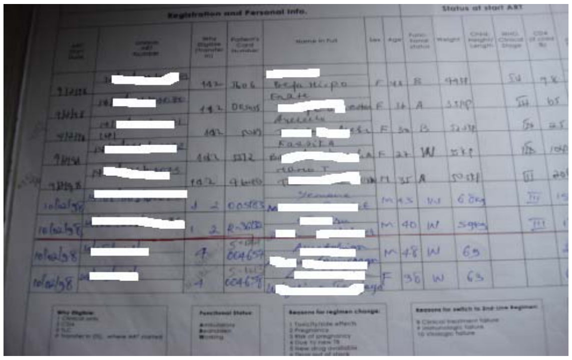


Figure 6.15: Underlining with red

Figure 6.16: Attempt to differentiate status

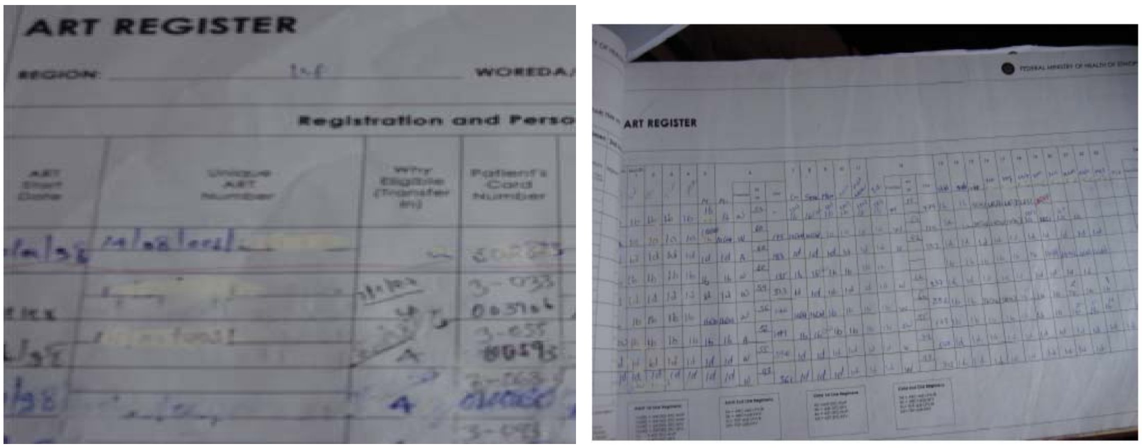


Figure 6.17: Sample untidy pages*

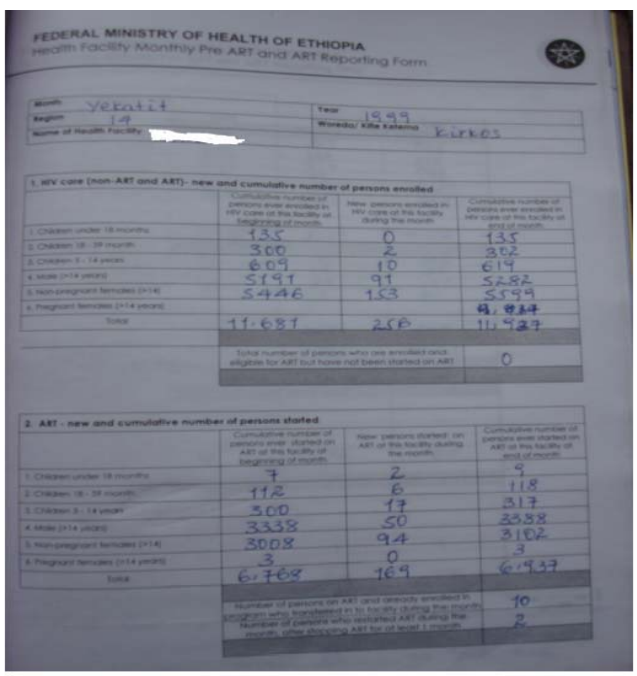
In addition, the ART register had only 24 columns to capture the patient’s monthly progress, and if a patient on ART was followed up for more than 24 months (as would be expected), a new register was opened with very incoherent links to the earlier register. Moreover, at the end of every month’s registration, clerks are supposed to leave some spaces for patients who started ART in that month in another clinic and would be transferred in to their clinic any time in the future. These patients have to be registered in the same month and year of their batch in the clinic where they are transferred to as doing so is necessary for example for during cohort analysis. Yet, clerks are not sure how much space to leave for these would-be coming patients. A clerk from one of the biggest clinics related her experience concerning this to us as follows:

> *As for me, I often prefer to simply leave 3 pages or so at the end of every month. But sometimes this may not be enough since we don’t know in advance how many patients of a particular month will be transferred in to our clinic. In this case, as you can see here, I have torn a new page from a new register and attached it on to here where I have more transferred in patients as more patients than we have expected were transferred in and the space we previously left was not enough.*

* Editing with fluid are not ours.

Having done these, a clerk then had to prepare reports of varying levels of difficulty primarily from the two registers. Two of the reports, Monthly Pre-ART and ART (see Figure 6.19), required organizing the data based on age and sex, and adding up all the cumulative data in addition to reporting that particular month's counting. Using the monthly regimen report (see Figure 6.20), the amount and type of regimen consumed in a particular month was reported again stratified by age and sex. A clerk usually sought help of her friends in the clinics while making the calculations required for the reports (see Figure 6.18). Also, if there was a patient to be transferred out to another clinic, a clerk and the nurses had to find the patient's file to compile the necessary information and issue a transfer out approval letter.

Figure 6.18: Friends helping a clerk tallying for a monthly report



FEDERAL MINISTRY OF HEALTH OF ETHIOPIA
Health Facility Monthly Pre ART and ART Reporting Form

Month	Yekatit	Year	1999
Region	14	Woreda/ Kifle Ketema	Kirkos
Name of Health Facility			

1. HIV care (non-ART and ART)- new and cumulative number of persons enrolled

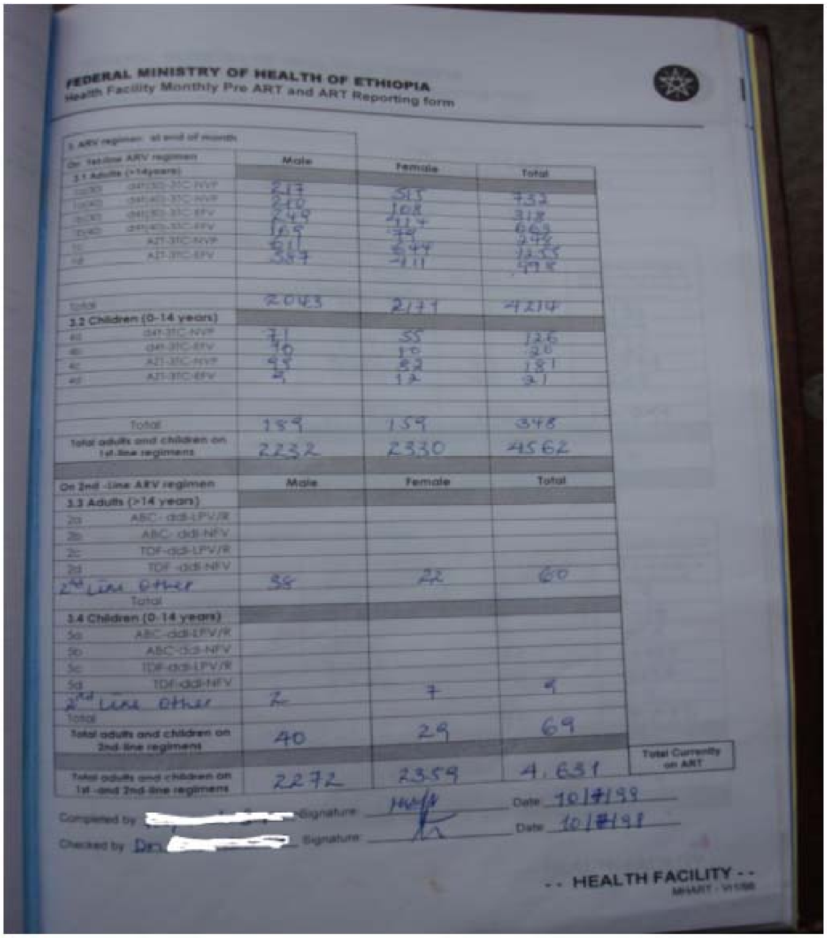
	Cumulative number of persons ever enrolled in HIV care at this facility at beginning of month	New persons enrolled in HIV care at this facility during the month	Cumulative number of persons ever enrolled in HIV care at this facility at end of month
1. Children under 18 months	135	0	135
2. Children 18 - 59 month	300	2	302
3. Children 5 - 14 years	609	10	619
4. Male (>14 years)	5191	91	5282
5. Non-pregnant females (>14)	5446	153	5599
6. Pregnant females (>14 years)			[illegible]
Total	11.681	256	11,937
	Total number of persons who are enrolled and eligible for ART but have not been started on ART		0

2. ART - new and cumulative number of persons started

	Cumulative number of persons ever started on ART at this facility at beginning of month	New persons started on ART at this facility during the month	Cumulative number of persons ever started on ART at this facility at end of month
1. Children under 18 months	7	2	9
2. Children 18 - 59 month	112	6	118
3. Children 5 - 14 years	300	17	317
4. Male (>14 years)	3338	50	3388
5. Non-pregnant females (>14)	3008	94	3102
6. Pregnant females (>14 years)	3	0	3
Total	6,768	169	6,937
	Number of persons on ART and already enrolled in program who transferred in to facility during the month		10
	Number of persons who restarted ART during the month, after stopping ART for at least 1 month		2

Figure 6.19: Monthly Pre-ART and ART report*

* Clinic names and names of people who signed on the reports are deliberately removed when pictures are taken directly from the field.



FEDERAL MINISTRY OF HEALTH OF ETHIOPIA
Health Facility Monthly Pre ART and ART Reporting form

On 1st-line ARV regimen	Male	Female	Total
3.1 Adults (>14years)			
[illegible]	[illegible]	515	732
[illegible]	[illegible]	108	318
[illegible]	[illegible]	[illegible]	[illegible]
[illegible]	165	[illegible]	[illegible]
AZT-3TC-NVP	[illegible]	544	[illegible]
AZT-3TC-EFV	[illegible]	[illegible]	[illegible]
Total	2043	2171	4214
3.2 Children (0-14 years)			
4a d4T-3TC-NVP	71	55	126
4b d4T-3TC-EFV	10	10	20
4c AZT-3TC-NVP	99	82	181
4d AZT-3TC-EFV	[illegible]	12	21
Total	189	159	348
Total adults and children on 1st-line regimens	2232	2330	4562
On 2nd -Line ARV regimen	Male	Female	Total
3.3 Adults (>14 years)			
2a ABC- ddI-LPV/R			
2b ABC- ddI-NFV			
2c TDF-ddI-LPV/R			
2d TDF -ddI-NFV			
2nd Line Other	38	22	60
Total			
3.4 Children (0-14 years)			
5a ABC-ddI-LPV/R			
5b ABC-ddI-NFV			
5c TDF-ddI-LPV/R			
5d TDF-ddI-NFV			
2nd Line Other	2	7	9
Total			
Total adults and children on 2nd-line regimens	40	29	69
Total adults and children on 1st -and 2nd-line regimens	2272	2359	4,631

Total Currently on ART

Completed by Signature Date 10/7/99
Checked by Dr. Signature Date 10/7/99

-- HEALTH FACILITY --

Figure 6.20: Monthly regimen report

We found the most complex report to be prepared by the clerk to be the cohort report (see Figures 6.21 and 6.22). This report summarizes what has happened to a group of patients 6, 12, 18, (and so on) months after the start of ART. For example, the report gives details of how many of the patients in a group: have kept following the treatment without interruption, have stopped, dropped follow-up, died, are taking a particular regimen split, are in which (working, ambulatory, or bedridden) functional status, and are transferred in or out. This report allowed investigation into both the status of a group of patients and also the performance of clinics. In addition to mere counting, statistics such as arithmetic means (for example CD4 for children), medians (CD4 of patients whose CD4 count was 200 or more) and percentages (of cohorts alive and still on ART) needed to be computed. In preparing a cohort report, clerks needed to refer to many registers and the various columns to be able to evaluate each patient in a batch against the 16 cohort variables. Hence, the multiplicity of registers and columns to be traversed, the number of cohort variables, the number of patients in a batch (who started ART in the same month), and the complexity of calculations involved, made this report an extremely difficult and a time consuming one to prepare. Some photographs are provided below to illustrate this complexity.

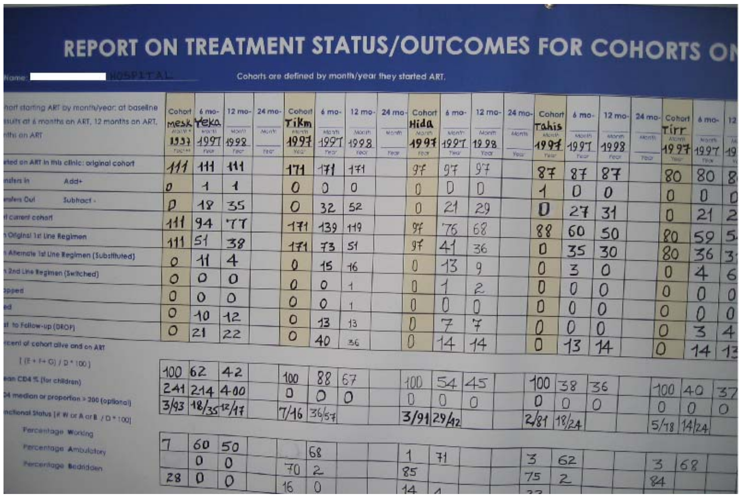


Figure 6.21: Partial view of a cohort report of all months of an Ethiopian year (1997) – taken from a wall of a clinic

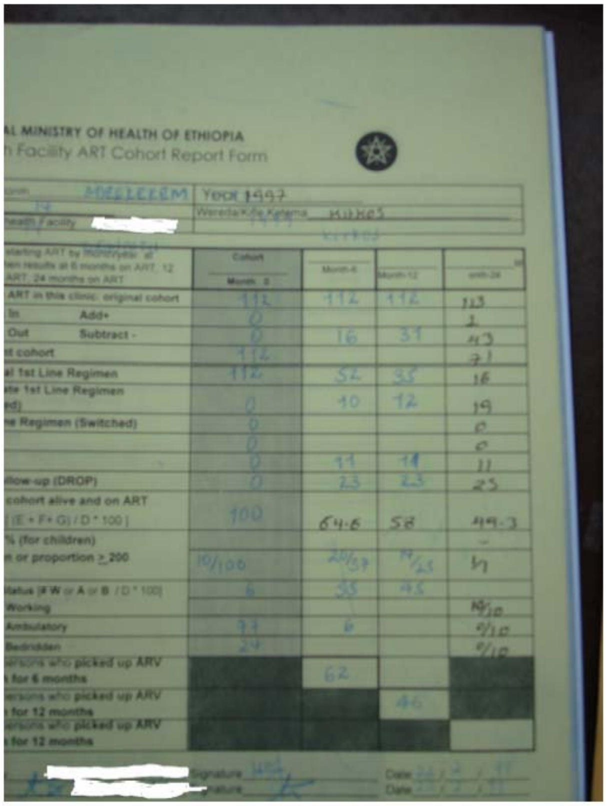


Figure 6.22: A cohort report for Meskerem (September) 1997

Due to this difficulty of preparing a cohort report, some stakeholders such as the JHU (Johns Hopkins University) and members of the HIV/AIDS task force tried to support this process. For instance, the supporting stakeholders sent some clerks to the clinics to copy demographic information of some of the patients (who had followed treatment for more than 24 months) into a new register. This made the cohort work a bit easier as some aspects of the information got consolidated in one register, which however was done by referring to past registers. Furthermore, the data capturing and reporting formats were standardized nationally so as to make comparative analysis easier.

Hence, as clerks are busy filling up forms and preparing reports to those in need, we observed that very less emphasis is given to accuracies and also to learning as to what the progress of individual patients looks like. Given the difficult nature of the follow-up form for a doctor to learn at a glance particularly about the ART progress of a patient since the form is used to capture both Pre-ART and ART data, it should have been vital for clerks to feed the doctors with analyzed data about the patients' progress. In fact, the clerks are employed with a position of data manager.

The situation analysis conducted by us helped us to identify the basic reports and additional facilities required by the ART system (see Table 6.2 below).

Data Entry	Reports	Other Facilities
Intake	Monthly Pre-ART report	Edit facility
Follow-up	Monthly ART report	Appointments
Pre-ART	Monthly Regimen report	Searching
ART	Cohort Analysis	Transfer out approval letter

Table 6.2: What the ART system requires

Furthermore, the key challenges identified by us around the workflow for the reporting system is summarized in Table 6.3 below.

Problem areas: ART workflow, data capturing and reporting formats and registers
• Size limitation of follow-up form (serves only for 18 months) and the ART register (serves only for 24 months). • High workload to enter data into two registers. • Problems of copying data from one register to the other for cohort analysis • Difficulty to easily distinguish different kinds (eg. transferred in and transferred out) of patients. Clerks invented distinguishing marks which were prone to error • Difficulty to count from registers. • Extreme difficulty to do analysis (eg. cohort) from the existing registers • Untidy forms and registers which were continuously corrected. • Too many patients to be served each day (new or returning). • Difficulty to search a file every time a patient visits the clinic. • Difficulties in appointment scheduling which adversely affected both the patients and the physicians.

Table 6.3: Key problems identified around the workflow, formats and registers of the ART program.

In the next subsection, we describe some of the other key challenges that we observed in the ART clinics.

6.3.3 Key Challenges Observed in the ART Clinics

> *“I am really tired of the manual work. If they don’t get me software soon I will leave the job. … Any working system that comes first, I will immediately start using it without ... It is only me who knows how much I am suffering.”* – A data clerk to the research team

We saw some positive aspects through our situation analysis such as the use of single standardized formats and approaches to data collection and reporting across the ART clinics in the country. Furthermore, we saw the ready availability of computers in the clinics, and which were manned by clerks who were in most cases computer literate. With a focus on the ART initiative, we discuss the problems identified under three categories: magnitude of manual workload; fragmentation; and variations in work practices. These are now discussed.

Magnitude of Manual Workload

During the initial stage of our study of the pre-existing manual system, a clerk in our pilot site at ZMH told us:

> *“Why do you have to wait until Monday?”* – A data clerk to the research team

> *I am really tired of the manual work. If they don’t get me software soon, I will leave the job. You don’t know how tired of I am. I was employed to work on a computer system but they don’t yet have any system. Hasn’t it become two years and so since they have been telling me “system will come, system will come”? None so far! … Any working system that comes first, I will immediately start using it without even having permission from my bosses. It is only me who knows how much I am suffering.*

Also, when told about our efforts to build an ART system, another clerk working at the Menelik ART clinic said:

> *Why don’t you install it to me right now if you really have one? ...*

Still another clerk at Yekatit ART clinic echoed a similar thought:

> *Why do you have to wait until Monday? Can’t you do it tomorrow or something? …*

The above quotes reflect the magnitude of manual work that the clerks at the level of the clinics were experiencing (see Figure 6.23) and how desperately they were crying out for a system which they believed would alleviate their problems. They appeared tired of the promises being made by the powers to be about the arrival of a new system, and were now ready to be subversive and adopt any system that could meet their local needs, with or without the consent of their “bosses.”

In addition to the staff at the clinics that were directly affected by the absence of an effective system, similar challenges were also experienced at the regional bureau:

> *…We want every hour updatable report accessible right here in the bureau. We have technical limitation, not financial. …* (The regional HIV/AIDS program manager, AACGHB, April, 2007)

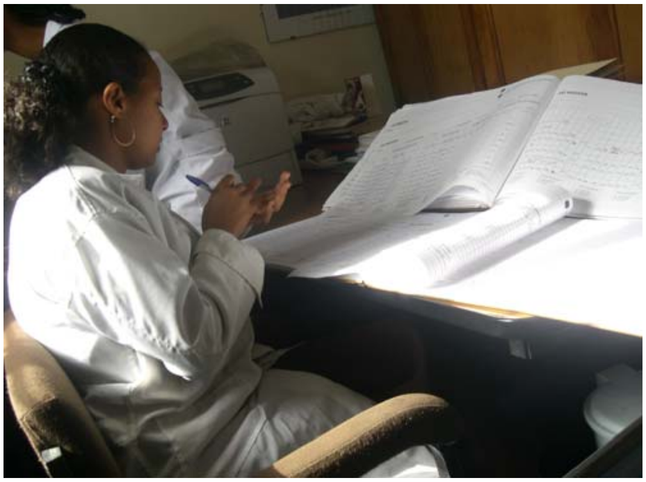


Figure 6.23: A clerk at work

> *We have only aggregating ART system [Health Mapper] with which we sum up what the clerks bring us. But the ART data increased and kept exploding day after day because of this new ART scaling movement. Therefore, the clerks started to delay to submit their reports to us and sometimes unacceptably wrong data. For example, you know that the ever enrolled patients figure should be always increasing. But the clerk from Yekatit once brought us two thousand something while she reported three thousand something the previous month. … We are now having e-mail, internet connection to facilitate report. We want to directly suck timely and accurate report form system. Health Mapper has big problems. … It … lacks the newly coming regimens. It is difficult to analyze regimens given this problem.* (Data manager, AACGHB, April, 2007)

Figure 6.24: A clerk and nurses searching info in a congested room

While the magnitude of workload was magnified in the case of ZMH which had an extremely high patient load (more than 12,000 patient registrations), even the clinics with smaller workloads experienced similar workload challenges. Further, there were problems of poor data quality, the enormity of backlog data, and poor resources for data entry. For instance, we could observe how, because of the heavy patient-loads and difficulties in retrieving data, the clerks were often forced to compromise on the quality of the data (and hence the report). For example, we once found a patient registered 4 times, 2 of which were done on the same date, by the same clerk and on the same page of the register. We also observed 4 people (2 nurses and 2 data clerks) failing to find information about a patient after searching multiple (nearly 20) registers (see Figure 6.25) for over half an hour (see Figure 6.24).

> *"…Zewditu is like an island. It is isolated. Do you know that HAPCO allocated 203, 000 Birr for data cleaning?"* – Regional health bureau's IT specialist to the research team

Figure 6.25: Multiple registers to work with

Given this, some of the stakeholders even doubted whether a well designed system will work effectively in ZMH, because of the needs for a high degree of data cleaning that was needed to take place. The regional program manager said if this cleaning did not take place it would lead to garbage in, garbage out. However, this cleaning could not take place without a system first being present (see the details in chapter 7).

> *"If the system works at Zewditu, it must be sick."* – An attendant from an American University in a task force meeting (in response to the regional HIV/AIDS program manager's acknowledgment of the system's being doing fine at Zewditu)

An IT specialist from the regional health bureau's IT team explained:

> *Because they [JHU] know that the problem there is very adverse, they don't want to touch Zewditu. They don't trust Zewditu's paper. For your surprise, last time they were going*

here and there to help the clerks do the cohort report. They did at Gandhi, where it is much simpler to do, and went straight to Black Lion passing Zewditu and didn't come back there again.[#] Zewditu is like an island. It is isolated. Do you know that HAPCO allocated Birr 203, 000 for data cleaning?

> *"Report is not an easy thing to do. Please think! You have to count from about 18 registers. … I am a human being. I get tired. You can't blame me. … Sometimes too many patients come … If I am absent for a day, think of what happens. … The biggest problem is reporting. We should go ahead and work hard together to make and use this system for reporting."* – A data clerk to the research team

This may help to understand why, when the regional program manager later declared in a meeting that our system was working fine at Zewditu, an attendant from JHU disagreed saying:

If the system works at Zewditu, it must be sick.

On top of the problems about data capture and entry, there were additional issues of data and report quality (see Figure 6.26) and the time taken to generate reports. For example, clerks told us it took them about 2-3 days to prepare a monthly report which may be delayed up to 6 days, and it took 4 clerks 2 months to prepare a cohort report working overnight (see Figure 6.27). A data clerk lamented:

Report is not an easy thing to do. Please think! You have to count from about 18 registers. These people [the bureau] they don't complain about my report delay because they know the difficulty. I am a human being. I get tired. You can't blame me. … Sometimes too many patients come … If I am absent for a day, think of what happens. … The nurses, they seem content that the system helped them in searching. But that is not the biggest thing … the biggest problem is reporting. We should go ahead and work hard together to make and use this system for reporting.

The following conversation between the research team and the data clerk further emphasizes the issues of data quality and its relation to volume of workload.

> *"We don't actually simply add figures [on the reports]. … But … we can't count all over again and again. I tell you, I swear, the regimen report is extremely difficult to count. We know that a person might have changed medicine but we simply report what he took … the previous month."* – A data clerk to the research team

<u>Research team:</u> *"When we were with [name omitted] and you the other time, [name omitted] told us that some figures are simply added to the report. Don't you think [interrupted]"*

<u>Data clerk:</u> *"We don't actually simply add figures. But we copy report from the past month excluding the dead and the like. And then we add the new ones and the medicine they take and report, or we sometimes guess. We can't count all over again and again. I tell you, I*

[#] Geographically, when driving from Gandhi Memorial Hospital to Black Lion Hospital, one passes through Zewditu which is nearer to Gandhi than to Black Lion.

swear, the regimen report is extremely difficult to count. We know that a person might have changed medicine but we simply report what he took … the previous month."

<u>Research team:</u> *"So, how much do you say is then the quality of the report?"*

<u>Data clerk</u> (swift reply): *"Zero! No one understands the problem. It is because I surely know it practically that I am telling you now."*

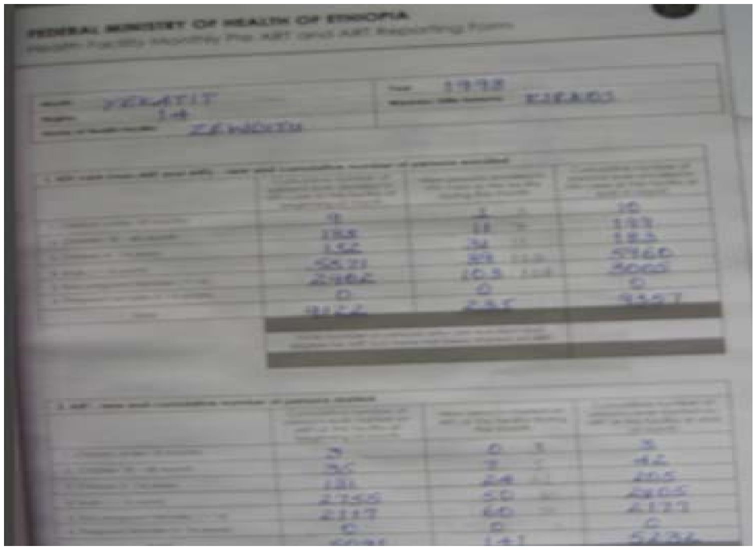

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Figure 6.26: Poor quality report (See different figures in one column)

Figure 6.27: Clerks preparing reports

In addition to the clinics, the regional health bureau, and the stakeholders, researchers were also affected by the absence of systems. One researcher told us:

I went to the clinics to see if I can make some correlations between HIV/AIDS and other diseases. Facts are gathered at lower level, in the clinics. …We need professions at that *level. …It is TB which is usually correlated with HIV…but I thought other diseases may possibly be well correlated with HIV in our country. …I think data must completely be entered into software.*

We also observed some researchers dealing with the registers themselves to compile data for their research since clerks do not volunteer to help them. In fact, at the beginning of our project, a researcher who was a medical doctor asked us if we can provide him with a database for the work he was conducting manually. Also, when a researcher makes informal deals with clerks (as we found a case in our observation) seeking help in this regard, the clerks compile the data in such a way that it is far from being appealing for analysis, thus obviously affecting the quality of the researches (see Figure 6.28).

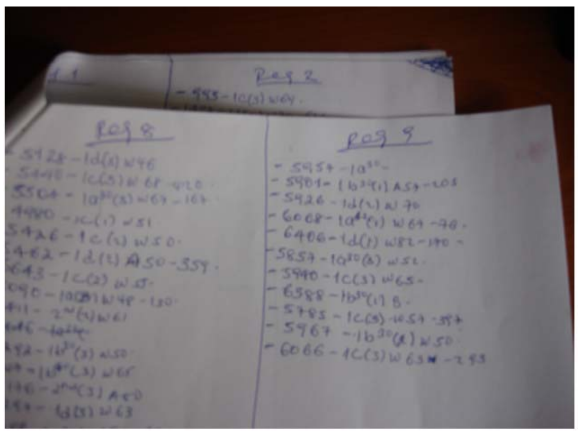


Figure 6.28: Data compiled for a researcher [Reg stands for register]

Fragmentation

We also identified various pressing problems particularly related to the fragmentation of different forms. For instance, within the ART program, while the treatment of pediatric and adult patients was done at two different locations, the data clerks were supposed to record this in the same format, and create aggregated reports. We saw various examples of how the same data around a patient was being captured again and again. As another instance of fragmentation, before a patient started the actual ARV drug, he/she needed to be under Pre-ART treatment, which was taking place in the same ART clinic. However, when the patient moved from Pre-ART to ART, demographic details already captured in Pre-ART were recaptured in a different register. Furthermore, after a physician filled in some data about a particular patient on a Follow-up form, the same data had to be copied and filled in to either the Pre-ART or ART registers by the clerk. Large amounts of time were spent in entering details about a single patient, and with nearly 350 patients arriving every day in the larger clinics (see Figure 6.29), a significant proportion of the data clerks' time was spent on filling forms.

Figure 6.29: Patients waiting for turns

Fragmentation also was present across the various HIV/AIDS initiatives. For instance, ART (both pediatric and adult), PMTCT, and ART pharmacy activities, although they usually worked in the same physical compound of the hospitals, their respective work practices were largely uncoordinated. For example, regimen consumption was counted both at the ART pharmacy and also reported from the ART clinic. This then contributed to the duplication and magnification of the workloads and also to poor quality reports. In fact, staffs from both the ART clinic and the ART pharmacy told us there were frequent mismatches between reports which were supposed to be the same.

Variations in Work Practices

Although nationally standardized data capturing and reporting formats were used in the ART clinics across the country, the surrounding work practices –the processes surrounding how health workers perform the data collection, compilation, analysis and presentation –were very diverse. For example, we observed clerks inventing their own formats and procedures to ease their reporting work. Due to the immensity of the workload and the urgency for the monthly report by the bureau, a clerk in one clinic invented her own data capturing form (see Figure 6.30) which collected only the most important variables from the actual follow-up card which was filled while a patient was being treated by doctors. This invention affected the quality of data as it did not, for example, have a column to uniquely identify a record for latter counting and analysis. Furthermore, this also adversely influenced our implementation efforts as we needed to compare and verify (with the clerks and the IT team) the manual report with the system generated report.

Figure 6.30: A locally invented data capturing form

If we particularly consider ZMH, due to its size and the absence of unique identifiers, the above problems were magnified. For example, improper (eg. 234 for both 234/2006 and 234/2007) patient card number was assigned by the card room of the hospital, and the data clerks were reluctant (perhaps due to workload) to go a level up and discuss to correct the wrong. Distinguishing and identifying Pre-ART and ART patients was difficult in this scenario and made the report preparation problematic. Furthermore, the patients' next visit date was not filled in this clinic as the staff felt that it will not anyway be used to search patients manually. This condition directly affected the patients as it increased their waiting time due to poor scheduling. In fact, clerks told us that sometimes some patients would go home without being treated as the doctors were exhausted at the end of the day. Such skipping of treatment is clinically dangerous in antiretroviral therapy as it contributes to the building of resistance. In an opposing situation, the invention of a local serial number at Gandhi Memorial Hospital (GMH), a much smaller clinic than ZMH, helped us (and the clerk) to uniquely identify a patient and quicken data entry which at the same time reduced duplication of entries.

There were also other differences in the work practices among the different clinics in relation to workflow; way of counting for a report in the cases, for example, of reporting the number (and date) of patients who are "Lost", "Drop" (dropped treatment), "Dead", "Transferred In", "Transferred Out", and "Changed Regimen." These differences were especially true when comparing Addis sites with those in

SNNPR, another region in the south. For example, as the SNNPR implementer (a medical doctor by training) who had the chance to compare sites both from the two regions found out, a clerk in one clinic in SNNPR never captured and reported "Drop" due to lack of training on this. The report submitted by the medical doctor to the SNNPR region further highlights the variations and diversity in work practices. We reproduce below some excerpts from his report (see Table 6.4).

To: SNNPR Health Bureau …

This report is drawn from a study I carried out in the region for … The study was conducted in two regions (Addis Ababa and SNNPR) after obtaining permission from the respective health bureaus. …

FINDINGS …

1. *Here are some examples of differences between the clinics on the way some of the data elements/variables are understood and reported.*
   - *In one of the clinics a patient is said to be reported as "Lost" when he/she misses three appointments whereas, such patients are reported as "Drop" by the rest, which reported patients who missed rather a single appointment as "Lost". The clerks from the former clinic said they never used "Drop" in their reports since the establishment of the clinic and that they have never formally been told about the differences and didn't get the chance to attend trainings.*
   - *Another important difference identified was on the way transfer in (TI) patients are counted. Clerks from two of the clinics never included TI patients in their cumulative number of patients ever enrolled in HIV care at their facility, while in one of the clinics they said they add them to this section starting from the next month of the patient's arrival (example, if the patient is TI in September, then they add the patient to the cumulative starting from October)*
2. *It was observed that not all of the individuals involved in the preparation of reports are trained on how to carry out their work. …*
3. *None of the interviewed data managers (one from each clinic and includes trained and untrained) is confident in doing the cohort analysis report. They all said they could not do it alone and that they needed assistance. …*

DISCUSSION AND RECOMMENDATIONS

As stated earlier only a few scenarios have been created and tested to see if the reporting has been uniform across the clinics. This is considered vital because of the fact that a single monitoring and evaluation guideline is being followed in the country and this requires a similar handling of various scenarios in all clinics during recording and reporting. Identifying even a single difference then becomes of interest so long as it has implication in the overall monitoring and evaluation of the programme. For example, lack of uniform handling of TI and TO patients may result in either over- or under-reporting of cases. …

Table 6.4: Field work report showing variations in work practices

These variations had significant implications on our software development work as we had to repeatedly make changes to incorporate these variations.

In general, our situation analysis identified the following key problems: (1) high workload on the clerks in the ART clinics, (2) significant degree of fragmentation both within ART and across programs, (3) multiplicity of work practices which made it difficult to make things uniform. Table 6.5 below summarizes the key problems of the pre-existing manual system identified during the situation analysis.

Problem areas: Magnitude of manual workload, fragmentations within and across programs, and variations in work practices		
Problems associated with magnitude of manual workload	**Problems associated with fragmentation**	**Problems associated with variations in work practices**
▪ Difficulty in retrieving data. ▪ Difficulty in preparing reports. ▪ Difficulties in analysis (eg. cohort analysis) ▪ Compromised quality of data which affected system implementation. ▪ Delayed reports. ▪ Inaccurate and poor quality reports. ▪ Large volumes of backlog data. ▪ Poor resources for data entry.	▪ Multiple and uncoordinated points of data capturing. ▪ Large amounts of time spent in entering details about a single patient. ▪ Significant proportion of clerks' time was spent on filling forms. ▪ Duplication and magnification of workload. ▪ Mismatch between reports from different initiatives in the HIV/AIDS program.	▪ Local invention of formats and procedures– affected quality of data and reports negatively ▪ Influenced development and implementation efforts

Table 6.5: Summary of key problems identified during situation analysis

In summary, we have described in this chapter particularly the political challenges of gaining entry into Ethiopian HIV/AIDS program to start the development and implementation of an HIS that would ART management. Through a situation analysis, we have also identified various problems in the actual running of the manual system of the ART program. After having identified these key problems, in the next chapter we discuss our action research interventions aimed at addressing these problems to improve the current situation, and also the various socio-technical-political challenges we still needed to bear in the efforts to make the ART system work. This will constitute the second fragment of our concrete research activities.

7 Concrete Research Activities: Action Research Interventions

7.1 Introduction

This chapter contains descriptions on the remaining part of our concrete research activities. The chapter provides narrative descriptions of the various action research interventions carried out in our research to address the problems identified during the situation analysis, the outcomes observed, and our reflections and evaluations of these interventions. Furthermore, still sticking our primary focus on political issues, we discuss the various challenges we faced and the strategies adopted in designing, developing, implementing, scaling up, and sustaining the IS* supporting the country's ART management once we gained entry (see chapter 6). These processes represent the action taking and evaluating phases respectively in the action research cycle.

As depicted on Figure 7.1, once we gained entry and the prototype was developed, this research was conducted in such a way that the activities of requirements elicitation, situation analysis, development, onsite training and data entry, implementation, and scaling up of the system went on largely in parallel throughout the study. Perfectly segregating these processes is thus not really easy. However, for the sake of simplifying the discussion, we will attempt to separately describe in this chapter the specific efforts we exerted to alleviate the existing problems. Accordingly, the chapter is divided into five broader sections hereafter. Section 7.2 describes how the system development process went about. The discussion focuses on the cultivation of the prototype which we developed soon after gaining entry. Section 7.3 discusses the challenges surrounding our implementation activities and the strategies adopted to address them. It also provides region-wise comparisons of these activities. Section 7.4 focuses particularly on the political conditions that bottlenecked our efforts to scale up the system specifically in the Addis Ababa region. After we summarize the outcomes of the action taking phase in section 7.5, an evaluation will be presented in section 7.6 to observe the changes brought about by the action taking phase. Reflections as to what should be taken in the subsequent action research iterations will also be presented at the end of the last section.

* Out of the two systems in our project (see chapter 3), this chapter concerns IHAMS-ART, unless otherwise stated.

As a continuation of the research activities from chapter 6 (see Figure 6.9), in the figure below, we schematically depict the overall sequence of the research activities carried out which is followed by detailed descriptions of the different components.

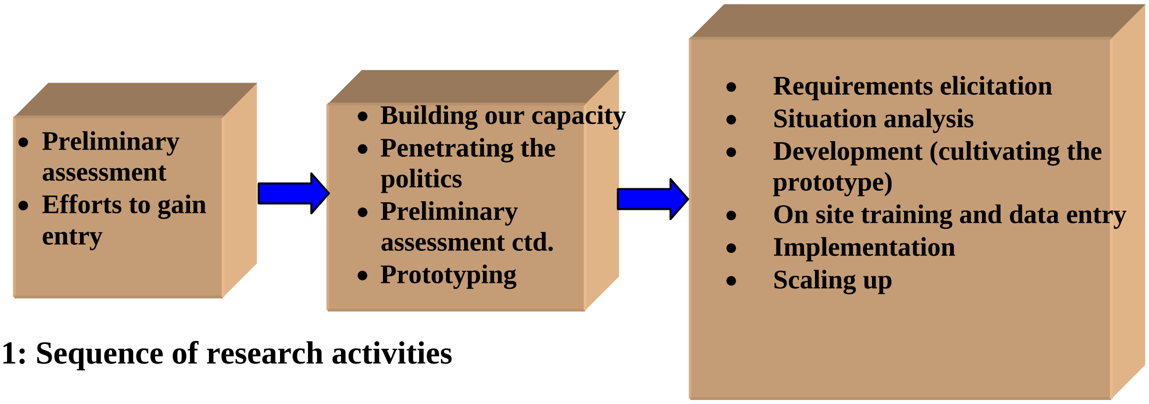


Figure 7.1: Sequence of research activities

7.2 Development – Cultivating the Prototype

We adopted an evolutionary prototyping approach where first a prototype was rapidly developed based on abstract specifications, and was initially installed in two clinics where data entry was initiated through clerks paid by HISP funds. Constantly working with the prototype helped us to ask more meaningful questions to the clinic staff, to gain invaluable experience around the requirements and to accordingly make more effective modifications to the system (see Figures 7.2 and 7.3). Though we did not necessarily perform one activity after the other, the development work can be categorized into three groups: improving workflow; incorporating basic functionalities; and functional scaling of the system. These are now each discussed.

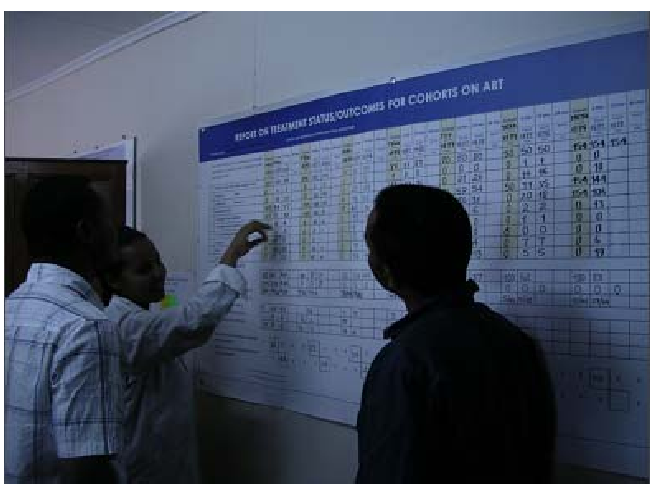


Figure 7.2: A clerk helping us understand requirements

Figure 7.3: Development taking place

Improving Workflow

The first version of the prototype, in which only the basic functionalities have been put in place as priority areas, reflected the existing fragmentation in the program (see chapter 6). To deal with these issues, we improved the technical workflow of the system, the database, and the data capturing styles – just to mention a few of the facets. For instance, the new workflow required users to enter basic data only from two points – intake and follow-up (see Figure 7.4), and not from four points as it initially was. Accordingly, the database was better structured in such a way that redundancy was avoided and consistency secured. These changes helped to save time in data capturing because of the elimination of some of the existing redundancies. A clerk acknowledged:

> *It is a short method. It is fine now. It is not difficult for me working because you fill only intake and follow-up and then you have everything you want. It shortens your working time.*

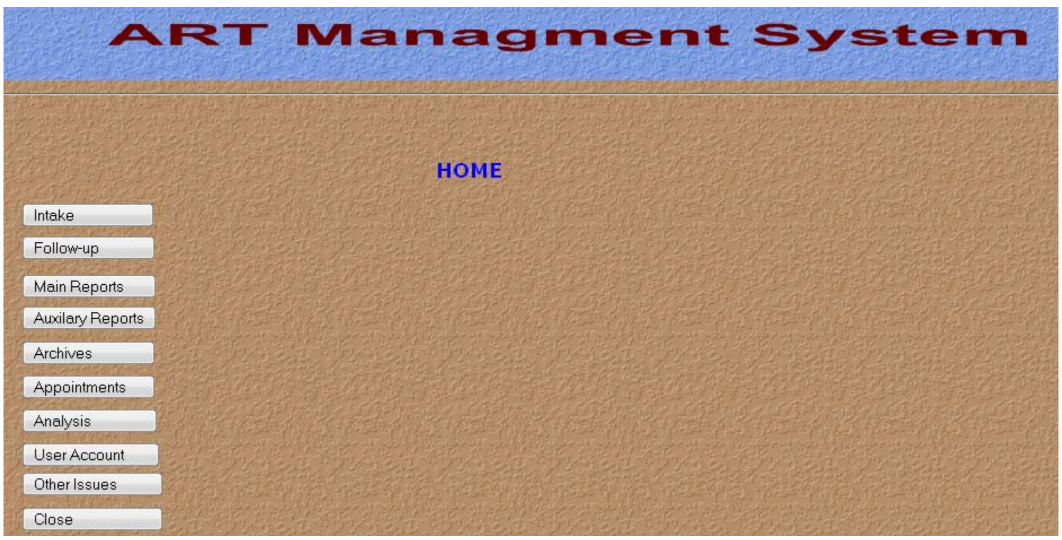


Figure 7.4: Screenshot – Home page of IHAMS-ART

Incorporating Basic Functionalities

While improving the workflow of the system, we were at the same time incorporating the basic functionalities identified through a simultaneous situation analysis. This included all the data capturing forms, editing facilities and all the routine reports required by the system. When incorporating the basic functionalities, we gave priority to make the system easily learnable for the users, for example by trying to replicate the logic and workflow of the manual system so as to keep the transition gradual. We deliberately tried to the extent possible to make the arrangement of the data elements on the data capturing formats to be similar to the existing paper format, and same was the case with the reports. Talking about how these helped her, a clerk said:

> *When I do the data entry, it is easy. Everything I see on the paper, it is there on the system. You did it the same as the form. Here [shown on Figure 7.5], for example, after filling marital status I immediately find level of education. Exactly like in the paper. It is not difficult to follow.*

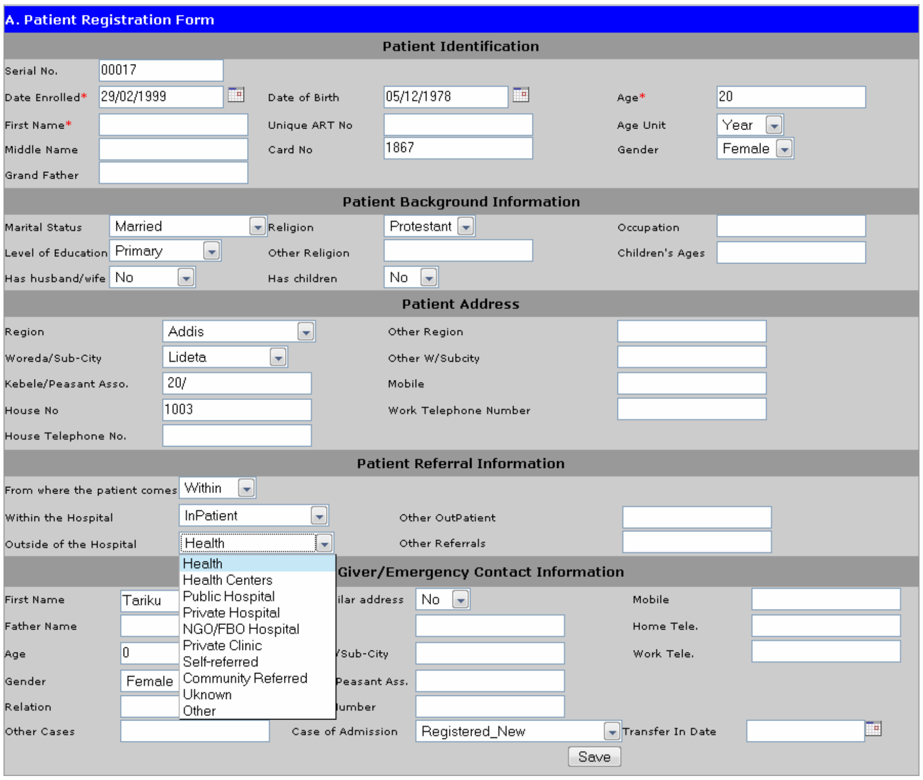


Figure 7.5: Screenshot – Intake (first section) data entry form

Moreover, we improved the accuracy of reports as we gradually better understood the correct underlying logic by which the reports were computed. The accuracy and speed of report generation as well as their similarity with the paper formats (compare, for example, Figure 7.6 with Figure 6.21 in chapter 6) helped to gain for us the approval of the clerks.

Another important area of emphasis was improving the ease of use, especially because of the high volumes of data that needed to be dealt with. For instance, in addition to the use of tools such as combo and check boxes to reduce typing work, we carefully arranged the form elements in the data capturing format so that elements which are often filled can be easily and quickly accessed. Most importantly, data capturing was significantly eased by what we might call a "replicate functionality" of the system, which helped to automatically replicate the previous month's follow-up information to the current month as far as possible if the information was replicable. For example, there were six data elements concerning what family planning method a patient used. If it was filled in the previous month that the patient used some of these, there should be no need to waste time reentering these in the current month as chances for change are found to be rare. Hence, the system was made in such a way that it automatically replicated, and gave them facilities to edit the data where required to accommodate changes that may have taken place. Similarly, in the manual system whether a patient was "new" or "repeat" (an important requirement in the reports) was captured every time the patient came to the clinic. But we know that a patient could be new only once and would be a repeat one after that. Hence, we automatically replicated that the patient was a repeat case from then on without the clerk's intervention. Given that there were more than 115 data elements (most of them being replicable) in the follow-up form, we found that these features saved large volumes of time, and also improved data quality levels through strengthened validation. A clerk from one of the biggest clinics acknowledged:

FEDERAL MINISTRY OF HEALTH OF ETHIOPIA

Health Facility Monthly Pre-ART and ART Reporting Form

Month	Hamle	Year	1999
Region	14	Woreda/Kifle Ketama	Kirkos
Name of Health Facility	Zewditu Memorial Hospital		

1. HIV care(non-ART and ART) - new and cumulative number of persons enrolled

	Cumulative number of persons ever enrolled in HIV care at this facility at beginning of month	New persons enrolled in HIV care at this facility during the month	Cumulative number of persons ever enrolled in HIV care at this facility at end of month
1.Children under 18 months	0	0	0
2.Children 18 - 60 months	1	0	1
3. Children 5 - 14 years	4	0	4
4. Male (>14 years)	4244	52	4296
5. Non-pregnant females(>14 years)	4757	70	4827
6. pregnant females (>14 years)	2	0	2
Total	9008	122	9130
	Total number of persons who are enrolled and eligible for ART but have not been started on ART		8

2. ART - new and cumulative number of persons started

	Cumulative number of persons ever started on ART at this facility at beginning of month	New persons started on ART at this facility during the month	Cumulative number of persons ever started on ART at this facility at end of month
1.Children under 18 months	0	0	0
2.Children 18 - 60 months	0	0	0
3. Children 5 - 14 years	4	0	4
4. Male (>14 years)	3515	42	3557
5. Non -pregnant females(>14 years)	3623	61	3684
6. pregnant females (>14 years)	1	0	1
Total	7143	103	7246
	Number of persons on ART and already enrolled in program who transferred into facility during the month		2
	Number of persons restarted ART during the month, after stopping ART for at least 1 month		4

Figure 7.6: Screenshot – Monthly Pre-ART and ART report (real) made exactly like in the paper format

> *Now I don't change many things unnecessarily again and again. Look at this [a line of patient record on the system]. Functional status is the same as that of the past month, WHO stage is the same, Regime is the same … and the system brings them all well filled to me. I don't have to change or fill these again unless there is change. It is a great relief.*

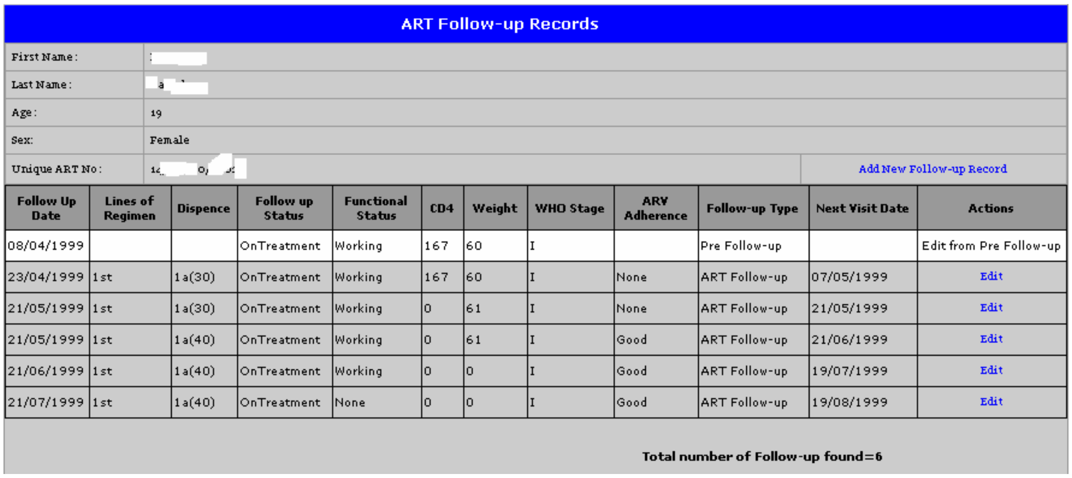
In addition, data quality improvements were made by capturing the data in the same format (for example spelling of regimen). We also created many special ways to validate data elements (such as age and sex) on which the reports were directly based. For instance, while we initially kept the two sexes (very important in reports) in a combo box, we observed that the clerks usually used the default value. We thus needed to put a control in the system and made the clerks necessarily choose the right sex before moving forward. Concerning this, a clerk said:

> *In the past, sometimes I used to leave female as it is. I used to forget it. And when I later check, I often find mismatches between what I believe I entered and what the system report displays; and I used to become angry. Now, this thing stops me to consciously think and fill in the right sex. It annoys you when it stops you when you want to proceed to save but it controls me so that I go back to the card to check and get the right sex, I don't make mistakes now.*

Other basic functionalities were also incorporated. As never before, clerks were given simple and basic options to search patient information based on a variety of criteria relevant to them – name, age, sex, enrollment date, ART start date, follow-up date, card number, unique ART number, serial number, and patient status (such as Pre-ART or ART, on treatment, lost, drop, restart, dead, transferred out, transferred in). In addition to incorporating these basic functionalities which were part of the "official" requirement, we also used our own initiative to add features which we felt would be useful to the users. For example, we enabled users to easily differentiate the patient's status just by seeing different color codes (see Figure 7.7). We also provided links on every page so that a user could go anywhere from any page. Moreover, we created a page from which a clerk could easily find every important piece of information about a patient (including follow-ups, intake sections, and the patient's and his/her caregiver's addresses). Regarding these functionalities, a clerk said:

> *In the previous version, there was a long journey to go to perform a task. You click one thing and when it is opened you find another thing to click and so on until you reach where you want to be. Now you have everything everywhere. You don't have to remember where to find what. And it saves my time. …I like particularly this one here very much because being here I can know which patient's follow-up is not entered at all. It helps me to be complete about a particular patient.*

Furthermore, we made the follow-up and intake forms manageable and easily understandable unlike the paper formats (especially the follow-up form) which were congested with codes. The incorporation of these basic and also advanced features was well appreciated by the clerks. Even the nurses appreciated these features, for example they could see patient information while data entry was not yet completed, and also could retrieve specific information easily. It helped them in stopping the issue of duplicate cards which sometimes they had to do when they could not locate a patient in the paper database for whatever reason.



ART Follow-up Records

First Name:	
Last Name:	
Age:	19
Sex:	Female
Unique ART No:	Add New Follow-up Record

Follow Up Date	Lines of Regimen	Dispence	Follow up Status	Functional Status	CD4	Weight	WHO Stage	ARV Adherence	Follow-up Type	Next Visit Date	Actions
08/04/1999			OnTreatment	Working	167	60	I		Pre Follow-up		Edit from Pre Follow-up
23/04/1999	1st	1a(30)	OnTreatment	Working	167	60	I	None	ART Follow-up	07/05/1999	Edit
21/05/1999	1st	1a(30)	OnTreatment	Working	0	61	I	None	ART Follow-up	21/05/1999	Edit
21/05/1999	1st	1a(40)	OnTreatment	Working	0	61	I	Good	ART Follow-up	21/06/1999	Edit
21/06/1999	1st	1a(40)	OnTreatment	Working	0	0	I	Good	ART Follow-up	19/07/1999	Edit
21/07/1999	1st	1a(40)	OnTreatment	None	0	0	I	Good	ART Follow-up	19/08/1999	Edit

Total number of Follow-up found=6

Figure 7.7: Screenshot – All follow-up records of an individual patient with edit links– only main variables in one screen view

Functional Scaling

We continued to gradually but continually scale up the system functionally by adding new features even though they were not formally required, but which we felt was needed. For example, we designed the cohort report in such a way that the entire history of a group of patients starting ART in a certain month could be seen from that month till the current month, not just up to 6, 12, and 24 months as was specified in the report formats. In addition to telling the progress of a group of patients, these reports helped to evaluate the performance of a clinic as the cohort report also included information on drop outs and other variables that helped to analyze performance. All the reports were designed such that they could be generated for any time period, and not just monthly which was the "official" requirement. In addition, we incorporated an appointment scheduling feature to allow clerks to schedule patient visits. Further, we incorporated facilities for doing complex searches, validation rules and the generation of patient transfer out approval letters containing vital information about a patient when transferred to another facility. This is an important feature since the national ART M & E system, and hence the national ART program management, is severely affected as there is significant patient mobility – many cases of transfer in and out.

Furthermore, as we kept on cultivating the system, it gradually evolved in such a way so to meet diverse needs identified by us as being relevant to health workers at different levels. For example, on our own initiative, we designed an individual patient's progress report which depicted the entire history of the patient from the first day of treatment till the current time, including key details of CD4 count, weight, adherence levels, and functional status during each follow-up. This report was found to be very useful by doctors to easily learn about the progress of a patient in a ready made and organized manner.

At the clerical level too, the functional scaling of the system contributed to quickening the generation of quality reports. For instance, as a form of the fragmentation problem mentioned in the previous chapter, in one of the hospitals we worked with, the pediatric ART was done in a different clinic from that of the adult. And further it was the adult clinic's responsibility to receive reports from the pediatric ward and prepare region specific summary reports. Hence, in order to encourage reporting, we incorporated functionality where by the system could receive the pediatric data and put the reports together. In addition, clerks were particularly provided with functionalities of searching based on dates (such as the follow-up date) and nature of patient (Pre-ART, ART, transferred out, transferred in) which the clerks found extremely useful as a lot of their time was spent searching for particular records.

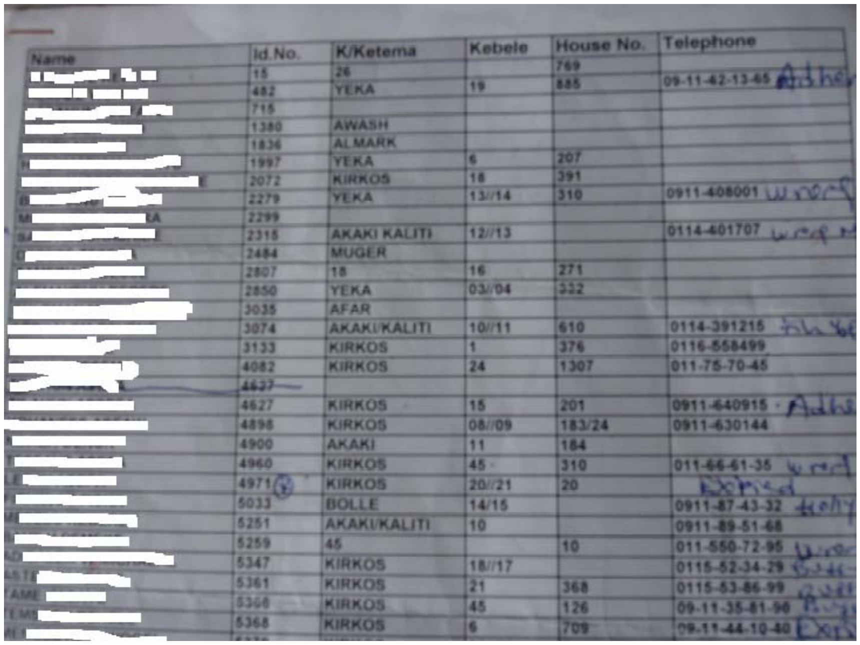
We incorporated important functionalities at the clinical level too, such as to inform patients who are "LOST" augmented with the patient's and his/her caregiver's addresses. Similar functionality was also provided for patients who dropped out or stopped treatment (see Figure 7.8) or showed poor adherence. Given the key role of the clinics in trying to strengthen adherence, the significance of these functionalities in point can not be overemphasized. After we demonstrated new version of the system with these particular features to a data clerk in one of the biggest clinics, she said:

Lost/Drop Patients

Date Enrolled	Follow-up Date	Unique ART No	Card No	First Name	Last Name	Sex	Age	Follow-up Status	Action
03/04/1999	14/07/1999	14[redacted]	3002/99	[redacted]	[redacted]	Female	45	Lost	Address
13/04/1999	03/07/1999	14/[redacted]	3312/99	[redacted]	[redacted]	Female	20	Drop	Address
30/05/1999	03/07/1999	14[redacted]	041/99	[redacted]	[redacted]	Female	27	Lost	Address
05/06/1999	12/07/1999	14/[redacted]	5014/99	[redacted]	[redacted]	Female	26	Drop	Address
04/05/1999	12/07/1999	14/[redacted]	3967/99	[redacted]	[redacted]	Female	27	Lost	Address
								Total Patients:	5

Figure 7.8: Screenshot – Lost/Drop patients with link to the patient's and his/ her caregiver's address

This is very, very important! You see this? [The one shown on Figure 7.9] Last time, we were asked to pick up and list down lost and drop out patients with their addresses including telephone number so that Hiwot and Medan Act [are NGOs] will call them for help. And we prepared this. … It took us four days for the three of us to do it from about eleven registers. If we could use this feature of the system, this couldn't have happened. I think the bureau now understood all these and that is why they called us a meeting last week where we discussed about how to immediately start using the system.



Name	Id.No.	K/Ketema	Kebele	House No.	Telephone
	15	26		769	
	482	YEKA	19	885	09-11-42-13-65
	715				
	1380	AWASH			
	1836	ALMARK			
	1997	YEKA	6	207	
	2072	KIRKOS	18	391	
	2279	YEKA	13//14	310	0911-408001
	2299				
	2318	AKAKI KALITI	12//13		0114-401707
	2484	MUGER			
	2807	18	16	271	
	2850	YEKA	03//04	332	
	3035	AFAR			
	3074	AKAKI/KALITI	10//11	610	0114-391215
	3133	KIRKOS	1	376	0116-558499
	4082	KIRKOS	24	1307	011-75-70-45
	~~4627~~				
	4627	KIRKOS	15	201	0911-640915
	4898	KIRKOS	08//09	183/24	0911-630144
	4900	AKAKI	11	184	
	4960	KIRKOS	45	310	011-66-61-35
	4971	KIRKOS	20//21	20	
	5033	BOLLE	14/15		0911-87-43-32
	5251	AKAKI/KALITI	10		0911-89-51-68
	5259	45		10	011-550-72-95
	5347	KIRKOS	18//17		0115-52-34-29
	5361	KIRKOS	21	368	0115-53-86-99
	5368	KIRKOS	45	126	09-11-35-81-96
	5368	KIRKOS	6	709	09-11-44-10-40

Figure 7.9: Some pages of lost and drop out patients took 4 days for 3 clerks to collect form about 11 registers

The system also provided other specific benefits at the clinic level. For instance it helped to improve the quality of backlog and current data. While we loosened the system so as to initially accept the backlog data with all its defects, the aim was to make visible the kinds of defects on a monthly basis. Using these features, it was possible to correct and avoid duplication of card numbers, the unique ART number etc. In addition, there were features that provide information concerning variables directly related to the treatment of the patient such as CD4, next visit date, weight, functional status, regimen split etc. The usefulness of these features extended beyond the clinic level and could potentially support also the regional level. Moreover, the system helped the clinic by informing them about the new cases (such as dead, lost, drop out, stop, restart, and on treatment) in a month. Further, it supported the systematic archiving of Pre-ART, ART, intake, and follow-up formats exactly like in the manual system.

For the regional level, some tools to support analysis were provided. This included the identification of patients stabilized under ART with a summary progress report. These were already found to be practically very useful by the bureau. For example, in July 2006, there were intensive national movements to scale up the ART treatment in the country by enrolling more patients. The Addis health bureau thus needed to scale down stabilized patients and transfer them from the hospitals they were being treated to their nearest health facilities so that new patients could be admitted to start the treatment in the hospitals (AACGHB, 2006). As the variables to analyze stable patients with their nearest health facility were many, the bureau found doing the analysis manually a cumbersome task. We then had to use the system to generate rapidly a list of these stable patients based on the criteria provided to us, something which the bureau deeply appreciated.

By and large, the different features of the system had particular significance to health workers at different levels which helped us enroll important actors to secure political backing. Table 7.1 below summarizes the major features of the system.

Feature	Descriptions
Technology	Open source (PHP/MYSQL) and web-based tools were used
Ease of use and learnability	The work was eased by the kind of data capturing form elements used, and replications of past entries to current patient encounter; and was also made easily learnable as the data entry forms could be easily followed by users who have been working on the manual system
Time savings	Quick data entry from only two points – intake and follow-up; and also by other features that quicken data entry.
	Quick generation of monthly reports and cohort analysis
Data quality improvements	Errors during data entry, duplicate entry, etc are reduced
	Complete data capturing and hence inviting for different researches
	Improved data validation that improved, for example, report accuracy
	Improved confidentiality with user authentication system
Improved analysis	Temporal analysis eg., advanced cohort analysis, advanced individual progress report
	Facility comparisons eg., average months patients picked up ART without interruption
	Simple and complex searching
	Improved follow-up of patient and his/her adherence

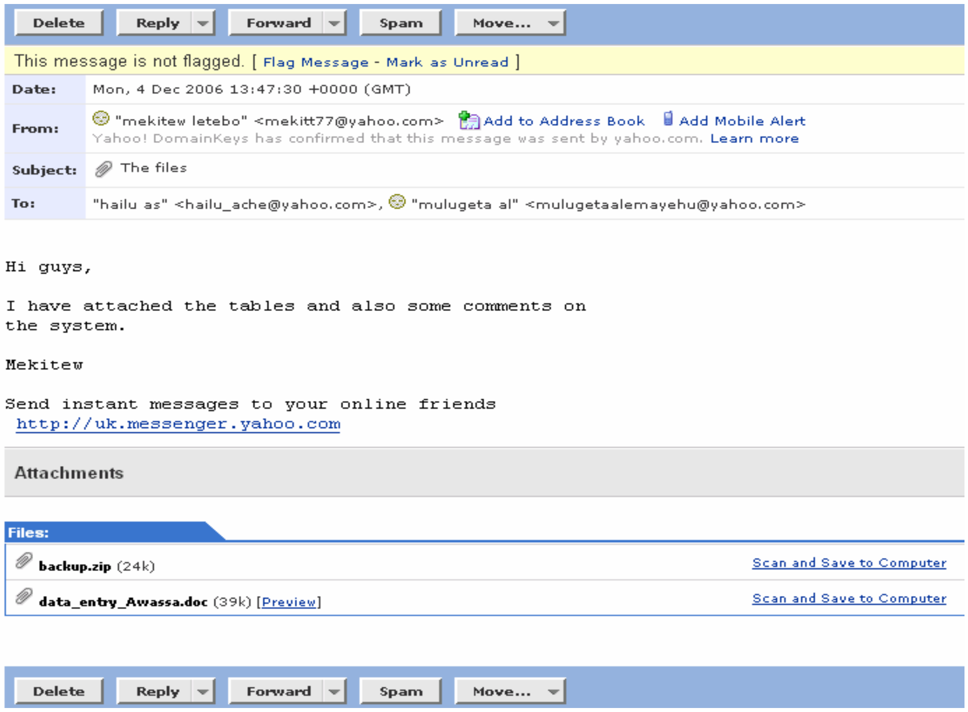
Table 7.1: Some features of IHAMS-ART

Various technical challenges had to be dealt with during the cultivation process. For example, the workflow needed to be changed time and again to accommodate the different practices. The poor infrastructure conditions coupled with our own lack of experience of working with open source technologies (PHP/MYSQL) also slowed down the development process. For example, after considerable amount of data was entered, the clerks informed us the presence of bugs relating to dates.

This happened because, although all ART data capturing and reporting formats were in English, the practice was to capture and report based on the Ethiopian Calendar (EC) which, as discussed in chapter 5, followed a different system. As a result, the dates, for example, in the Ethiopian 13th month were forcibly converted to 00/00/00 in the MySQL database. Discovering this problem later, we had to amend the problems and subsequently migrate huge amounts of data into the new version of the system which was based on the Ethiopian calendar. Also, since we followed a hard coding programming style sticking to the Ethiopian ART requirements, we could not take the system to other HISP affiliated countries such as India and South Africa even if we got chances. Furthermore, as we kept developing the system (IHAMS-ART), we came to realize that we have ended up in a code which is not sufficiently malleable to mold into shape[*], and have missed our target of IHAMS. It was these phenomena that latter contributed to calling for a simultaneous engagement of ourselves in the development of the other "improvised" system (Debo) when we got the exposure to be in South Africa. As mentioned in chapter 3, Debo, a system under development, is not only going to be an IHAMS but it is also designed in such a way that it is flexible and customizable.

We exchanged frequent e-mails with the professor and the SNNPR implementer detailing the concerns we had about the development and implementation processes. The comments and criticisms received particularly from the SNNPR implementer (a medical doctor by training) had profound impacts on our cultivation process. These communications also helped to address some technical problems the doctor encountered in his effort of implementing the system in that region. We give below some examples gained through e-mail exchanges with this doctor.

[*] Because the detail of these phenomena is a wide discussion in itself, not interesting to this thesis, we opt not to include it here as we also felt it would make the thesis more unwieldy.



Delete | Reply | Forward | Spam | Move...

This message is not flagged. [Flag Message - Mark as Unread]

Date:	Mon, 4 Dec 2006 13:47:30 +0000 (GMT)
From:	"mekitew letebo" <mekitt77@yahoo.com> Add to Address Book Add Mobile Alert Yahoo! DomainKeys has confirmed that this message was sent by yahoo.com. Learn more
Subject:	The files
To:	"hailu as" <hailu_ache@yahoo.com>, "mulugeta al" <mulugetaalemayehu@yahoo.com>

Hi guys,

I have attached the tables and also some comments on the system.

Mekitew

Send instant messages to your online friends http://uk.messenger.yahoo.com

Attachments

Files:

backup.zip (24k) Scan and Save to Computer

data_entry_Awassa.doc (39k) [Preview] Scan and Save to Computer

Delete | Reply | Forward | Spam | Move...

The tables he was referring to were database tables which, after he talked to us on the phone, we discovered to have troubled him when conducting an informal training to data clerks during the data entry process in SNNPR region. Part of the comments he made in the separate attachment of that mail reads:

Dear Hailu and Mulugeta,
I can see that the system is now much more user friendly than it was at the beginning. Besides, entering a huge amount of backlog data is no more a formidable task due to the new developments.
I have the following comments, which I believe, make it even better. I think we need to address them before further scaling is considered. I observed most of these during data entry at Awassa referral hospital on December 2 and 3 (weekend).

1. ***Intake- section A*** *– under patient background it says 'has husband/wife' I am not sure if we need that even if it is there on the manual system. I believe …*
2. **…**

…

6. ***Finally,*** *It appears to us that we lost all the data we entered over the past two days (a complete entry for 72 patients and only intake forms filled out for 6 patients). It happened after a second power failure in an hour while we were working on the system. In case you need it this was what it says …*

   ERROR: MySQL said table 'ihams –art intake' is marked as crashed and should be repaired.

I have copied the folder containing the data following your instructions and have attached it to this message. I hope you will look into it and come up with a solution soon.

Thank You!

The following are some of what we communicated after the aforementioned problems were fixed:

Date:	Tue, 5 Dec 2006 15:25:25 +0000 (GMT)
From:	"mekitew letebo" <mekitt77@yahoo.com> Add to Address Book Add Mobile Alert Yahoo! DomainKeys has confirmed that this message was sent by yahoo.com. Learn more
Subject:	Thanks!
To:	"hailu as" <hailu_ache@yahoo.com>, "mulugeta al" <mulugetaalemayehu@yahoo.com>

Hi guys,

Thanks for your immediate response. I have finished entering the lost data and checked the reports against the number of patients we entered. Everything appears to be okay.

mekitew

Date:	Mon, 18 Dec 2006 08:36:41 +0000 (GMT)
From:	"mekitew letebo" <mekitt77@yahoo.com> Add to Address Book Add Mobile Alert Yahoo! DomainKeys has confirmed that this message was sent by yahoo.com. Learn more
Subject:	Hi
To:	"mulugeta al" <mulugetaalemayehu@yahoo.com>, "hailu as" <hailu_ache@yahoo.com>

Hi guys,
How are you? I hope you are done with the cohort report. I am sending you an excerpt from my research diary which contains some stuff that should be addressed before I leave for the two sites. ... We continued data entry at Awassa referral hospital. I also tried to compare the first month reports to the manually prepared ones. There were some discrepancies. They were due to some reasons discussed below: … No one is going to accept our system if the manual system should still be used for some of the tasks.
Hoping to hear from you soon,
Mekitew,

After some of the problems he was referring to were addressed, he wrote the following to the professor in chapter 3 who supervising us and also him:

Date:	Thu, 28 Dec 2006 13:58:09 +0000 (GMT)
From:	"mekitew letebo" <mekitt77@yahoo.com> Add to Address Book Add Mobile Alert Yahoo! DomainKeys has confirmed that this message was sent by yahoo.com. Learn more
Subject:	proposal
To:	"Sundeep Sahay" <sundeep.sahay@gmail.com>
CC:	"hailu as" <hailu_ache@yahoo.com>, "mulugeta al" <mulugetaalemayehu@yahoo.com>

Dear professor,

I hope you have arrived safely. Attached here is the proposal we submitted to AARHB. I am now in Butajira. I got updates from Hailu and Mulugeta and then installed the system in the clinic here, conducted my interviwes and got my questionnaire filled out. The data clerk is very much excited about it. We have started data entry and made the matching with the patients we entered. The reports matched perfectly. He was able to examine each possibility and each variable in detail. He was very happy with the results and promised to continue data entry. He is probably the first person to thank us to the extent I had expected. We will complete entering a one month data by tomorrow and I am planning to leave for the other site immediately after that to buy some time for the work in Addis.
Regards!

While the system development was still going on, similar attempts were made by us and some of the HISP research members (mentioned in chapter 3) to take the system to regions other than Addis and SNNPR – Amhara, Oromia, Benishangul, and Somali. However, as discussed in the next section, they all ended up unsuccessfully. Nevertheless, we have in general worked as a team in different regions and on various tasks such as getting the clerks involved, making the system learnable and easier to use, and convincing users at various levels (including the regional manager) of the usefulness of the system. This helped to a certain degree to deal with the challenges of resistance to the system which we faced at various levels from clerks to influential stakeholders during implementation and scaling up efforts.

In summary, a cultivation approach was used to gradually improve the system and address the various socio-technical challenges encountered during the development process. As strategies to realize the cultivation approach, the clinic staff were made to participate in the process through evolutionary prototyping and incremental approaches. This was useful as it helped to effectively develop the system by gradually improving the workflow and incorporating basic functionalities. The incremental functional scaling of the system was also an important process to make it serve the diverse needs of the health workers in its vicinity and, with this, to embed it organizationally. Furthermore, these incremental approaches were used to simultaneously develop and gradually mature political relationships for subsequent implementations.

Table 7.2 below summarizes the key activities in the development process.

<table>
<tr><td colspan="3">Activities: Improving workflow, Incorporating basic functionalities, Functional scaling</td></tr>
<tr><th>Activates under Improving Workflow</th><th>Activates under Incorporating the basic functionalities</th><th>Activates under Functional Scaling</th></tr>
<tr><td>▪ Multiple points of data entry of manual work removed
▪ Redundancy avoided and consistency secured
▪ Data capturing time reduced</td><td>▪ All data capturing formats were designed with edit facility
▪ The logic of all required reports was put in place
▪ The system was designed in an easily learnable and time saving fashion:
o Logic and workflow of the manual work was somehow replicated
o Arrangement of data elements on data capturing formats were made similar to the paper formats; and same for reports
▪ Ease of use of the system was considered to save data capturing time:
o Combo and check boxes were used to reduce typing work and increase data quality
o Many data elements from past follow-up were made to be automatically replicated</td><td>▪ Dynamic cohort analysis (entire history of a group of patients from ART start time to current month) was made possible, not just after 6,12, 24 months as it was in the “official” requirement
▪ Reports were made to be generated for any time period, not just monthly as in the “formal” requirement
▪ Complex searches were incorporated
▪ System evolved in such a way so to meet diverse needs at different levels:
o At doctors’ level Eg.
• Individual patient’s progress report depicting entire history of the patient from first day till current day of treatment was made presentable to a doctor in a ready made and organized manner
o At clerical level Eg.
• Quick quality reports
• Searches based on follow-up date and other</td></tr>
</table>

	to the current month whenever applicable o *Follow-up and intake forms were made much more easily manageable and understandable than they were in the paper system* o *Strengthened validation to increased data quality* ▪ Other basic functionalities were incorporated: o *Simple and basic search options were provided* o *Color codes were used to easily differentiate patients' status* o *Links were provided to go anywhere form any page* o *A page was created from which a clerk can easily find every important information about a patient (eg. all follow-ups, intake data, and the patient's and his/her caregiver's addresses)*	*important criteria interesting to them* o ***At clinical level Eg.*** • *Lost/drop out patients were made to be displayed with the patient's and caregiver's addresses* • *Poor adherent patients were made to be displayed with the patient's and caregiver's addresses* • *Mechanism was created for clerks to sum up pediatric and adult reports* • *Data quality checker was incorporated* • *Functionality to see the number of new cases (dead, lost, drop out, stop, restart, and on treatment) in a month was created* • *Systematic archiving of formats exactly like in the manual system was created* o ***At Regional level Eg.*** • *Analysis tools helpful for the health bureau were incorporated such as to identify stabilized patients and the nearest health facility to their residence*

Table 7.2: Summary of key activities of the development process

7.3 Implementation

In this section, we discuss the different challenges we came across while trying to accomplish implementation activities and the strategies we adopted to address them. We start the discussion by describing what served us as the basis for implementation and then focus on some issues which were involved in realizing implementation. With respect to these issues, a measure of comparison is made on the efforts exerted in Addis with those in the other regions.

Basis for Implementation

As soon as the regional program manager, an influential person who played a vital role in the overall process, laid the foundation by granting us access into the area, we installed the prototype that created the initial basis for the realization of the actual implementation. We were initially allowed to install the prototype in 3 clinics in Addis Ababa region. But, as pointed out in section 7.2, we could do so only in 2 of them (at Menelik and Zewditu Memorial Hospitals). This was because, despite the securing of a formal permission for installation, we encountered challenges from a clerk in one of the clinics who complained about the prototype to the regional program manager. The regional manager suggested that we leave her alone and work in the remaining two hospitals until the system matures. We also got the unique permission to access real patient data. The complex setting of Zewditu not only gave us the representative picture of the problems in the program and the significant role that an IS could play in alleviating some of these problems, but also was important to enroll more actors into our network as the clinic staff was desperately looking for a system to help address the problems they were experiencing day to day.

After we installed the prototype, the clerks in these clinics typically recommended the hiring of some of their friends for the data entry work, which we did beginning from May 2006. This helped us to strengthen their favorable attitude towards us, and also to informally keep the data secure. Our hiring of the assistant data clerks immediately, though trivial it might seem, was a very crucial turning point to practically initiate the implementation process at an early stage of the project. Had we not done so, the work wouldn't have gone thus far since the regular data clerks said that they are too busy to carry out both the manual work and the system in parallel. We would then need permission and resources from the regional bureau to hire more clerks, which may have not been easily forthcoming. After we ourselves hired the assistant clerks who started the entry of real patient data right away, however, people started to value the system and consider the project as a real one, and this helped to gradually enroll more supporters of the project in our network.

For instance, as data entry went on (see Figure 7.10), some of the remaining clinic staff who were indifferent at first started to see the usefulness of the system. For example, when the head of one of the clinics observed that the system had eased the work of the nurses, for example while searching patient records, she started to communicate with us in a more substantive way and started to express her other major concerns such as around reporting and appointments scheduling. In addition to the clinic staff, we also made the IT team of the regional health bureau become part of the network by inviting them to see what is going on around the system and how it was benefiting users especially at Zewditu.

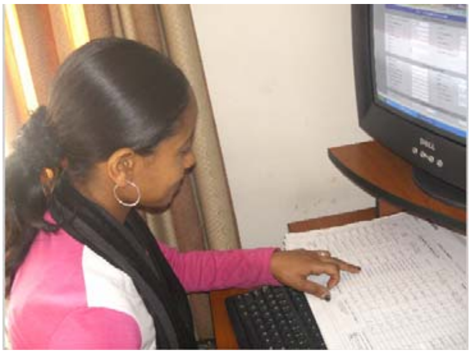


Figure 7.10: Data entry going on in one clinic by an assistant clerk

Nevertheless, it was not the mere enrollment of these actors which made the difference in implementation. Once we got these people from different administrative levels – lower, middle, and higher – into the network, we had to work more to build their trust in us and gain more political support.

> *"…That this system fails means I failed. …"* – A data clerk to the research team

The process of data entry was not only a means of cultivating the system but also helped develop a social glue between us and the health staff and secure their trust in our intentions which provided the basis for future success. Though negative by itself, the absence of formal requirements documentation gave us room to work closely and on a personal level with the data clerks and the rest of the clinic staff. Since there were many things which we could not understand just by analyzing the documents (data capturing and reporting formats), we depended on them for explanations of these issues. This would not have been possible through formal channels. Besides working on weekends in their place, we sometimes needed to invite the clerks to come to our working place, which helped to stimulate mutual learning, develop stronger social glue, helped us to understand the logic of their work, and build the confidence of the clerks in us when viewed in the context of our overall HISP team.

> *"…Most of the people coming with the systems just talk and go …They just give you the system and go away telling you to start using their system … Different people talk different things about systems, and promise to bring… system …. All their talk is practically zero. …I have learnt that system development and implementation is a practically hard process anyway. …"* – A data clerk to the research team

Figure 7.11: Discussion with a clerk and some of the clinic staff

Figure 7.12: Discussion with the regional health bureau's IT team

Our frequent presentations, demonstrations, and meetings and discussions with the different health staff – clerks, the clinic head, and the bureau's IT team (see Figures 7.11 and 7.12) – were also other opportunities of gradually developing social glue and building trust. For instance, by making use of presentations and demonstrations, we taught the IT team about the workflow and the requirements which made them happy since they initially had limited idea about it. In addition to strengthening our attachment with them, we used some of the informal social gatherings with the IT team to let them know some facts about us such as our using of open source software, web-based tools, and that HISP-Ethiopia program based in Addis Ababa University which could help to ensure the provision of continuous and sustained support. Moreover, our working closely with the health staff helped them to better understand the complexities of the ART system, and better appreciate our efforts.

When cultivating the system while the data entry was going on, we collected feedback from the clinic staff and the IT team. This opened ways for them to participate and be part of the overall process, and also to strengthen the quality of the system development work. We incorporated in the system many of their needs that we found from their suggestions, which was appreciated and also strengthened their sense of ownership and belongingness of the system. For instance, when discussing about if our system fails for some reason, a clerk went on to the extent of saying:

> *What do you mean? You worked all the time with me. I even asked others some questions which I couldn't answer when you asked me. And you knew the work very well now. … So, that this system fails means I failed. Just keep working, forget the politics. I believe no other system compares yours.*

A clerk related her existing experience with us as compared to earlier attempts by the bureau to introduce other systems:

> *I have seen about four systems so far. Most of the people coming with the systems just talk and go showing some things on the system without making any effort to work with us, to understand our problems in detail, and to help us. They just give you the system and go away telling you to start using their system without even properly demonstrating the systems. For one of the systems, I started some data entry. I just evaluated using my little IT knowledge and discarded it. … This system is not perfect too but you have always been working with us and I understand the system very well. For others, they all bring me a system at the end of their work and want to try the system on me. On this one, however, it is not only me but also the doctors, you, the nurses, the head … all participated. That is why it reached here. Even if you were not trained on the manual system, you could understand because of me. … Different people talk different things about systems, and promise to bring us system on this and that day. All their talk is practically zero. … Some of them, even if they have system, they are afraid to install here in Zewditu. Why do they fear? They should not. They simply call it software. Of course, I know why they are afraid. They know that our*

data is much and their software [Access-based] is not capable of holding all that. … Other systems do not accept much data but this one it takes in thousands which, I think, means it is good. As a computer science student, I have learnt that system development and implementation is practically a hard process anyway.

Features	"Official" requirements	Value added features
Data Capturing	▪ Multiple points of data capturing – Intake form, Follow-up form, Pre-ART register, and ART register	▪ Data captured only from intake and follow-up ▪ Data capturing time was reduced o *Combo and check boxes were used to reduce typing work and increase data quality* o *Many data elements from past follow-up were made to be automatically replicated to the current month whenever applicable* o *Follow-up and intake forms were made much more easily manageable and understandable than they were in the paper system* o *Strengthened validation to increased data quality*
Reporting	▪ All the standard reports: Monthly Pre-ART report, Monthly ART report, Monthly Regimen report, Cohort report – 6, 12, 24 months analysis	▪ All the standard reports (now quick and quality) plus: o *Dynamic cohort analysis (entire history of a group of patients from ART start time to current month) was made possible, not just after 6,12, 24 months as it was in the "official" requirement* o *Reports were made to be generated for any time period, not just monthly as in the "formal" requirement*
Others	▪ Other "official" facilities required– edit, appointment scheduling, basic search, transfer out approval letter	▪ All the "official" requirements plus: o *Complex search options were provided* o *Editing was made much cleaner* o *Color codes were used to easily differentiate patients' status* o *Links were provided to go anywhere form any page* o *A page was created from which a clerk can easily find every important information about a patient (eg. all follow-ups, intake data, and the patient's and his/her caregiver's addresses)* ▪ Specific needs of people at different level were satisfied: o ***At doctors' level Eg.*** • *Individual patient's progress report depicting entire history of the patient from first day till current day of treatment was made presentable to a doctor in a ready made and organized manner* o ***At clerical level Eg.*** • *Quick quality reports* • *Searches based on follow-up date and other important criteria interesting to them* o ***At clinical level Eg.*** • *Lost/drop out patients were made to be displayed with the patient's and caregiver's addresses* • *Poor adherent patients were made to be displayed with the patient's and caregiver's addresses* • *Mechanism was created for clerks to sum up pediatric and adult reports* • *Data quality checker was incorporated* • *Functionality to see the number of new cases (dead, lost, drop out, stop, restart, and on treatment) in a month was created* • *Systematic archiving of formats exactly like in the manual system was created* o ***At Regional level Eg.*** • *Analysis tools helpful for the health bureau were incorporated such as to identify stabilized patients and the nearest health facility to their residence*

Table 7.3: Value added features helpful to gain trust

Most importantly, because we had a good database with real patient data while we were cultivating the prototype, we could discern what was needed to be done to satisfy the specific reporting needs of different levels of the health staff. Hence, in addition to merely meeting the “official” requirements, we incorporated various value added features which impressed these people (see Table 7.3). As system development proceeded, the clerks and the IT team started to ally with us, since they found that they could discuss their problems with us, and this mutual sharing process helped to instill trust in the relationship. This contributed to them taking ownership of the system. This also strengthened our political backing as they gave positive feedback about the system to their regional manager. This positive feedback, plus regular demos to the regional manager displaying steady improvements, and that we were rapidly responding to his various improvements, made him also feel a stronger sense of ownership, and refer to it as “our system.”

After data entry was carried out for one month particularly in the two clinics, we compared and contrasted the reports generated from our system with the manual reports. Nearly a 99% matching of figures was seen, and errors were mostly identified due to illegible handwriting or data entry mistakes. The logic of the computer system was accepted to be correct, thus helping to further build the users' sense of trust in the system (see Figure 7.13). So both on the technical and social fronts, we inspired confidence in them.

Figure 7.13: Discussion while data entry is going on

In addition to our different activities in relation to system development, onsite training, and implementation interventions, we played multiple other roles towards making the system work. For example, we had to help the regional health bureau by making presentations on their behalf to different stakeholders (such as donor agencies and federal authorities) to strengthen our political support. At an early stage of our work we had to provide many explanations about the workflow of the ART program and the problems of the manual system to the IT team who were unaware of the issues at that time. We also needed to progressively manage the expectations of the bureau by clarifying that system development is a gradual process and incorporating new functionalities will take time. Moreover, we acted as consultants while providing in depth explanations, for example, about the pros and cons of different development technologies to both the IT team and the program manager. The bureau had rather general ideas about the benefits of using computers, but did not understand the details very well such as how the problem of poor data quality is related to the deeper problem of the lack of a unique identifier. Building this awareness and knowledge was an important part of our work.

Besides these, we were also involved in bringing practical changes in the work procedures at the clinics to enable the data entry process. For instance, the clerks were very sensitive to any additional work assigned to them. A clerk said:

> *We don't have to bring card from doctors' rooms. The nurses working there should bring us. We can use the time to do some data entry if I am also working on the system.*

We have, accordingly, arranged this and it has remained to be the culture in that clinic. Furthermore, discussions with the doctors also enabled changes in the way the nurses filled the follow-up cards while the doctor was treating a patient. Since there was large number of patients in one clinic, the doctors and the nurses felt that filling the next follow-up dates column was meaningless as it was not possible to search the patients manually using these dates. As a result, often patients had to wait long times for their turns, and sometimes were even sent back untreated violating the rules of ART adherence. With the system in place, we made the staff fill the next visit dates on the system so that it could be practically used for managing patient visits. Moreover, we also initiated the clinic staff to start actually using the system sooner, for example to search patient records, which made them value the system more.

On top of these, we provided supervision and support services to clerks while data entry was going on. A clerk appreciated our support as follows:

> *It is because you are close to us that this work is continuing so far. When we call you, you come immediately.*

Table 7.4 below summarizes the basis for system implementation.

<table>
<tr><td colspan="3">Basis for implementation: Getting clinic and bureau staff involved, Establishing and developing social base and building trust, playing multiple roles</td></tr>
<tr><th>Ways to get clinic and bureau staff involved</th><th>Ways to develop social glue and trust</th><th>Multiple roles we played</th></tr>
<tr>
<td>▪ The regional program manager
o By means of the reputation of HISP work on DHIS in the region
o The link the local HISP team previously established with him
o Repeated discussions, presentations, and system demonstrations to him
o Incorporation of his requirements in the system
▪ Clerks and other clinic staff
o Hiring of the clerks friends as assistant clerks for data entry
o Working closely with them
o Repeated discussions, and system demonstrations to them
o Onsite training
▪ Bureau’s IT team
o Inviting them to see the system as used in the clinics
o Repeated discussions, and system demonstrations to them</td>
<td>▪ Data entry and getting the system start functioning
▪ Working closely with the clinic and bureau staff
▪ Our being inquisitive and knowing the ART program in depth
▪ Frequent presentations, demos, meetings and discussions
▪ Collecting feedbacks from them and showing them that they are incorporated
▪ Verifying the correctness of the reports from the system</td>
<td>▪ System study, development, training users and implementing
▪ Helping the regional health bureau in dealing politically with other stakeholders
▪ Clarifying the different aspects of system development and implementation to the bureau staff as they lacked previous experience on these issues
▪ Clarifying the ART work and the problems in the manual work to the bureau staff
▪ Bringing procedural changes in the clinics to facilitate data entry and use of the system
▪ Providing supervision and support services during data entry</td>
</tr>
</table>

Table 7.4: Summary of the basis for implementation

By and large, the initial installation of the prototype in the two clinics where it was possible to do so, our immediate hiring of the assistant clerks, and practically initiating the data entry process, all together facilitated the improvements in the prototyping process. We provide below some specific details about the dual significance of this:

1. *In relation to development* – it helped us to elicit and better understand the full requirements of the ART program based on which we gradually cultivated and improved the system. As we progressively demonstrated its different features, people at different levels started to value the system more, and simultaneously better acknowledge the problems in the manual system.
2. *In relation to implementation* – it served as a basis for further implementation. Our playing multiple roles, helping the people at different levels such as by providing functionalities interesting to them, and progressively verifying the correctness of the logic of the system, made the people involved develop trust in us and the system. Positive feedback received from these various sources also helped to improve the political backing for our system, and hence for subsequent further implementations.

Realizing Implementation

Given the above mentioned basis, the system was further installed in a total of 10 different clinics in Addis Ababa and SNNPR (see Figure 7.14) with the simultaneous maturing of the prototype. This initial scaling up of the system to these different clinics was made possible by making use of individual resources such as our scholarship as masters and doctoral students and HISP project support.

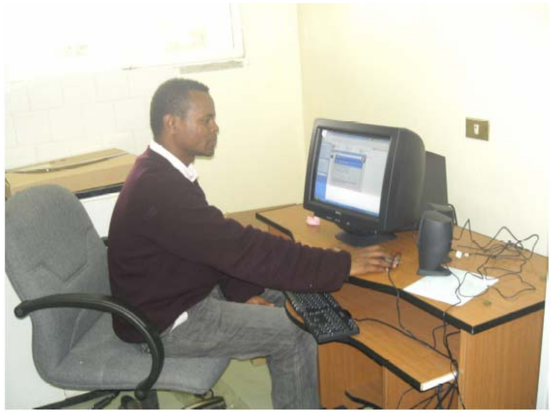


Figure 7.14: Installing the system in one clinic in SNNPR region

We had different experiences from these efforts. In three of the clinics in Addis where we implemented the system, data entry was taking place smoothly and the system was being partially used. We were also working towards making the system fully functional but continued to experience certain challenges. For instance, while the reporting functionality was fully in place, it was not properly used because of the skepticism around the quality of the paper data. However, cleaning of data manually was an extremely complex and time consuming task, something which we were not fully equipped to do. It was also very difficult for us to continually financially support the data entry cost, which was a fundamental precondition to carry out data quality checks using the system.

In each of the clinics at Awassa, Hosana, and Butajira in the SNNPR region where the system was introduced, the SNNPR implementer could succeed initiating data entry processes. He also confirmed to a clerk at Butajira, as he said, a "100 % matching" of the system generated and manual reports. Comparing to us his experience with that of Addis Ababa where he also spent some time with us, he commented in an e-mail:

"…The situation in Zewditu was probably the other extreme. Too many patients and long duration of the service, and thus exceedingly huge backlog data; the associated poor data handling and improvised approaches to information management; … were among the problems I witnessed during my observation in the clinic. These, I believe, were – and probably will remain to be – setbacks to the implementation work there. Honestly speaking I am very much concerned about the prospects of our efforts in that particular clinic. …" – The SNNPR implementer to the research team

The implementation in the SNNPR as compared to that in AA [Addis Ababa], especially Zewditu, was less complicated. The lessons from my observation in Zewditu were invaluable in informing the implementation in SNNPR. There, I had chosen clinics that are manageable in terms of the size of the backlog data. So data entry was not a big challenge. In general I found Butajira to be an ideal environment to implement and use IHAMS-ART: the clinic had only about 400 patients; data handling was fairly good; the data clerk was very excited to have a system and was able to learn the ins and outs of it very fast; and he was also able to challenge some aspects of the system. Besides, I didn't have to pay the clerk for the data entry. In fact, he was enormously grateful for the offer. I was surprised to find him entering data when I visited the clinic for a second time without prior notice. On the whole, I had nothing to complain about the implementation there except that I couldn't offer a fully functional system despite my promise to do so.

The situation in Zewditu was probably the other extreme. Too many patients and long duration of the service, and thus exceedingly huge backlog data; the associated poor data handling and improvised approaches to information management; data entry being conducted by an individual who didn't have any experience of the work; and lack of hardware were among the problems I witnessed during my observation in the clinic. These, I believe, were – and probably will remain to be – setbacks to the implementation work there. Honestly speaking, I am very much concerned about the prospects of our efforts in that particular clinic.

Nevertheless, despite the financial constraints and other challenges of implementation, users of the system have appreciated the successful functioning of the system especially as compared to what they experienced in the past. This appreciation is reflected in the following quote from a clerk:

> *"…The two systems are different like the heaven and the earth. …"* – A data clerk to the research team

As for me, the system is very important as we are enrolling up to 50 new patients every month. At first it was not clear for me as I was not trained well but now it is very good as you are helping me. …The two systems are different like the heaven and the earth. Whereas for the other system [Access-based system from JHU] you need the manual system to run in parallel, this one is simple to use and complete and you don't need the manual system with it. … They [JHU] told me only on the phone that a system is already installed in my machine without my knowledge and they asked me to start using the system. They never worked with me and showed their system like you are doing now with me. They never even visited me except one day after I did data entry of 250 patients. As the system focuses only on some important variables, it was easy for me to start data entry without their help. But all of a sudden they called and told me again to stop using their system, I think because of your system and the health bureau warned them for installing without being formal.

News about the successful working of the Addis system spread through the informal network of staff from the different health bureaus, and also by means of conferences and workshops which we attended. Other regions such as Amhara, Somali and Benishangul, also faced with similar pressing problems relating to ART management as in Addis, also started to approach the HISP team to come and implement their system. In certain cases, like in SNNPR region where, as mentioned above, there was an implementer who attempted to formally deal with health officials in the region (see chapter 6), we could successfully install the system in some clinics. In others, we were thwarted due to various reasons. For example, by the support of a HISP employed researcher who was working around DHIS in Oromia region, we got formal permissions from the regional health bureau to pilot the system in some clinics in the region. But, at the last minute, this permission was cancelled when the region realized that Columbia University was also supposed to be doing a similar project. Interestingly, the bureau had not known about this effort, indicating that the university had started this work without the regional bureau's permission, probably on the behest of the Federal level. Nevertheless, though we were allowed to pilot in still other clinics in that region, we were discouraged because, apart from other reasons, the clinics were found in remote places where finding transportation is hard as the roads taking to there are too rough (see Mekonnen and Lagebo, 2005).

In another region, Amhara, we were again invited to implement the system in 28 clinics, but because of the travel costs involved, which the region was unable to support, we could not start there. Financial support was not forthcoming, because the request for the system had come from a clinic level staff rather than a decision maker. Nevertheless, had there been adequate resources, we believe that the interests displayed at micro-levels could have been exploited to mobilize political backing so that the system is implemented at least in some clinics in these regions as was the case in SNNPR. However, we did not have the human resource to make the necessary, particularly political, deals in these regions though only limited effort was exerted in Amhara region for some time by the doctoral student mentioned in chapter 3. Likewise, very little efforts were exerted by us and the other members in HISP to take the system to Somali and Benishangul where similar interests were displayed from micro-levels.

Moreover, the allocation of clinics to American universities was not convenient to the effort of spreading the system. CDC (Centre for Disease Control), within the framework of the US aid regime, had divided the country into four regions (not necessarily corresponding to the Ethiopian administrative boundaries), and assigned four American Universities to each administer one "region". For example, Johns Hopkins University (JHU) was responsible for some ART clinics in Addis Ababa, some in SNNPR region, and others in Gambela region. This division was problematic as it implied the need for different regional bureaus and stakeholders to get involved and magnify the political situation surrounding our implementation endeavors. Given the relatively decentralized governance structure of Ethiopia, it may have contributed to the situation in Oromia where the region was not aware of the activities of Columbia University. Furthermore, we were told by the CDC manager in Ethiopia that funding requests for region specific activities needed to be routed through these American universities. As a result, we felt the local national university (Addis Ababa University) which hosts HISP and our project was being marginalized at the expense of the American ones. Maybe that is but the reality of international aid.

Nevertheless, our being resident in Addis made differences especially as compared to the implementation efforts in other regions. It enabled us to play the multiple roles required, to provide close and continuous support, and to make the necessary deals with respect to the interconnected micro- and macro-level socio-technical-political issues prevailing in the development and implementation processes. Various political challenges were particularly continuously faced and needed to be addressed in this region, for example convincing stakeholders such as JHU who were keen on promoting their own system, and sometimes diverse agendas (see section 7.4). While distance, infrastructure, and other socio-technical issues such as lack of human resources to make the necessary deals for implementation were issues in the other regions, probably the political pressures were less extreme than in Addis where all the major stakeholders were active. Still, as opposed to the case in Addis where we made a measure of further scaling up possible despite political challenges (see the next section), failure to deals with the political conditions prevailing in these other regions hampered the system form being scaled up to more clinics there.

In summary, with respect to both development and implementation gradual and incremental approaches were used to address various socio-technical-political challenges, to cultivate the system, to enroll different health workers by meeting their diverse needs which also helped to embed the system institutionally.

7.4 Scaling up

As in the cases of gaining entry and implementation, scaling up the system has also been surrounded by various considerations especially political ones. This section presents the different stumbling blocks around the effort to making a large scale implementation of the system specifically in the Addis region, and how we tried to step over them. When discussing political challenges, we especially focus on the rivalry we had particularly with one ART partner in this region.

Struggle for MOU

With respect to scaling, we decided to keep our focus in Addis Ababa region, and pursue horizontal scaling (a vast scale implementation in more facilities within the region) more actively than to other regions. This decision was due to our resource constraints to make the necessary deals in other regions and the need to also try and finish our thesis on time.

Even so, without proper funding for data entry, the clerks in Addis did not feel fully responsible to make the change over to the system. Due to this and other various issues, we were forced to stop the data entry process in one of the clinics, as we felt the regional bureau should instead be responsible for funding this process. Different stakeholders through various independent initiatives tried to introduce computers in different corners of the clinic thus significantly contributing to the fragmentation of systems. The missing coordinating role we felt should be played more actively by the regional health bureau.

> *"…Why is it that we are not directly consulted about evaluation and selection of systems? After all, it is we who are ultimately using the system whatsoever. We know who is practically helping us. …… We should be involved in system selection. Others don't know our problem. …"* – A clinic head in a system evaluation meeting

Given this setting, the Addis program manager formally tried to evaluate our system with various other competing ones in the presence of important stakeholders from the federal ministry, national HAPCO, and some American universities. These guests were given the evaluation criteria prepared by the bureau's IT team, which was criticized by another system owner who claimed that it was biased towards the HISP system. After the presentations, the attendees had varying opinions, for example, a data manager from national HAPCO said:

> *The other time I saw your system at Zewditu, it was not like this. You are keeping changing the system [to mean your system is not stable].*

Another bureau staff who chaired the evaluation meeting, said:

> *I am not sure what is behind these evaluation criteria. … I think we better establish a committee to reevaluate the systems.*

> *"…These people may be buying out more time … We should now move forward aggressively. …"* – The regional HIV/AIDS program manager to the research team

A clinic head (also a medical doctor) with whom we had worked for a long time, supported us arguing:

> *Why is it that we are not directly consulted about evaluation and selection of systems? After all, it is we who are ultimately using the system whatsoever. We know who is practically helping us. These guys have always been with us for a long time and we know how much they exert their effort in this work without personal benefit. Our work has become very easy because of them. When we want to search something now, we find it immediately. And we know how much they will help us in the future. We don't anymore want people to give us software and run away tomorrow. … We should be involved in system selection. Others don't know our problem.*

The meeting ended up inconclusive, and the chairman decided to establish a new evaluation committee in two weeks time. The regional program manager, who could not attend the meeting, subsequently told us:

> *We gave them this chance only to see if we can get a better system. We have been working with you formally up till now. I can't see why we have to involve ourselves in such a mess. I think we better sign MOU with you to solve all these problems.*

> *"…As a team work, we know that your system is much better than others' and we will definitely go for its launching soon anyway. But we were afraid of being blackmailed as others might use their hidden power to hinder our progress. …"* – The regional HIV/AIDS program manager to the research team

Accordingly, a MOU and an accompanying implementation plan was prepared and scheduled to be signed the next day by HISP-Ethiopia and Addis Ababa City Administration Health Bureau. Yet, things did not happen as expected, and the program manager's plans for the MOU were strongly criticized by JHU who claimed to have their own working system. They argued "if the system works at Zewditu, it must be sick." As a result of such and other criticisms, the program manager had to suspend the decision on the MOU and also needed to include some of the other systems in the evaluation. We objected against making another presentation, as we felt that we had made enough of them, and the bureau had the necessary information to make whatever decision they wanted. Stating where we stand, we presented to the program manager the following three options:

- let the bureau use its power to take a final decision on system selection. We don't have time to wait because of our academic responsibilities.
- let the case be suspended till we come back after completing our studies, or
- let the systems be tested with real data at Zewditu, and not in the artificial conditions of a demonstration hall.

> *"…They are supporters. They are just meant to help the bureau in the area it seeks their support, not to dictate and do whatever they wish to do. …"* – Regional health bureau's IT specialist to the research team

The program manager disagreed with the second option as he said they "desperately need a system now". He said:

> *As a team work, we know that your system is much better than others' and we will definitely go for its launching soon anyway. But we were afraid of being blackmailed as others might use their hidden power to hinder our progress. All what I wanted was to give them a single chance just this time so that they can see that we did not accept their system merely because their system is not as capable as yours, and there is no other reason behind. Otherwise we know that we can use our power to decide as you said. After all, you have always been formal with us throughout. When I told the taskforce in a meeting how the work started and is going on under our supervision, they even said "it is an appreciable process." … I think we have done wrong even in inviting that man to demonstrate his software. Our motive was humble but things are taking different form now. … I will now listen to all what you are saying after this. So I think we can decide. Why do we go into all these unnecessary complexities? Let us go ahead for the MOU; that will help to quit all the problems we are experiencing now. As you said these people may be buying out more time to come up late with their other system. We should now move forward aggressively.*

The processes were unclear, and we were not sure why, if our system was selected, the bureau wanted JHU to support the implementation, despite being our competitor for the system. In a meeting with the program manager and the IT team, the IT specialist of the bureau said:

> *They are supporters. They are just meant to help the bureau in the area it seeks their support, not to dictate and do whatever they wish to do.*

> *"Let us go ahead for the MOU; that will help to quit all the problems we are experiencing now."* – The regional HIV/AIDS program manager to the research team

Ultimately, after a very long process, we signed a MOU in March 2007 with the Addis Ababa City Administration Health Bureau to scale up the system in a phased manner to all 67 ART clinics in the capital, including government hospitals and health centers, federal hospitals, private hospitals, and NGO clinics. The bureau has also sent a letter (signed by Federal HAPCO) to all the federal hospitals in the region so that they can support the implementation. At the same time, though ended up unsuccessfully, through other team members, a measure of attempt was also made to get a MOU signed in Amahara region, while the regional program manager and the IT specialist made arguments in relevant circles to make the system a national one. With the political legitimacy provided by the Addis MOU, and our continuing improvements to the system, we believe the potential has been created for our system to gain a national recognition. But the political battles still remain to be fought with along the way. Some of these challenges are now discussed.

The Aftermath of the MOU

Implementing the MOU plans involved mobilizing costs of implementation, including employment of more data clerks, training, data entry, and backlog data cleaning. JHU which receives fund from CDC was directly responsible to provide the necessary support in question in the Addis region. So the bureau sent the implementation proposal to JHU (and also to the ministry, federal and Addis Ababa HAPCOs) while expecting a quick reply. Meanwhile, after the signing of the MOU, JHU had sent their M & E deputy country director to see our system in the field without taking requisite permission from the bureau. The clerks thus refused permission for the JHU staff, a decision which was not taken very kindly by JHU.

In the mean time, as per the schedule in the implementation proposal, we started executing the plans by conducting a walkthrough of the system at Gandhi Memorial Hospital with the bureau's IT team, in order to test the system with live data before scaling, and to recheck the effectiveness of all the functionalities of the system.

> *"…I saw a yellow light on the manual system. …"* – Regional health bureau's IT specialist to the research team

After doing the data entry, discrepancies were observed which we argued with the IT team, were not due to the logical incorrectness of the system but primarily due to data entry mistakes (such as filling of wrong date) committed by the clerk. To attest this we had to literarily sit down full time continuously for three weeks with the IT team manually counting the records and tracing the discrepancies. Although we were dealing only with one month data of a small clinic chosen for the walkthrough, the IT team told us that it was a very painful experience for them. Three outcomes arose from this walkthrough session:

1. We confirmed the logical correctness of the system to the IT team and dispelled existing doubts which some members had towards the system. The nature and underlying reasons for the data quality problems were emphasized, and an IT specialist later admitted:

   When I worked with you on the walkthrough of the system at Gandhi and verifying the reports from your system and the manual system, I saw a yellow light on the manual system.

   Based on various discussions and feedback, we still incorporated some additional functionalities to deal with data quality issues (see chapter 8).
2. The IT team was convinced about the need for conducting intensive formal training to the clerks before starting the use of the system.
3. The team also acknowledged, more than ever, the urgency of putting the system in place before the problem gets out of hand even in the smaller clinics.

> *"…Unless they invent software that accepts data and cleans it by itself we will use your system. … All of us are well aware that a system built with all these make up of expertise is far superior than a system developed by one developer however intelligent he is. …"* – The regional HIV/AIDS program manager to the research team

While these events were happening, the country director of JHU asked the program manager to see the system demonstrated to his team so as to support the implementation process in Addis and also SNNPR region for which they were also responsible. Being a non-technical person, he believed that JHU had already invested a lot in a new system, and thus without demonstration, he said, it will be difficult to get his staff to accept an external system. We were once again requested by the regional program manager to demonstrate the system to them. Discerning that we were reluctant to do so, he comforted us in different ways (see section 7.6).

Figure 7.15: Discussion after system demonstration

We then agreed and the demonstration was conducted in April, 2007 at the conference hall of JHU office and attended by the JHU technical team and other staff, some members from the international HISP team, bureau staff including the program manager and IT team, and other JHU invitees including a USAID's ICT consultant in East Africa (see Figure 7.15). In addition to demonstrating all the features of the system, we also discussed the technologies used in the development.

Three outcomes could be inferred from the demonstration:

1. **System was "accepted"**

   People did not have any serious complaints except asking why we incorporated all the data elements as in the paper formats, a question responded to by the program manager. Many of the audience appreciated our efforts, and a JHU attendant said that "it is a work to be commended."

> *"…To have a software product is easy. The actual challenge is the implementation and how to get the product actually used. …"*
> *"… Implementing software in Ethiopia is a really, really big challenge. …"* – Two JHU staff members in a system demonstration meeting

2. **Concerns about implementation**

Concerns were raised about our capability to overcome the implementation challenges including the cleaning of backlog data and creating skilled human resources to carry out the tasks. Two JHU staff members said:

> *To have a software product is easy. The actual challenge is the implementation and how to get the product actually used.*
>
> *Implementing software in Ethiopia is a really, really big challenge.*

The JHU country director proposed collaborative work with us:

> *By collaborating with us you can have three different angles when you say ART. We have a lot of experience on the manual system and on system implementation.*

The program manager complemented this by saying:

> *If we do something good here in Addis it is a reputation for the federal ministry and if we fail …*

3. **Concerns about JHU's system**

Another concern JHU emphasized was what to do about the data in their Access-based system implemented in some clinics in the region. The deputy country director explained the origins of the system as follows:

> *It was developed just to reply to CDC's urgent call of enabling the data clerks analyze their data. … As I told you [the research team] the other time on the phone, we don't even call it a system or software program. It is just something that we want it help us alleviate the problem. …But we have invested so much money for the system and its implementation and we don't want it to be for nothing. We should at least secure the data.*

We promised to take the responsibility of migrating all the data from their system to ours. The program manager tried to strengthen the JHU staffs' confidence in us by saying:

> *At first I stopped these guys form going on to study because the ministry said a system is coming. But, after a month, they said it failed so I gave these guys a chance to try and address the problem. … As I told you [the country director] when you were in my office the other time, developing software was our challenge. I was really impressed when I see them coming with a system after two weeks. I was excited; I was just merely interested in how it is developed… I have learnt a lot about software, implementation, and many other things from the process.*

The country director commented on the underlying reasons for the fragmentation problems:

> *The real problem is that of the ministry. They should have directed the whole process so that efforts would not be duplicated. Had they done so, you and we would have worked together. The time has now come where we collaborate. …If you [his colleagues] now do not have any criticisms on the system, we should think about the cross pollination and the way forward with these guys.*

As no one complained, JHU decided to revise and comment on the implementation proposal to go ahead to supporting the implementation process. In fact, it was agreed to sign a tripartite agreement among HISP, JHU, and the regional health bureau.

Nevertheless, despite all these discussions, JHU kept introducing preconditions to support, and the long promised support never came. Although other stakeholders such as AAHAPCO informally had told the bureau that they can get money for implementation, it was impossible for them to formally come into the picture because of JHU's ambiguous position. Since JHU was primarily responsible for the region, their position needed to be first cleared with respect to support. Hence, the bureau made us demonstrate the system (to JHU's technical team) on the field once again. So we demonstrated the system to the technical team live in two clinics (Zewditu and Gandhi). However, from the general atmosphere in this demo session, we did not find the intention of the technical team to merely see our system functions, but to apparently learn what and how we have developed the system. For example, while the country director told the regional program manager that the aim of this demonstration session was to check if all the required functionalities are incorporated and the logic of the system is correct, and not conduct an evaluation, their questions to us felt as a fault finding exercise, rather than to provide constructive criticisms.

> *"…The bureau is weak, the system as a whole is weak. So whatever the case, we have to get JHU in the pipeline anyway, at least for financial and data cleaning support. …On one hand, we need their support. What is perplexing, on the other hand, is that there is a war; they are launching on a war against us. …"* – Regional health bureau's IT specialist to the research team

Following this demonstration, the program manager requested the country director to give him back the implementation proposal with comments, and fixed appointments for discussions which the JHU cancelled 3 times. Finally, the country director said he will send the system evaluation report rather than the revised proposal, a comment which disappointed the manager. The program manager then made his IT team to write another evaluation report from his side to be submitted to national and Addis Ababa HAPCO, WHO, and the federal ministry to counter attack what he called their "blackmailing" of him and the bureau. In the mean time, JHU installed their system in 4 clinics in the region and told the IT team that both their and our systems will work together and help each other. The IT specialist lamented explaining the tension between ignoring and seeking JHU saying:

> *The bureau is weak, the system as a whole is weak. So whatever the case, we have to get JHU in the pipeline anyway, at least for financial and data cleaning support. …On one hand, we need their support. What is perplexing, on the other hand, is that there is a war; they are launching on a war against us.*

In general, in this chapter we have described the various challenges that shaped our development, implementation, and scaling processes. Though identified as the key conditions influencing these processes, the political situations surrounding the effort of making work the ART system were discussed in terms of limited number of parties including us. However, the situation is also manifested with regard to our relation among the other stakeholders. For example, when the national HAPCO's data manager learnt that the system she was supporting failed, she allied herself with us to go against JHU telling us that we have to go ahead implementing in more clinics before they do. She also worked out and facilitated some funds from WHO and national HAPCO to support our implementation process. We were also informed through secondary sources that an official from an American University declared in a meeting in USA that the ART reports from Ethiopia were not trustworthy. The national HAPCO responded to this by asking the regional health bureau to make the ART reporting completely electronic, on promise of funds from the Global Fund and AAHAPCO.

In summary, though we were able to implement the system in some clinics where it is functioning at present, we could not succeed practically in scaling up the system as per the Addis MOU, primarily due to implementation funds not being made available for political reasons.

Table 7.5 below summarizes the key challenges identified and the strategies we adopted throughout our project – in the design, development, implementation, and scaling processes of the ART management system.

Activities	Challenges	Strategies
Design and development	▪ Gaining entry ▪ Lack of requirements documentation ▪ Our lack of experience both on HIV/AIDS and health information systems development ▪ Fragmentation within the ART program ▪ Diversity of work practices ▪ Incompatibility of the Ethiopian calendar with MYSQL database	▪ Enrolling the regional program manager ▪ Building our domain specific and technical capacities ▪ Participant observation ▪ Team work with public health and HIS experts ▪ Rapid prototyping constantly working with it to cultivate the system ▪ Periodic discussions and meetings, and presentations and demos to the clinic and bureau staff ▪ Working closely with clerks and bureau's IT team
Implementation and scaling	▪ The politics surrounding the ART program ▪ Implementation expenses ▪ Enormity of backlog data and its poor quality ▪ Lack of human resources (eg. data entry clerks)	▪ Hiring assistant clerks who are the friends of the regular clerks and starting data entry right away ▪ Developing social base and building the trust of the clinic and bureau staff in us ▪ System walkthrough with the bureau's IT team ▪ Verifying the correctness of the logic of the system ▪ Repeated demos and presentations to other stakeholders ▪ Playing multiple roles

Table 7.5: Challenges and corresponding strategies adopted in the design, development, implementation, and scaling of ART management system

After these descriptions of our action research interventions, in the following section we present the outcomes of the action taking phase and current status of the project.

7.5 Outcomes of the Action Taking – Current Status of the Project

In the *Situation Analysis* chapter (6), we discussed the findings of the situation analysis which represented the diagnosis phase of the action research cycle. In that phase, we were able to detect primarily the prevalence of political tensions surrounding the Ethiopian HIV/AIDS management and identify the problems particularly around the pre-existing ART program. Apart from the description of our penetrating this political quagmire to gain entry (an action in itself) in chapter 6, in the proceeding sections of this very chapter we discussed the different actions –design, development, implementation and scaling up processes, while continuously trying to infiltrate the ongoing politics – which were taken to improve the weaknesses in the country's HIV/AIDS management. We also presented the various socio-technical conditions that surrounded these processes and how we have attempted to make the system work within these conditions. These interventions have led to some observable changes specifically in the ART program. For example, some clerks have been given informal onsite training on how to work on the system and we have an electronic version of the data in some clinics as clerks were able to apply the skills they obtained from the training. In this section, we will describe some observable changes, and some reflections over future steps.

Technically, as demonstrated through various demonstration efforts, the system was found to be functionally fairly mature with respect to the basic and some other 'luxury' functionalities. However, given primarily the described political impediments, the system spread has only taken place in 10 (including 3 from SNNPR) of the 67 clinics designated in the MOU. Still, from these clinics, the system was actually being practically used only in three of them in Addis, performing the basic functions and being well appreciated by health workers at different levels (see section 7.2).

In addition to simplifying data capturing, the system has helped these clinics in other ways. For example, it has speeded up searching, especially required in clinics with high patient loads. Also, the system has helped to reduce lost records, especially in the congested clinics with poor record keeping facilities. These benefits were acknowledged by the head of one of such clinics. Further, the head told us that they were printing out all important history details of a patient, something not easily available in the past. Also clerks and nurses have told us that the system has relieved them from referring to many log books searching information about a patient. In addition, in one of the smallest clinics we have been, a clerk had already started using the system for appointment scheduling, and to compare the manual and computer generated reports. Electronic reports are still not officially accepted by the bureau. In some clinics the system is being used for some limited analysis.

True, these contributions of the system should not be underestimated especially as seen from the difficult condition in which the bigger clinics are. Nonetheless, that did not satisfy all the people in the vicinity of the system. Consider the complaints of two clerks form one of the biggest clinics, and the conversation the research team had with one of them:

> *…Every one here considers the report is only the clerk's work. They are seeing the usefulness of the system only for searching a file when they are in trouble. They don't care about reports. …*
>
> *…They [the nurses] seem content with the system that it helped them in searching. But that is not the biggest thing … the biggest problem is reporting. We should go ahead and work hard together to make and use this system for reporting. …*
>
> Research team: *"What is the major hindrance for reporting from the system?"*
>
> Data clerk: *"No one should ask this. Why do you ask me? It is the backlog data problem.…"*

Yes, most notably, even in these clinics, the real potential of the system is underutilized as the system is not being used for the most important reasons it was meant. And, there is a chain of complex socio-technical problems contributing to that. For instance, for the system to be used for reporting, the prerequisites for reporting must be fulfilled. For example, completing data entry including the backlog data is a necessary, though not a sufficient, condition for reporting. Nevertheless, for data entry to take place, amongst other problems hindering the achievement of this particular case, the data has to be cleaned at least with regard to the problem of unique patient identifier. Paradoxically, however, to clean the data itself requires completing data entry. Why? During a discussion concerning this in one of the biggest clinics, a staff from a supporting stakeholder assigned to get the paper files in order, told us:

> *From our experience, we have discovered that it is completely impossible to clean the data manually. Because the number of patients, especially here, is too many with several same names and duplicate patient files. … So what we were actually planning is to create a simple spreadsheet using Excel or Access without needing a database, just to capture only the names and …of all patients in the clinic and order them perhaps using enrollment date. …Now, learning that we have your system, we thought 'why not we use their system' since you have already started data entry here, instead of starting entry from scratch. …Then we can use the system to assign serial number or whatever and properly arrange the paper file on the shelves.*

This is, thus, like the classic chicken and egg problem. You need clean data for a system to function properly including for reporting cases. At the same time, you need a system to clean the data as cleaning the data manually, particularly in the bigger clinics, is unthinkable. For example, we found one of the most common names in Ethiopia (Tigist) registered in one of the biggest clinics more than 100 times. When trying to assign unique identifier manually in such a big clinic where the card number and other identifiers were not put properly in place, we needed to make sure whether this Tigist is not the same as the other Tigists by further investigating the patient's second and third names. And a similar process had to be followed with the names of nearly 12,000 patients in just one clinic. Moreover, there were times when clerks issued multiple files for a patient when they failed to find the original file for different reasons. In fact, as mentioned in chapter 6, we once found a patient registered 4 times and hence having four files. Hence, chances are quite high to find duplicate patient files. However, it should be noted that cleaning the data is not merely assigning proper unique identifiers and removing duplications, but involves various other tasks which makes manual cleaning impossible. For example, we found several patients whose ART start date was recorded as an occurrence before the patient's enrollment date into the HIV care. This should not normally happen, and when it does, it significantly affects the reports which are all date dependent. Thus, cleaning the data without being aided by a system is agreed to be virtually impossible.

As a strategy to reconcile these problems, we designed the system in such a way that it could initially accept "dirty" data which can latter on be cleaned using the system. Even so, getting the data entry process done has proved to be difficult so far, mostly due to resource constraints. However, even in those clinics where we made simple informal onsite training and data entry possible through our own funds, data cleaning and at least reporting has not taken place satisfactorily, for reasons such as high volume of backlog data, data entry clerks doing other jobs, and no dedicated computer. A regular data clerk and the head of this clinic said:

> *When she [the assistant clerk] enters the current daily data [refill or new], she stops the backlog entry, and when she enters the backlog data, she has to stop the daily data. What can she do? I even appreciate her. We have too many [about 350] refill and new patients in a day.* (A regular data clerk)

> *We now have to work together to get this system used for reporting after solving the data entry problem by mass. Otherwise, even if this one clerk does it day and night she can't finish it. I see her always entering data. She is working hard but she couldn't finish. As for me it is not surprising that she didn't finish. You see? The data is too much. We had it since 1995 [Ethiopian Calendar].* (A clinic head)

Even after data entry for some months was completed in one bigger clinic, we had to confirm the correctness of the report from the system to the clinic and the bureau staff. Although we succeeded in some cases, we found it difficult trying to figure out the reasons for the discrepancy between the manual and the corresponding system generated reports. For example, there was often guess work involved in the figures of manual reports which was very difficult to trace and rectify. A clerk confessed:

> *You see Mule [member of the research team], don't tell this to any one but sometimes the … [deliberately omitted] asks us to simply add some figures on to the report before we submit, for she fears that we might have wrongly counted lower. So the report from this system and this report will never match. In my opinion, it is the system's report that is correct. The problem at first was that I did not know that some patients take medicine for many months when they come once. So I did not fill all those follow-ups. But once you told me this last time when we compared reports, I started to fill these too. So the report is fine now. I believe this one.*

Although we confirmed the correctness of the logic of the system to the clinic staff in some of the clinics, dealing with the problem in its entirety requires the bureau to make a total commitment to the system and in their efforts to clean up data quality. There are of course various other concerns that need to be addressed. A clerk explained a facet of the complexity of the situation as follows:

> *They will kill me if they hear me saying this but the doctors are really incomplete. They are making me work like a doctor. For example, it is the doctors' work to fill functional status but it is always me who do so. I sometimes have to advise the patients and make some measurements. When I ask them their name and the like at their registration, the patients weep and I weep too. It is painful to act like a doctor at the same time. You became worried. I usually develop headache. … To use the system properly you need to get me the doctors and nurses sit and discuss and work together. Since their salary is small they are discouraged and they don't care about the work. They are very discouraged to use the system. They don't care about software. They are happy if I leave the computer for them to do whatever they want. One day they said 'you entered much data into the other system and they told you to stop. Now you do this and they will tell you to stop again at the end of the day.' … In this hospital ART is given very less significance. They don't care if it functions or not. They sometimes think I am doing things for my personal benefit. I can't discuss my complaints frankly because they find ways to kick me out of my job. If I complain I can't be absent from job for any reason – you may be sick, go to school… – as they will be looking for faults. So I just stay quiet and continue the work.*

Hence, reporting could not be done from the system so far for several complex reasons including the impossibility of having clean data in the system. However, the difficulty of having clean data in the system for it to function properly is not only a stumbling block to do reporting from the system but also to use its other important features. For instance, proper appointment scheduling has a direct impact on the patients' waiting time as well as its impact on the clinic staff. In addition to convincing the physicians to fill in the patients' next visit date, we have incorporated in the system the important functionality that facilitates scheduling. Yet, it remained unused. The same holds true for the system's other important functionalities as Lost/Drop, Poor/Fair adherence, and individual patient's progress reports.

In summary, we could see two specific sets of observable changes and one urgent area of improvement. These are:

1. *Data capturing,*
2. *Information retrieval, and*
3. *Reporting.*

*1. Data Capturing: **Simplified and Improvised***

Previously, in the manual system, data capturing used to be done from multiple entry points involving multiple forms and registers, often with a lot of recopying of information. Also, due to the limitations of the follow-up form and the ART register, clerks needed to create new follow-up forms for a patient (after about 18 months) and new ART registers for patients followed up for more than 24 months. In both cases, demographic information had to be rewritten and there were very incoherent links to earlier registers. This not only resulted in fragmentation of information but also made counting and analysis difficult. There were a huge number of data elements both in the intake (about 305) and follow-up (about 115) formats which was very time consuming both for the clerks and nurses. Even after data was filled, analysis was nearly impossible.

We redesigned the system to have a single point entry for demographic information and the overall data capturing was made to be only from two points. Fragmentation of patient follow-up information was also avoided as the next month's follow-up could be smoothly appended to the previous months' records in the system. In addition, the use of combo and check boxes as well as the systematic way of bringing replicable data from past month to the present, reduced typing work and made data capturing much simpler. The simplicity of data capturing was further enhanced by replicating the logic and workflow of the manual system so as to keep the transition gradual, for keeping the data screen formats similar to the paper formats. Given the limited human resources that exist in the clinics, these features of the system, the clerks said, saved quite a considerable amount of their time. Moreover, on top of controlling the format of data from the combo and check boxes, the validation rules we inscribed in the system improved the quality of data and hence also the reports.

2. Information Retrieval: ***Speeded up***

As mentioned in the situation analysis, the enormity of the backlog data, the number of registers to be referred to, and the way the data was being captured have all made information retrieval very difficult. At one time, we observed 4 people (2 nurses and 2 data clerks) failing to find information about a patient after searching multiple (nearly 20) registers for over half an hour. The system has contributed significantly to speeding up the searching process.

For instance, in one of the bigger clinics it has now become a daily custom for clerks to run to the system when they need to find information about patients. Clerks, nurses, and doctors have acknowledged that information retrieval has become much easier in the clinic especially because the system provides number of search options – name, age, sex, enrollment date, ART start date, follow-up date, card number, unique ART number, serial number, and patient status (such as Pre-ART or ART, on treatment, lost, drop, restart, dead, transferred out, transferred in). In addition, the search result is displayed in such a way that one can simply differentiate the patient status (on Pre-ART, ART, on treatment, lost, drop, dead, restart, transferred in, or transferred out) just by seeing different color codes. The provision of links on every page so that a user can go to anywhere from any page and the provision of a particular page from which a clerk can easily find every important piece of information (including follow-ups, intake sections, and the patient's and his/her caregiver's address) about a patient, has made searching even easier.

3. Reporting: ***Seeks Urgent Attention***

Whereas the abovementioned functionalities of the system are being used to a certain extent, the area where the system is most wanted – reporting – was not well exploited. Many reasons contributed to this, including the rather nascent stage of the implementation process. As a result, the status quo of preparing manual reports has continued despite the presence of the system. For instance, to get reporting done from the system, backlog and present data has to be entered the system, and the data has to be cleaned. This requires dedicated funding which was not easily forthcoming, leading to the status quo. A high level of commitment is thus required to urgently make this change over, which will further contribute to a larger uptake of the system. Given the pains, mentioned in chapter 6, to manually prepare reports, prompt actions should be taken to start reporting from the system. Otherwise, the country's ART M & E system, an important input to determine the progress of the national ART program such as by yielding cohort analysis reports, will be tremendously affected.

Overall, from both the technical and implementation perspective, we have gained a measure of success and we now have the basis to scale up the system. However, to achieve the full potential of the system, the financial hurdles need to be solved, and the bureau has to provide a full commitment to the system.

7.6 Evaluating the Outcomes – What Needs to be Done for the Future?

While the actions were still going on, we undertook an evaluation of the outcomes a year after data entry in some sites started to take place. The aim of the evaluation was to know whether the various socio-technical-political challenges surrounding the efforts to introduce and make work – study, design, develop, implement, scale up, and sustain – an IS that supports the Ethiopian ART management have been effectively addressed, and how have our efforts practically alleviated the problems identified through the situation analysis. In this section, we outline the results of our evaluation. Where changes were yet unsuccessful, some framework for the next iteration of the action research cycle will be provided.

In general, it can be said that:

- *the political situations surrounding the Ethiopian ART management have arguably been penetrated especially in the capital region as we could gain entry and then subsequently secure a legal permission to develop, implement and scale up an ART management system in all the clinics in the region. Furthermore, provided that a steady and continuous effort is kept exerted, there is the prospect of scaling it up to the national level with the support of the Addis regional program manager and the bureau staff,*
- *a number of socio-political problems encountered at different healthcare levels – from clerical and clinic levels to regional and national levels – and at various stages in the processes of making the system work were addressed to the extent possible. This included placing important functionalities in the system, practically initiating the process by employing assistant clerks and motivating the clinic staff to actually start using the system, enabling regional level health workers to see the value and significance of the system, and providing practical supports in areas possible,*
- *technical problems encountered were addressed by building our own capacity with in the HISP team and exchanging database tables over emails with non-technical team members working in regions other than ours,*
- *in spite of lack of pre-existing documentation, domain specific problems encountered were addressed again by building our own capacity within the HISP team and exchanging mails,*
- *the full requirements of the ART program was gathered, identified the problems of the manual system were identified, and an IS was accordingly designed and developed to support its management,*
- *through a team work, we implemented the software in some clinics in the two regions in the country, and exposed the system to also other regions,*

- *we introduced some changes in some of the clinics where we implemented the system which has thus far practically eased the works of data capturing and information retrieval, and addressed some other problems identified through the situation analysis, and,*
- *the continued efforts we are exerting around improving the system, and the continuous support we are providing to health workers around the system have the potential to sustain the system.*

These practical achievements can be discerned from the expressions of various health workers we met in the course of the project. For example, in a discussion with the bureau's IT team at the later stage of the study, the IT specialist appreciated:

> *I am really very happy about you people. I learnt a lot from this process. I was employed late after you started it. I was very surprised to see copies of the different letters you submitted and received from the bureau and how formal you have been. I felt later that we were wrong to invite that man to demonstrate his system coming from no where given that you have been formal throughout like no one else. But these things are very difficult and messy. We were just forced …And your choice of Zewditu was really a tough site. …This free software thing is a unique experience for me, different in our country. …Normally they give you the requirement and you bid but you are students and helped us in many ways for free, as far as I know. I don't know if you have personal gain or something. …We know that you have been troubled a lot by the manual system which actually shouldn't have been your problem to deal with as developers. There should have been requirements documentation. … Plus, people have been and still are negatively following you. But we appreciate the way you compromised. I am really very happy about you because you are local, your intimacy with the bureau and the clinics, you work without benefit, I don't know. We are getting you quickly every time we wanted you and at your own expenses. I am frustrating if the work continues like this in your absence. We learnt a lot from you. … You are really good diplomats.*

Also a clinic head encouraged us by saying:

> *There are many things disappointing here even for us especially in connection with the different stakeholders. So you don't have to be discouraged. You should be strong to get everything done… we should do things together after this. I can see that you are really hurt working alone so far.*

That the political condition has successfully been penetrated can be sensed from the following quote of the regional program manager spoken at about the signing of the MOU:

> *Unless they invent software that accepts data and cleans it by itself we will use your system. Even if the systems are equal the bureau has already signed MOU with you and the process has been formal. It is over. All of us are well aware that a system built with all these make up of expertise is far superior than a system developed by one developer however intelligent he is. … As a team work, we know that your system is much better than others' and we will definitely go for its launching soon anyway. …So let us demonstrate to them and help the*

country director convince the staff. It will be a tangible testimony that our system is better than theirs.

The health workers both in Addis and in SNNPR have also acknowledged the value of the system and praised the actions taken to relieve some of their problems (see sections 7.2 and 7.3). Consider, for example, a conversation we made with a clerk from one of the smallest clinics said:

Research team: *"Do you think software is required for this work?"*

Data clerk: *"What do you mean? Definitely! Because, no work is pure here. See the registers.*

Research team: *"What do you think will happen if the work runs without software after this?"*

Data clerk: *"We simply become dirty as before. …There is no really any correct manual report."*

Moreover, a clinic head who also was a medical doctor in one of the biggest clinics said the following about the system:

> *As compared to other systems that I have seen in different places, this system is full. Nothing is lacking from it. It is something big for the country. I don't know how much it is estimated in terms of money. But it is very good. …The system has practical benefits. We are using it for searching to get the data when a patient's card is lost. You know? It is very difficult to search manually. Imagine! There are about 22 registers. You also make mistakes when counting manually from them for reports … We have made some changes on our work because of you. For example, we started filling the next visit date after you told us that it is required to use the system's appointment feature.*

In addition to the bureau and the clinic staff, people from other HIV/AIDS stakeholder groups also saw the value of the system. For example in two different meetings, two people said that "it is a work to be commended" and "it is an appreciable process".

Therefore, it can be said that some observable changes have been seen and the action research was successful with respect to: penetrating the politics to gain entry and also to make it work, addressing the various socio-technical challenges encountered, eliciting the requirements of the system, identifying the problems in the manual system, developing and implementing a system that alleviates these problems, and making it be used in some areas to a certain extent. Also onsite training has been given to clerks and we have some electronic patient records from some clinics. Further, efforts are currently being exerted to sustain the system where it is working and also to scale it up both functionally and geographically.

It is not, however, by any means possible to say that there were significant improvements in the ART management overall. Given the sustained socio-political challenges being faced and the fact that it is an ongoing research, we acknowledge that the action taking phase has not improved the system entirely and there is a long road to travel in the future. What we can, however, say here is we have successfully moved aside particularly some of the political stumbling blocks and introduced the seeds of change in two regions in the country. But we were not successful to scale up these changes, for example, due to lack of human resources to make the necessary political deal in regions other than Addis, and different other contextual factors. There are thus many issues yet to be resolved. We plan to further these processes in our subsequent action research iterations. For example, we believe that in the subsequent action research cycles, the following points need to be dealt with to improve the situation:

1. *Implementation and scaling up*

Proper implementation and scaling up of the system as per the Addis MOU has to be worked out. But, firstly, the primary impediments to these have to be removed including obtaining the financial resources, conducting formal training, data entry, and data cleaning. Removing these obstacles will pave the way firstly to start reporting from the system, and then to scale it geographically. Apparently, this necessitates the need to making the necessary political deals with relevant stakeholders and regional health bureaus. We should also further build up capacity with respect to implementation resources such as trained people who can scale up the system by paying what it seeks.

2. *Making Data Used for Action and Planning – Exploiting the Systems' Features*

Once the data entry and cleaning work is done, we have to work to show the practical benefits of the system by making the region use the system for change in addition to for reporting. This can be done by exploiting the other built-in functionalities of the system and fully utilizing them. This way the system can be made to be embedded as part of the overall organizational arrangements. For example, at the clinical level, we have to try and make the doctors get each and every individual patient's progress report in a certain set interval of time. The next action research iteration should also emphasize on the use of the system for proper appointment scheduling so as to reduce the burden on the clinic staff and the patients themselves. Moreover, since the clinics are having telephone lines now, patients should be made to benefit from the functionalities of the system where lost/drop and fair/poor adherence are reported to ensure continuous follow-up and the expected high level adherence. Also, at the clinic and bureau levels, the dynamic cohort functionality of the system should be used for action and planning. In fact this feature should be well exploited to improve the country's ART M & E and through which the national ART program. There needs to be an increase in effort in working with the health bureau and other responsible bodies to bring about change in this regard, and get these features of the system used for the betterment of ART management.

3. Standardizing/Setting Procedures

In connection with the system and the data in it, there are some problems which seek setting up procedures for security purposes. For instance, in two of the clinics where we have been working, the computer is also used by several staff members for different purposes, thought it is theoretically assigned by the bureau to be used solely for ART work. This exposed the data to unauthorized persons, minimized the clerks' time to work on the computer, and slowed down the data entry process. A clerk complained:

> *All the people here want the computer. They share my time asking me to teach them word, excel, access. That was why I told you and the IT team to uninstall these programs. … I want to work on the data entry overtime without payment but I don't have the office key and the computer is not issued by my name. So my boss, that nurse, wants me to leave the office at around 4:00 before she locks as she is responsible for the properties in the clinic. And I am not allowed to work on Saturdays. It is difficult to work in weekdays as they want to use the computer when I work and I can't say 'no'.*

Sadly enough, the absence of procedures on how to use the machines endangered the physical data as well. For instance, in a clinic in the Addis region where data entry was nearly completed, a staff from JHU took the computer to format it without the clerk's and the bureau's knowledge which could have resulted in the loss of all the data entered, if we had not previously taken data backups.

In addition, there are additional problems in relation to data backups. We observed that the clerks do not seem to know their responsibilities and accountabilities as well as the different risks in relation with electronic patient data. So, proper procedures have to be set so that they can secure the computer and the data and take regular backups. Moreover, since there are frequent power interruptions while data entry was going on, we experienced database crashes in some clinics where UPSs were not used. Since one of these happened with the SNNPR implementer who was not very familiar with the technologies used we needed to address the technical challenges encountered through emails (see section 7.2). Hence, appropriate measures should be taken to avoid crashes in addition to ensuring backups and security.

Furthermore, we need to make a transition plan from the manual to the computer based system.

4. Technical Considerations

While the system is complete in a sense that all the data in the ART program can be captured and all the required reports and analysis can be done from it, there are yet aspects to be improved in relation to the internal features of the system. For example, as it is now, the system is hard coded and fixed to the current requirements of the Ethiopian ART program. Hence, it is not adaptable not only to specific contexts of other countries as was originally our vision (see chapter 3) but also to the dynamic requirements of the Ethiopian HIV/AIDS management. For example, since there have been changes of ART formats three times while we were undertaking development, we needed to amend the code accordingly. So to adapt the system to this kind of emergent requirements and dynamic environment as well as to other countries, it requires designing a flexible system and migrating the data from the current system to it. In addition, the current system lacks graphical analysis tools and GIS features which need to be considered.

Also, as it is now, the system is functioning on standalone machines thought it can also function on the web environment. So, effort has to be exerted to demonstrate the power of the system to the bureau by at least linking up doctors, nurses, and data clerks and enabling them to share data. Moreover, to improve the efficiency of the system, such as when processing complex reports (for example the cohort analysis) where patient number is higher, some improvements have to be made. Furthermore, as ART has strong link with the other programs (such as VCT, PMTCT, and Pharmacy) under HIV/AIDS management, an integrated system is crucial for the program. In fact, effort has to be gradually exerted to slowly expand the ART system and fulfill the original IHAMS vision that was initially promised to the regional health bureau. Actually, our Debo project, mentioned in chapter 3, was initiated especially with this last motivation.

Therefore, given these technical and political considerations, there is a need to accomplish the above tasks and more in the next iteration of the action research cycle for making further improvements in the management of the ART program. Using Table 7.6, we have provided a summary with respect to the key features of the different facets of the action research cycle: situation analysis; action interventions taken; outcomes and the evaluations of the outcomes; and some inputs on further action.

Action research phase	**Activities**	**Findings**
Diagnosis: Situation Analysis	▪ Problems related to the politics of gaining entry to design, develop, implement, and scale up an ART management	▪ The politics surrounding HIV/AIDS management is

	system were identified ▪ Problems related to the ART workflow were identified ▪ Problems related to the data capturing formats and registers were identified ▪ Problems related to magnitude of workload were identified ▪ Problems related to fragmentation were identified ▪ Problems related to variation of work practices identified	detected to be one of the biggest challenges to introduce a supporting IS ▪ That the manual ART management system urgently needs an IS was discovered
Action planning	▪ Planned to penetrate the politics and introduce a supporting IS o Team work o Building our own capacity o Rapid prototyping o Enrolling the champions o Developing social glue and building trust o Playing multiple roles o Participant observations, periodic discussions and meetings, and presentations and demonstrations to the bureau and clinic staff o User participation	▪ To introduce a supporting IS, the importance of dealing with the political situations surrounding HIV/AIDS management in developing countries was discovered ▪ Enrolling people on power and those working on ground and working closely with them was found to be an effective strategy to infiltrate the politics and introduce the system
Action taking	▪ Designed and Developed an ART management system ▪ Trained data entry clerks onsite and Implemented the system ▪ Dealt with the politics to the extent of signing a MOU to scale up the system in the Addis region	▪ Our working with the clinic and bureau staff and gradually cultivating the system were found to be effective strategies in getting a working system
Evaluation: Outcomes of the action taking	▪ The politics was successfully penetrated ▪ The full requirements of the ART program were appropriately elicited ▪ Data capturing was found to be simplified and improvised ▪ Information retrieval was speeded up ▪ Reporting was found to be still needing urgent attention	▪ System is found to be technically fairly matured ▪ Failure to get the data entry and data cleaning works done is found to be the major impediment to reporting from the system
Specifying learning: Evaluating the outcomes	▪ The action research is regarded as successful in o Penetrating the politics o Gathering the full requirements of the program and accordingly designing, developing, implementing, and scaling up the system o Introducing some changes ▪ The study was found unsuccessful in the following areas to be considered in the subsequent action research iterations: o Realizing scaling as per the Addis MOU o Making data used for action and planning o Standardizing office procedures and taking proper backup and security measures o Further advancing the system technically	▪ Implementation related costs were found to be a source of inertia for further changes ▪ The full functionalities of the system remained unexploited

Table 7.6: Summary of the action research activities

In the next chapter we present the analysis of the empirical findings, representing the specifying learning phase of the action research cycle, by drawing up on the existing knowledge in literature and the theoretical concepts articulated in the literature review chapter (2).

8 Analysis and Discussions

If the politics does not fly, the system never will. – The Research Team

8.1 Introduction

By drawing upon the theoretical concepts articulated in chapter 2, this chapter presents the analysis of the empirical findings discussed in chapters 6 and 7. While we have provided rather protracted discussions of our various intervention efforts in Ethiopia, the analytical focus here is on the processes of practically making work ISs to support HIV/AIDS management in this country. The analysis thus meets the three research questions articulated in the *introduction* chapter: *1) What does "making it work" mean for ISs to support HIV/AIDS management in Ethiopia? 2) What key conditions especially shape the processes of "making it work" in the context of ISs to support ART management in Ethiopia? 3) Practically, what are some approaches and specific strategies of "making it work" around ISs to support ART management in Ethiopia?* Based on the answers to those questions, we provide summaries on key aspects of making work such systems, with the aim to determine more general implications.

The rest of the chapter is organized around three main sections. Section 8.2 starts the analysis by discussing the various challenges we encountered while trying to introduce and make work an IS that would support the management of HIV/AIDS in Ethiopia. Section 8.3 presents the "making it work" perspective as applied by us to address these challenges. The section describes the major facets of "making it work", and also the specific strategies we adopted to make our project work politically. Finally, in section 8.4 we position our analysis with respect to broader debates on related issues in IS literature, and draw the key implications of "making it work".

8.2 Analysis: Challenges to Make Work an HIV/AIDS Management IS

As it provides the basis to investigate the challenges, we start the analysis firstly by briefly investigating key information related problems in the Ethiopian HIV/AIDS management, and why it requires a supporting IS. Then, we examine the key issues that challenged our attempt to provide such an IS. This will help to develop an overall understanding of what is really required to make work in practice an efficiently supporting IS, and also to discern patterns and draw more general conclusions.

With a focus on ART management, we also compare in the following discussions some HIV/AIDS management related issues with those of other diseases and their treatments.

Why HIV/AIDS Management Requires a Supporting Electronic IS

As we have discussed broadly (chapter 4) and in particular with respect to Ethiopia (chapter 5), HIV/AIDS management, by its very nature, is a very complex process that calls for the coordination of a large number of initiatives and resources, "high on priority" being the management of information. Commenting broadly on what lies at the heart of problems that challenge the management of this disease in developing countries, RHINO (2004a) noted:

> *"It is important to realize that HIV/AIDS care and support requires a fundamentally different approach than prior public health initiatives. Earlier interventions such as… malaria treatment are time-limited activities. The activity is complete at the close of treatment. However, HIV/AIDS is a chronic disease that will require a lifetime of care and treatment activities. … HIV/AIDS care and support should be using a comprehensive chronic care model." (p. 2)*

This comprehensive care model consists of a number of actors including various local and international initiatives, and also national to facility level stakeholders. With this underlying character of HIV/AIDS management at the backdrop, through our situation analysis, we have also identified several problems influencing the informational management of the disease and its treatment in the specific developing country context of Ethiopia (see chapter 6).

ART management, our specific application domain and analytical focus, is particularly complex. Several underlying issues characterize this complexity, the peculiar nature of the treatment being the fundamental one (see chapter 4). Optimal treatment of AIDS, that is antiretroviral therapy (ART), requires good information on the current state of the patients as well as their past history of treatment and response to prior treatments. In general, the lifetime course of ART has necessitated: (1) the monitoring of lab and clinical conditions (e.g. adherence) overtime; (2) the strict monitoring of drug change due to the risk of treatment failure, significant toxicity of regimens, and risk of resistant virus strains developing as a result of poor adherence; (3) the mandatory smooth continuity of care when a patient on ART is transferred from one place to another so as to ensure the expected high level of adherence; and (4) the link ART seeks to establish with multiple other initiatives in the HIV/AIDS management (TB, OI, STI, VCT, PMTCT, ART Pharmacy etc).

All of these have, in turn, necessitated the capturing of extremely huge amount of ART follow-up information *on a regular and lifelong basis!* (RHINO, 2004b; RHINO, 2004d). Regularly playing with the huge amount of data for analyses purposes, we found, was very difficult for data managers who worked manually. These problems are further magnified by the number of patients which kept increasing due to the national ART scale up. An HIV/AIDS program manager who worked with us during our study lamented in an international conference about the case in his region saying: *"The work has become extremely unmanageable for us to do manually. …Patients' number is becoming out of hand."* As indicated by the following quote, this is the prevailing trend in other developing countries too:

> *"The growing number of patients in chronic HIV care and progressively on ART is a management challenge. Many developing countries are currently designing and scaling-up large HIV care and ART programmes in order to save and improve the lives of those infected and affected by the disease… In this context, the ability of countries to provide and sustain effective long term HIV care with ART … is critical. This requires an effective patient monitoring system integrated with care… and treatment at the health facility."* (RHINO 2004b, p. 9)

To see how demanding the requirements of patient monitoring and evaluation in ART can be, let us compare issues with the treatment of other diseases by keeping in perspective some of their data management activities. In most healthcare settings, patients are treated for acute episodic conditions such as TB and are rarely followed-up overtime. Hence, the IS most commonly found in developing countries' clinical facilities to support the information management of the treatment of such diseases consists of traditional paper-based medical records with limited utility for constructing a useful patient history, and that is often found sufficient. For example, registers are designed to address the needs of clinics to log daily activities or to track a limited number of discrete events that patients in the program are expected to experience. Most paper-based registers used for such acute diseases utilize only one line in a ledger for each patient record such that the amount of data collected per record is limited to the width of the page.

In contrast, the foundation of quality care and treatment for HIV/AIDS patients requires not only strong coordination among the various HIV/AIDS initiatives but also the ability to establish continuity of treatment and care. As mentioned above, when patients become eligible and ready for ART, they have increased information requirements including expanded individual patient encounter information to track detailed diagnosis and treatment activities. The key to continuity of care is, therefore, to establish an efficient monitoring system that can track clinically relevant information about individual patients chronologically and *over an indefinite period of time* in such a way that it can be easily retrieved at the patient's next encounter. Clearly, whatever the width of a ledger that can be practically available, paper-based register does not suffice, and is far from being suitable to manage such large amount of patient encounter information. Yet, patient encounter tracking is an essential core of the longitudinal antiretroviral treatment and its management. Each patient encounter, be it a brief one where basic information is collected and medications refilled or a more intensive one where more information is collected and analyzed, must be carefully recorded. Together, these individual encounter records constitute an important clinical record of a particular patient's situation overtime. It is important to remember that the primary purpose of collecting this information is to use it. And it is most useful at the point of care of individual patient which is where the clinician makes decisions on patient care, and hence needs to have complete and accurate information.

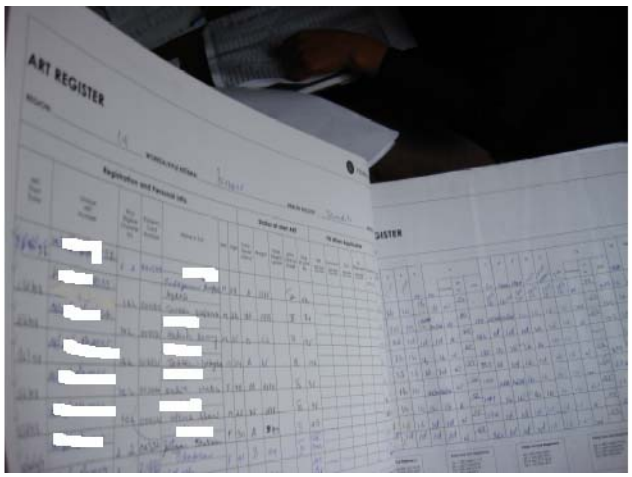


Figure 8.1: Part of the two pages of an ART register*

To offset the limitations of a single register (see Figure 8.1), we have seen data managers in Ethiopia to have continued the tracking of an individual patient's encounters fragmenting them in multiple registers each of which can help to register only 24 encounters. As a result, the number of registers to work with in the clinics increased not only because of the increasing number of patients but also because of the natural size limitation of the registers. For example, if a patient, or usually a group of patients, has been followed in one register for 24 months, a new register has to be opened to continue the follow up for another 24 months and so on. Thus when trying to prepare reports or make analysis in connection with a group of patients, all the relevant registers of several columns have to be referred making the analysis extremely difficult and sometimes impossible as discussed in chapter 6. In fact, some of the analyses required in the monthly reports (e.g. counting of regimen and of patients who are eligible but not yet ready for ART, transferred in, and restarted) necessarily required the navigation of

* Each register can hold information for about 1000 patients for 24 months, and there were about 20 registers to be dealt with in one of the clinics where we have been.

literarily all registers used in the clinic. For example, in one clinic where we have been, 20 registers needed to be regularly referred. An IT specialist we met from the Addis regional health bureau concluded: *"This condition makes an electronic system to be a mandatory requirement for ART management."*

Evidently, software that collects individual patient's information and presents it for review in a clear, convenient and useful format is very essential and can greatly improve patient care by giving clinicians a good picture of the patient's treatment history. The individual patient reporting can be made on a computer screen (if available for patient interaction) or more likely in printed paper format that can be presented at the time of the encounter. The individual patient report can then be easily evaluated carefully to ensure that it meets program needs and protocols for good patient care. As we have observed during our study in Ethiopia, without being aided by software to such capability, providers significantly reduce their effectiveness in caring for patients particularly if they are working in clinics that serve a large number of patients. Also, HIV/AIDS patients will have a variety of status at various times including their being on treatment, deceased, lost to follow-up, restart treatment etc. which can be easily filtered by an electronic system. Further, software system will enable viewing and summarizing the entire patients' records, aggregating patient records for analysis at the facility level, and greatly facilitates the conduct of ad hoc analysis for different strata of patients.

Moreover, in the treatment of such a chronic disease which requires continuous follow-up, the management of patient appointment is crucial. Patients must be scheduled at appropriate intervals to ensure medication continuity and that they receive proper care. An appointment system provides capabilities such as flagging overdue patients for personal contact to ensure that they receive continuous care and do not run out of medication which is quite dangerous in ART. It also facilitates the smooth flow of patients and the effectiveness of their care by matching patients' number to staff availability which is hard to do manually for all the working in a month especially in the larger clinics. We found that such important function of patient follow-up should necessarily be supported by an electronic appointment system. For example, in one big ART clinic in Ethiopia, it was very difficult for the health workers to determine who will see the doctors in the following day out of the tens of thousands of patients who had to be *all visited in a month*. Hence, even if the patients' next visit dates were written in their respective files and appointments were given to the patients, it was practically impossible to use this information as it required the traversing of all patient files. This significantly affected the patients since some of them were sent untreated in times when their number did not much with the number of staff available, and this in turn affected their adherence (see chapter 7).

Still, in most cases in developing countries, only paper medical record is available resulting in considerable injurious impacts. For example, as mentioned in chapter 6, the prevalence of such a situation in the Ethiopian ART management has been affecting the patients themselves, health workers at different levels, and various researchers. The delay and inaccuracy of reports, some of which were extremely complex and difficult to prepare manually, significantly affected particularly decision makers at various healthcare levels. The analysis of massive amounts of data has proven challenging and, in some cases, it became nearly impossible using papers, spreadsheets, or other inadequate and inappropriate tools for these tasks. For instance, an IT specialist from the Addis regional health bureau who worked with us once attempted to use a spreadsheet application (MS-Excel) to produce an aggregated cohort analysis report (one of the most difficult reports required) across facilities. He told us that he abandoned his attempt after a while since he understood that he "would need a stadium-wide spreadsheet" to make the analysis. Yet, as we have mentioned in chapter 6, the management of ART suffers from various other problems, both with respect to patient monitoring and evaluation. Summing up the existing situation in many developing countries, RHINO (2006) stated:

> *"Current information systems are primarily paper-based and typically consist of documents created locally to meet the immediate need. … The limitations of paper based information systems are a constraint to patient care, resource management, program management, monitoring and evaluation and research. The limitations … are due to the difficulty in tracking patients over time (longitudinal medical record) and the difficulty of aggregating data." (p. 1, 2)*

Facts on the ground thus clearly demonstrate that HIV/AIDS management demands a supporting electronic IS. Emphasizing this for ART management, RHINO (2004a) argued:

> "*[ART] requires a more intensive information system that collects information on individual patients over their lifetime … regarding each patient's condition, laboratory, and exam with specific fields such as CD4 count, and clinical condition and stage… ART requires disease management software …that can record AIDS specific information, provide decision support for care, monitor all cases for missed visits and outliers, as well as provide aggregate case management information. " (p. 36)*

Further, reporting, which is essential to patient, facility, and program management can take advantage of the routine collection of electronic information which can be easily filtered, sorted, and aggregated in such a way that it gives insight to the operation of the system. Patients' longitudinal encounter information is an important source of information to monitor the performance of the health system and can be used to improve patient care protocols. From a program monitoring perspective, longitudinal data retrieved from an electronic IS can provide key information useful to evaluate the performance of the program. In general, the provision of *"ART software creates complex choices for those hoping to simplify ART program implementation and monitoring"* (RHINO, 2004d, p. 4).

By and large, the extent of the epidemic, the complexity of the disease and its treatment, the wide variety of initiatives and responses that must be coordinated, and the diverse informational requirements needed to address all aspects of the epidemic, all inflicted "an immediate and pressing need" for efficient electronic systems to manage HIV/AIDS (RHINO, 2006, p. 1). Such systems must either supplement or complement existing tools. *"Only electronic systems will be able to properly track the large number of patients over long periods of time and be able to report on the effectiveness of treatment"* (RHINO, 2004d, p. 2). "*Without such systems, key patient diagnosis, tracking, follow-up and reporting tasks are inefficient, incomplete, or not performed at all. Long-range planning and quality assurance is nearly impossible*" (Crawford and Lester, 2004, p. 4). Given this, it is not surprising that, at all levels of HIV/AIDS management in developing countries including Ethiopia – national to health facility, there is a desperate crying for systems (Tierney et al. 2006, p. 253-254).

While it is crystal clear that HIV/AIDS management requires a supporting IS, various issues challenge the efforts to introduce and make work such an IS especially in developing countries' contexts, and this was rarely explored despite the prevalence of failure stories around such ISs, for example in Ethiopia. Following this, by navigating our ART system development and implementation efforts in Ethiopia, we elaborate upon some of the key issues that challenge IS development and implementation endeavors in the domain of HIV/AIDS. After that, we will discuss what is really required to make such systems work in practice.

The Major Challenges to Make Work HIV/AIDS Management Supporting ISs

Literatures have discussed various issues that challenge IS projects in developing countries. Within the context of this research, through our empirical analysis, we divide the key challenges we identified into three basic categories, namely, technical, social, and political, and show the particularities of these issues in the domain of HIV/AIDS management especially over HIS efforts in other areas. We argue that these *interrelated* challenges can be deeply understood and addressed through the "making it work" approach (see chapter 2) and its constituting approaches and strategies (see section 8.3).

1. Technical Challenges

Various socio-technical factors challenge IS projects in developing countries. While early IS researches were dominated by technology deterministic perspective, more recent works have argued about the importance of putting emphasis also on social aspects of IS implementation (Kling and Scacchi, 1982; Giddens, 1984; Hanseth and Monteiro, 1998). This argument is also reinforced through our analysis. However, since we found some technical issues in the particular environment of HIV/AIDS management to be noteworthy, we first discuss how these issues challenge the efforts to make work the supporting ISs. To place the discussion in context, we should keep in perspective the information context that needs to be addressed, that is, the complex data management needs of the various initiatives (e.g. ART) and stakeholders in the HIV/AIDS management system. Given this, we broadly categorize the technical challenges into two – design and technological concerns.

Full Spectrum Integration: When electronic HISs are considered for acute illnesses, often suffice it to deal with basic IS design issues, and the selection of the technology to be adopted is relatively less sophisticated. When it comes to HIV/AIDS management, however, the nature of the disease and its treatment tend to take these issues beyond the basics. For example, because of the complexity of HIV care, it requires a broad, multi-initiative approach with complex interactions (NHAPCO/FMOH, 2004a). As discussed in chapters 4 and 5, these various HIV/AIDS initiatives in developing countries including Ethiopia need to work very coordinately as HIV/AIDS care and support should be using a comprehensive care model (RHINO, 2004a). It is therefore important to realize that a supporting IS needs to operate in a long term chronic care environment which imposes special requirements.

For instance, helping these initiatives more effectively share and manage data to improve the effectiveness of HIV/AIDS management calls for the need to make the supporting ISs integrated. It is also critical that these systems be rooted in an understanding of the patterns and dynamics of communication among the initiatives. True, the challenges of integrating the full spectrum of HIV/AIDS management were rarely explored. Nevertheless, without a feature of integration, we argue, the effectiveness and efficiency of a supporting system is really questionable. For example, in our case, the ART system we developed (IHAMS-ART) helped to support the management of the treatment in various ways (see chapter 7). But the system's not being integrated with important initiatives, such as ART pharmacy which works very closely with the ART clinic, left the fragmentation problems of the manual system still persistent. For example, considerable discrepancies in regimen reports continued to affect the overall management of the disease, exactly as used to be the case in the manual system. This made our system challenged by some actors, and we have seen the difficulty of sustaining an IS in this domain if the feature of integration is missing.

Flexibility, Scalability and Customizability: Moreover, for successful implementation of HIV/AIDS management supporting ISs, it is important to design the systems in such a way that they can be constantly aligned with changing conditions which call for the flexibility and scalability of the IS. Designing the systems in a flexible way would make them functionally scalable with respect to data elements, reports, and more initiatives to be integrated with, and would also make them geographically scalable if customizability is supported by the flexibility. The features of flexibility, scalability and customizability are important in such ISs primarily because data collection needs in HIV/AIDS management are a moving target. To keep up with changes to existing forms and allow for newly introduced forms, a supporting IS must also allow continual changes in form design and deployment, and adding the needed information to the system must not be delayed. On top of this, the ease of modifying the content and format of the new information to accommodate changes as clinical care evolves should also be considered. We have seen the significance of this particularly for ART clinics which are not a homogenous environment. For example, while we were in the process of implementing IHAMS-ART, which was hard coded and not flexible, some of the Ethiopian ART data capturing formats were changed by the Ministry three times partly because of the link ART has with other initiatives, and also because additional report and analysis requirements emerged. Constantly incorporating these emergent requirements into our system proved demanding to us and slowed down the implementation processes and the over all project progress.

A good IS to support HIV/AIDS management should, therefore, allow users to modify some of the options for local use by providing the ability to have user definable fields to allow the capturing of information customized to local needs. In fact, we have also seen the need to provide with this the ability to structure this locally defined data by designating data types (text, numeric, date etc.), specific ranges, or by picking values from a user defined list. An interesting case in point is ARV medication tracking which is crucial to manage ART patients. The treatment of AIDS requires the prescribing and monitoring of complex regimens according to a specific protocol. Drug regimen, which is defined as a specific combination of drugs (typically three) given together, is an important and central concept in ART (see chapter 4). Patients will typically start with a certain regimen and this may change over time as they develop adverse reactions or resistance. Current therapy decisions thus depend on prior medication history and response, and there may be a replacement of just one or two drugs (called "substitution") or a complete shift to another regimen (called "switch") in the course of treatment.

The software should therefore be able to track medications not only by regimen but also by the constituted individual drug including dates and dosage. *The system must also include the ability to define standard drug regimens and to retain the various details of each of the constituted individual drugs in the regimen for later analysis of individual drug responses. It should also allow exceptions since as protocols will change overtime these regimens must also be easily changed.* For example, though we provided in the hard coded IHAMS-ART an exhaustive list of the then known possible regimen options, it was not possible to capture the regimes with which some patients were exceptionally needed to be treated. This forced the clinics depend on us to update the software every time a new regime emerges. Thus when designing the supporting IS, particular attention should be paid to the flexibility of the drug regimen features to ensure that they can be easily customized to program needs. Moreover, attention should also be given to the ease of drug data entry as this is an important function that will be performed most frequently with limited human resource, for example in Ethiopia, and if the data entry procedure is complex, confusing, or difficult, the data quality will suffer. In short, in addition to integration, flexibility is an important issue when designing systems for the management of HIV/AIDS. Yes, as RHINO summed it up, *"a worthy response to this pandemic will require coordinated, scalable, and flexible information systems."* (Mamlin et al., 2006, p. 1).

The Kind of Technologies to be Adopted: The nature of HIV/AIDS management and its key characteristics dictate not only the way the supporting system should be designed but also the kind of technologies themselves to be most appropriately adopted (both software and hardware). For example, the factors which determine how easily the software can be modified include the language, software architecture, data model design, and most importantly, the availability of the source code. Let us just focus only on one of these aspects. In order to make changes to the software, one must have access to the source code which is the ultimate guarantee to be able to fix problems and modify the software to meet local needs at any time and promptly. In our case, as mentioned in chapter 3, we used Free and Open Source Software (FOSS) tools to develop our software. We have seen that this is beneficial especially in light of the changing requirements that the client needed to get immediately incorporated, and also to reinstall the upgraded versions of the system in all of the implementation sites again and again. Given this context, FOSS seems particularly attractive for HIV/AIDS management in low resource environment. In fact it is believed that, in the context of HIV/AIDS management, "the best model for providing customization and building capacity in country is the open source software (OSS) model …that allows free copying and distribution, encourages modification and enhancement of the software" (RHINO, 2004c, p. 4).

Further, in addition to the need to link HIV/AIDS initiatives, the nature of ART alone, such as the need to smoothly continue the treatment even amid intensive patient mobility (cases of transfer in and out), also shapes the kind of technology to be adopted *"Because of the need to follow ART patients over their lifetimes, as they are seen at different sites, the best model for the software design is web based client server [architecture]. This permits sharing and linking of information overtime and over distance"* (RHINO, 2004c, p. 4-5). Accordingly, though these features are not yet exploited due to various infrastructural (such as absence of network) and some non-technical implementation related challenges to be mentioned later, we have used such technologies in our systems. Had these features been exploited, for example with regard to IHAMS-ART, they would have served at least to link up the ART clinic, ART card room, pediatric ART, PMTC, ART pharmacy which work very closely and often in the same compound in many of our sites. Nevertheless, as we will discuss in section 8.3, we found the kind of technologies that we chose to adopt (e.g. FOSS and web-based) to have political implications that put forth with our intervention efforts.

The immensity of the data and the often complex kind of analysis required in HIV/AIDS management also goes to the level of dictating the type of hardware technologies such as the size of RAM and the speed of CPU to be installed in the computer where patient information is stored and processed. As we have seen from our case, this is particularly important in ART management especially where there is a large number of patients each with large number of follow-up records each constituting huge amount of information. In this situation, the infrastructure must not only handle thousands of patient registrations and tens of thousands of their follow-up records, but also be scalable to tens of thousands of patient registrations and hundreds of thousands of follow-ups as seen in our sites. Nevertheless, though there are various initiatives in Ethiopia to furnish the ART clinics, they often provide computers with unsuitable specifications without properly understanding what is actually required to process ART information, and this challenges the implementation of a supporting IS.

For instance, in one of the ART clinics we worked, Zewditu Memorial Hospital, there were more than 12 000 patients with more than 150 000 follow-ups thus far. Out of these, about 10 000 patient were registered and about 51 000 follow-up records were captured into our system. Now, to generate some of the required reports (such as the cohort analysis report) the system seeks to traverse each patient's each follow-up record and needed to analyze many variables by performing several calculations and operations which require significant CPU time and RAM size. In effect, the system processed and executed considerably slowly which will be further worsened as the number of patients and their follow-ups captured into the system keeps increasing as is currently the case. As we will discuss later, this problem, though it was largely due to the very poor specifications of the computer on which the system was installed, it was politicized to be the fault of our system by some competent system providers.

The lack of technical infrastructure such as communication links between facilities in developing countries and the mandatory requirement of presenting complete past treatment history for current care forced many developing countries even to consider physical transport of the information on portable information storage technologies like smart cards, though not yet the case in Ethiopia. A smart card is a credit card size device that contains a computer memory chip originally developed and widely used for financial applications where it is used to store money or credit thus having rigorous data encryptions and security protocols. With this embedded security features and sufficiency to store individual patient's medical record entirely, smart cards are becoming a rapidly emerging technology with clear potential in the HIV/AIDS clinical realm. That they are relatively inexpensive and are ideal for storing longitudinal medical information is making smart cards to be issued for an individual patient which he or she would carry when receiving treatment. The card would be read at the treatment facility and updated with new patient visit, laboratory, or treatment information, and the data from the card can be duplicated at the facility for backup which thus becomes available in multiple locations. With this tradition of patients in a developing country maintaining possession of their own medical record, they can present their medical record and be treated at different facilities as they travel to work in different areas. The increasing use of smart cards emphasizes how much the nature of HIV/AIDS treatment and information support is technically demanding.

Other Design Concerns: The above mentioned situation also suggests that, for ISs that support HIV/AIDS management, design issues seek important consideration. For example, to process information efficiently with the available hardware technologies, ART requires efficient data models and algorithms. Nevertheless, technical problems that challenge even some of the most fundamental principles of IS design and development also surface in facilities where huge amount of backlog data has been accumulated. Theoretically, a system should be designed in such a way that each record or registration has a unique identifier – the backbone of record storage and retrieval in electronic systems. Nevertheless, the often poor quality of data encountered in such facilities, a legacy from the manual system, forces one to break this rule.

For example, in the facilities where we were working, Pre-ART and ART patients were treated in the same clinic and their cards were filed together but a registration number is assigned (if at all assigned) to a patient only when he/she is eligible for ART. The situation is that, (1) quite a number of files do not have unique identifiers, (2) by mistake, the same identifiers were assigned to multiple patients, (3) duplicate files were issued for a particular patient, and (4) there were more other problems with the data quality including spelling problems when registering patients. Given this situation it is difficult to perform data entry into any system that is properly designed as per the basic design principles of IS, or else the data needs to be successfully cleaned first of all. Yet, as discussed in chapters 6 and 7, it was extremely difficult to clean the data without being aided by a system, thus leading us to the classical chicken and egg problem. As a result, we were forced to be "out of the rule" and loosened our system temporarily, for example with respect of unique identifiers, until all the data is captured. Once this was done, the data needed to be cleaned systematically since the multiple records per patient (split record) in the system will have devastating consequences. In the mean time, as the clinics needed to use the system while data entry was going on, we had to also adjust our search algorithms encouraging a "fuzzy search" to find best matches by trying to identify a patient using alternative criteria which we initially restricted to an exact identifier and a name lookup before discovering the identifier problems in the backlog data.

Further, given the lack of standards and the variations of work practices (discussed in chapter 6) in the ART clinics, some requirements of ART management are difficult to implement technically. One of the key issues in IS design and development is the knowing of data type in advance so as to predetermine how to physically store and organize the data in the computer in such as way that it can be retrieved for later analysis and communication. But there are some cases where it is difficult to determine in advance exactly what data type an ART clinic uses for a certain data element, and when capturing the data as a text by way of generalization, different spellings were used by the health workers. Thus, though an important advantage to be exploited from electronic systems over the paper-based, validation is hard for such data elements. In this context, aggregation of information across facilities will ultimately be difficult even if a feature of flexibility is incorporated in the system. Hence it is not easy to use coded values to make later analysis possible which made some of the captured data really valueless. But the purpose of capturing data, after all, is to use it later for some purposes.

Similarly, as discussed in chapter 4, one of the basic principles of ART is monitoring the regularity of a patient's follow-up status, and ensuring the meeting of an exceptionally extremely high level of adherence (95%) required. This means that even if a patient does not show up to trigger a transaction (e.g. the capturing of follow-up information) in the clinic, his/her follow-up status (On treatment, Lost, Drop, Restart, Dead etc.) must be automatically updated every month as per an appointment. But the practice is that capturing of appointment dates is often neglected, and even if captured, due to variations of status definitions, we were not sure what status to make the system assign automatically for an unvisited individual patient. However, in the monthly reports it is necessarily expected that one status is assigned for each patient every month. Anyhow, while it may be theoretically possible to tackle such issues technically, in practice it requires the taking into account of several factors, for example the practices in the clinics, and also the technical complexity.

Due to the various system features that were deemed important for HIV/AIDS management and the challenges associated to meet them technically, "off-the-shelf" ISs can hardly meet the requirements.. Furthermore, though the requirements of HIV/AIDS management are broadly similar, there are variations across countries in terms of data capturing and reporting needs for example as we have compared those of Ethiopia, India, and South Africa. Together with the other challenges in HIV/AIDS and ART management, this condition makes it hard to find a suitable ready-made system, and necessitates the development of a system that fits to a specific environment, and which at the same time is very flexible and customizable to various local needs. Building such a system is inherently complex. The date problem we faced in the Ethiopian context demonstrates this situation.

ART management is full of date specific information which is very crucial both to monitor patient's follow-up status and adherence, and also for reporting. But, although all data capturing and reporting formats were in English, the practice was to capture and report based on the Ethiopian Calendar (EC) which, as mentioned in chapter 5, follows a different system. As a result, we discovered quite later during the data entry process that Ethiopian dates such as the 13^{th} month and 30^{th} of February were forcibly converted to garbage values in the MySQL database we used. This called for the need to develop a date converter, and then to clean and migrate huge amount of data into the revised version of the system (IHAMS-ART) which slowed down the implementation process. Worse yet, in the absence of a database technology that works with Ethiopian calendar system, the execution time that an interfacing date converter consumes *necessarily* affects the speed of the ART management system especially when dealing with a large number of patient records and their follow-up information. In our case, this condition was used by some actors to politicize our effort.

In summary, technical issues (for example, the data model and algorithms used) are not to be taken for granted when it comes to systems that would support HIV/AIDS management, and if not adequately addressed, may become causes for failures. Given huge amount of poor quality backlog data, lack of standards, variation of work practices, and lack of unique identifiers, developing a system by perfectly adhering to the established design principles of IT is not really easy. Hence the design and development of an ART system that meets what are called the "ideal" requirements, a complete description of all possible functions of ART software (RHINO, 2004c, p. 2), requires getting fundamentally beyond the basics of IT and system design and development principles. This is especially important given the need to make the system suitable to the messy situations in ART management, such as the case in Ethiopia mentioned above. Without addressing these technical issues, introducing and practically making work ART management systems will be an unattainable task in the context of Ethiopia. We also believe that the duplication of efforts around ART management supporting ISs that organizations such as PEPFAR lamented (discussed in chapter 1), and also the various system failure stories experienced in the Ethiopian ART clinics (see chapters 5 and 6) have implications on the technical challenges of designing such an IS. Nevertheless, as discussed in chapter 3, we are attempting to address some of these challenges by designing an integrated, flexible, and scalable system called Debo (see chapter 3), which we started based on the experiences from our work around IHAMS-ART.

2. Social Challenges

As emphasized in various IS researches (Kling and Scacchi, 1982; Giddens, 1984; Hanseth and Monteiro, 1998), merely taking a technical approach in IS projects has detrimental effect in making them practically work. Various complex social issues are of concern in IS development and implementation efforts. For instance, success in IS projects in developing countries largely depends on the participation of users from the client organization which has several foreseen benefits. However, the interactions IS developers and implementers make with users are not always smooth. Our attempt to work with health workers at different levels revealed some factors around HIV/AIDS management that caused users to go against implementation efforts even if they recognize the benefits of having a supporting system.

Expectations, Past Experience, and Workload: Since requirements documentation was not available in our case, we needed to work closely, and for a sustained period of time, with data clerks in the ART clinics to gather system requirements both before and after the development of our prototype. But working with these clerks was not really easy for various reasons including their expectations and past experience with systems. For example, we were initially formally allowed by the regional health bureau to install and work around the prototype in a certain clinic in Addis Ababa. Nevertheless, we encountered severe resistance from a data clerk working there as she expected a perfect system and was tired of system failure stories which she said she has been repeatedly experiencing. Expectation problems and fear of failure were also seen from upper level health care workers. For example, the regional HIV/AIDS program manager who granted us access to the clinics to implement our system was disturbed when he was informed that there were some features and requirements that our system lacked at an early stage of the prototype. His experience with failed systems in the past and his expectation to receive a full-fledged system in one shot had negatively affected our relationship with him until we addressed it later. Further, once we delivered the system, the clerks in the ART clinic who already had a high magnitude of workload (see chapter 6) objected to start data entry. At times, even who has to get the follow-up cards closer to the computer room became a controversial issue. In general, in this context, without devising strategies to develop social glue, build the users' trust, and manage their expectations, it was very difficult to gain their full support to elicit the requirements and slowly evolve a better and effective working system.

Multiplicity of Stakeholders and their Allocation: The implementation of ART management system in the context of Ethiopia is also challenged by the multiplicity of initiatives and stakeholders surrounding this initiative. Especially problematic is the way the clinics in the country were allocated to these stakeholders. Within the framework of the US aid regime, CDC (Centre for Disease Control) had divided the country into four regions which do not necessarily correspond to the country's administrative boundaries (see chapter 5), and it assigned four American Universities to administer each one "region". This means that different Universities and other stakeholders can have a share of clinics from a particular administrative region. This allocation posed a challenge to us because, when attempting to implement our system in one administrative region, we needed to deal with the various stakeholders involved with which our implementation effort came head on with political undertone.

Scarcity of Resources: The scarcity of various kinds of resources in developing countries is another bottleneck surrounding IS projects. For instance, whatever the type of technology to be adopted, the number of programmers developing the software determines implementation and scaling successes at least during the early stage of a project. In our case, since we started with a relatively small development team size, we have experienced difficulties to carry out the multiple activities the project demanded (see section 8.3). We especially encountered difficulties when attempting to scale up the system and provide support in a large number of sites in the various regions of the country. Although we established an organization of a multidisciplinary team (Lippeveld, 2000), the attempt to scale up the system in SNNPR region by means of a public health professional encountered technical challenges that sought immediate action. Though we were able to promptly respond to this problem over the internet while he was still in that region, the support could not continue once he left the region, thus terminating the project in that region. As a result, with the available resources, we were forced to confine our implementation work in the Addis region and pursue horizontal scaling despite the existence of needs for the system in the other regions of the country too.

Resource constraints also contributed to underutilization of the ART system once it is implemented, the basic reason being the immensity of workload which resulted from intensive patient transactions to meet the mandatory requirement of follow-up regularity and adherence. For example, in one of the bigger ART clinics where we implemented our system, there were 4 data clerks. Initially, the backlog data entry of patient registrations (and not follow-up cases) was made intensively. After reaching a certain stage, however, the manual work which the clerks were principally employed for started to suffer and took them away from the data entry work. Even if we employed assistant data clerks from our project funds to complete the data entry and cleaning work, even these clerks were socially obliged to support the regular clerks on the paper work. Further, the help of the regular data clerks was still required to access the required information and seek clarifications when needed. The overall situation slowed down the process and left the system underutilized. For example, though the staff used the system for searching (of patient registration) purposes, the system could not be used for reporting which required the completion of follow-up registrations. Frequent migrations of data clerks to other jobs after receiving training further intensified the resource problem.

In addition to being an impediment to the proper design of the system, the nature of the backlog data in the ART clinics we worked with magnified the challenges of the implementation processes especially when it is coupled with resource limitations. For example, to exploit the real potential of the system (such as reporting), data entry needed to be completed.. But a chain of complex problems made this difficult. For data entry to take place, amongst other things, the data has to be cleaned with respect to frustratingly many variables including patient identifiers. But as we tried to clarify in chapters 6 and 7, it is virtually impossible to clean the data manually as it required going through about 12 000 patient registrations in one clinic alone, leaving aside the tens of thousands, and in some places hundreds of thousands of follow-up registrations. Given this situation, financial hurdles needed to be solved including for the employment of more data clerks, their training, establishing networks, backlog data entry, and data cleaning. But this involved mobilizing costs for which the health department should have played a coordinating role and shown full commitment which it could not do due to political conditions (see section 8.3).

Even if these problems could be addressed, lack of local capacity to support the systems still keeps their sustainability in question. Ongoing operations such as maintenance and customization of the technologies require the availability of a cadre of local technical resources to ensure long term viability. Although support and sustainability is also an important issue in other disciplines, its importance for ISs in the domain of HIV/AIDS is emphasized by the nature of the disease and its treatment. As mentioned earlier, the supporting IS will require continuous maintenance and support to fix problems and stay up to date with required changes. A chronic care health information system will require chronic technical support and training of humans, regardless of the technology employed. This calls for a formal organization arrangement to support the software, and also dictates its level of funding and stability. In fact, without being a local organization it is very difficult to provide a prompt support in this dynamic context. Nevertheless, although there are many donors trying to support the Ethiopian HIV/AIDS management, virtually all of them are foreign. Further, even if there are quite a small number of local ones, they did not have sustainable funds.

In summary, the efforts to make work ISs that support HIV/AIDS management are challenged by various socio-technical issues. The "making it work" perspective which we will discuss in section 8.3 provides some practical approaches to address some of these issues. Yet, though the socio-technical challenges are clearly not to be taken for granted, our primary focus in this thesis is on the political aspects around the implementation processes.

3. Political Challenges

As discussed in chapter 1, the perspective we take on politics is that it: (1) is self serving and manipulative behavior played to promote self interests; (2) is manifested through struggle for resources, or informal means etc.; and (3) can occur at individual, group, organizational, or inter-organizational levels with resulting outcomes including conflicts, hence seeking to involve resolution mechanisms like coalition building (Drory, 1993; Drory and Romm, 1991). Some works have been done regarding the reasons behind IS implementation politics, the manifestations, and the associated effects (Kling, 1980; Keen, 1981; Markus, 1983). This thesis builds on the genre of IS research (Kling, 1980; Keen, 1981; Markus, 1983) more generally, and HIS implementation studies in the context of developing countries (Chilundo and Aanestad, 2003; Puri et al., 2004; Byrne, 2004; Mosse, 2004; Nhampossa, 2006).

More specifically, within the context of this research, through our empirical analysis, we found the political situations to exhibit some particularities. We identify the scope of politics around the introduction and making work of ISs to support HIV/AIDS management to include various issues and agendas that emanated from the nature of the disease and the multiple actors involved. While we will present in section 8.3 these issues and the various political roles we played from our side to make the project work, in the following discussions we only present the political conditions created from the other actors involved. In each of these discussions, we focus on *the cause of the politics* as we see it and who practiced it, *how it was manifested*, and *the resulting outcomes* that shaped the project (the specific strategies we adopted to address these challenges will also be discussed in section 8.3).

“Concealed Motives”: The obvious influencing character of ISs has been discussed to wreck political situations that shape implementation outcomes through explicit resistance (Markus, 1983). However, in our case, we found concealed motives manifested through intentional and tactical acts of influence to have significant detrimental impact on the efforts to introduce IS that support HIV/AIDS management. For instance, at the beginning of our effort, gaining entry in to the field of HIV/AIDS management in Ethiopia was extremely difficult for us because doors were tight closed both at the federal and regional levels. At the highest level, federal ministry officials used to promote the news, including openly in international conferences (see chapter 6), that a national system was about to come and that any effort around it would just mean a duplication. In fact, the regional program manager in the Addis health bureau from where we were attempting to gain entry and initiate our project in the country, was explicitly told by the HIV/AIDS Secretariat at the FMOH to stop our efforts since, he said, an ART system had already been developed abroad to be implemented nationally in a month’s time. Though we initially took this news to be genuine, we discovered only later that such promises had been made for several years before we started our effort, and that these tactics were used to prevent other initiatives. Later in the process, when we asked a staff at the Addis regional health bureau why the ministry officials said a system was about to come while there was actually no system yet, he told us:

> *"It is difficult to tell. I think there are concealed motives behind the claim. I believe they are significantly influenced by the rich donors around HIV/AIDS management. …Something might have already been exploited by the name of a system, and they have to hide it anyway. If so, you don't have to expect them to tell you this. … For that matter, ministry officials can be influenced by just one person from those donors. It is difficult to make any deal around HIV/AIDS without having as comparable a strength as these donors."*

In any case, the hidden interests at the federal level manifested through systematic influences made it difficult for us to gain entry into the area of HIV/AIDS management as it left regional level officials in a dilemma – whether to keep waiting for the promised system or to accept us and support our effort. For example, the HIV/AIDS program manager at the Oromia health bureau, who worked with HISP for several years around DHIS, admitted that he would get practical help from us to address his needs around HIV/AIDS management. However, for some unknown reasons, he clearly told us that he would not give a try to work with us though he could not yet get a working system. In short, the political weapons used were concealed and fired tactically in a way that it was very difficult to address

Mistrust and Skepticism: ISs are also seen to have a political side because of their potential to induce change with respect to issues such as access and control of information, and hence can be resisted (Keen, 1981). In the negative theory of IS politics, actors are said to oppose and counter IS implementations if they perceive them to result in domination (Morgan, 1997). In our case, we have seen that mistrust and skepticism resulting from past experience can also make IS to be severely resisted and to have political implications. We found the clinic and health bureau staff to have been affected by previous implementation efforts that did not take their needs into account. The repeated experiences of systems failures also made users to be skeptical about the practicality of further efforts including ours. Hence, these issues both at the micro- and macro-levels made gaining entry more difficult for us. Nevertheless, by playing the required political roles in our side to infiltrate the unfavorable condition, we later gained entry and developed a prototype and were granted some pilot sites to implement it (see in section 8.3 and also details in chapters 6 and 7).

Urgency for Solutions: Politics has been viewed to emanate from competition for power where ISs are rejected when perceived to lead to unwanted outcomes of the powerful (Markus, 1983; Kling, 1980). In our case, we found political support from actors who felt the urgent need for a system. For example, informed by us about the huge data management problems in the ART clinic, the client organization, Addis regional health bureau, became increasingly concerned about the situation where the number of patients became difficult to deal with manually. The bureau saw the need to urgently have a practically working system which would help to efficiently manage ART information and avoid the delays and lack of accuracy in the analysis reports which was being experienced repeatedly. It thus started to back our effort by providing more requirements, and also speaking in favor of us including in international conferences where our effort was resisted by federal level officials and other HIV/AIDS stakeholders. The regional program manager also defended ministry officials openly telling them that they have merely been promising systems for the past several years and that the region is forced to urgently look for solutions at its level. As we later encouraged the participation of its IT team in a prototyping process where the system was initially installed and data entry was started at ZMH, the bureau started to increasingly align with us. The same was true for the clinic staff which includes doctors, nurses and data clerks who were challenged by the complexity of the manual work. However, some conditions forced the users to withhold their support.

Fear of "Hidden Ditches": Fear of losing control of information is not the only factor that politicizes IS projects. Reflecting the prevalent political conditions where he did not want some adversaries to point out to shortcomings in the effort he had just started promoting, the program manager, who lacked previous experience working around IS projects, became very concerned about detailed functional issues of the system. In a conversation about his being ultra cautious with us, he said:

> *"At every corner they put hidden ditches for you to make wrong decisions and fall into. …You may be trapped and become phobic of being taken to another direction."*

Due to fear of being driven into the wrong direction, early in the process of the prototype, he always sought a witness of clerks and his own IT team at every step of the process around the evaluation and planning of our project. A similar spirit drove the IT team to be bureaucratic and demanding by requiring features in our system which they did not require from previous efforts, and this forced us to make extra investment in the development work.

Socio-Technical Problems: The various socio-technical issues we have discussed above also had political significance. For example, given the immensity of ART information to be processed and, of course, due to the design limitation of our system and the mandatory involvement of a date converter, the computers with very poor specifications available in the clinics processed some of the reports slowly. Consequently, while they could not yet find another working system, some of the actors involved in our effort– including the health bureau's IT team and the end users – used these issues to point as drawbacks to our system and to delay actions.

On the other hand, some of the stakeholders argued that we have used very sophisticated technologies which, they said, should have been used for regional data warehouse, and not at the clinical level. However, as we have tried to discuss, ART data management is very demanding in terms of technology, and traditional database technologies such as Access can not hold and process the huge amount of data especially in the bigger clinics. In fact, as witnessed by the end users, the bureau's IT team, and the stakeholders themselves (see chapter 7), Access-based database systems supplied by the various stakeholders were repeatedly reported to have dismally failed. Nevertheless, while the clinic staff and the bureau's IT team appreciated the advanced technologies we adopted, stakeholders have used it the other way round to politicize matters and deny the necessary support the bureau expected them to provide for the implementation of our system. Hence, though technical factors by themselves were important constraints in our project, they were sometimes politicized to make matters worse. Even so, we managed to convince the regional health bureau's IT team (see the strategies in section 8.3), and their positive feedback about the system made the bureau to arrange a MOU with us for a full-scale regional scale up of the system. Yet, this movement created the arena for a more severe politics.

Preservation and Advancing of Mandates: ISs can be a source of contention in an attempt to preserve or advance a mandate (Standing and Standing, 1998). In our case, after his IT team and the staff from the different clinics confirmed about the system's effectiveness, the program manager continued to openly advocate the system. He also declared in a regional HIV/AIDS taskforce meeting that he has got a working ART system and that the bureau seeks to go for a MOU and regional scaling. The different stakeholders contended against the program manager's decision saying that they were not given a chance to provide the systems which they claimed they had. Some of these stakeholders had the mandate of supporting the region with ISs and sought to preserve it. Others, though they had other mandates in the region, wanted to work around IS projects to advance their mandates. As a result, while none of the stakeholders could practically present a working system as attested by the bureau's IT team, their desire to preserve or advance their respective mandates led the bureau to a lengthy process of discussion which retarded our implementation.

Fear of "Being Blackmailed" and "Hidden Power": Following the taskforce meeting, different stakeholders through various independent initiatives brought systems and even tried to introduce some of them in different corners of the region without a formal acceptance of the health bureau. Though the program manager was confident about our system, he wanted it to be evaluated against other competing ones in the presence of important stakeholders including from the federal ministry, national HAPCO, and some American universities. Stating his motive to us just before an evaluation meeting, he told us:

> *"As a team work, we know that your system is much better than others' and we will definitely go for its launching soon anyway. But we were afraid of being blackmailed as others might use their hidden power to hinder our progress. All what I wanted was to give them a single chance just this time so that they can see that we did not accept their system merely because their system is not as capable as yours, and there is no other reason behind. Otherwise we know that we can use our power to decide. … Our motive was humble but things are taking different form now."*

Clearly, the program manager sincerely felt that, by making a series of system demonstration and evaluation meetings, stakeholders could be convinced that his sole reason behind selecting our system is its technical superiority over theirs, and there were not other underlying motives. Apparently, he also felt that, by doing so, he will prevent the stakeholders from using their "hidden power" in terms of their established link with the powers to be at the ministry. Unfortunately, as discussed below, things did not go as he expected. Further, the evaluation meetings were not only redundant and unreasonable to us but also often ended up inconclusive. Nevertheless, we eventually managed to get the MOU signed (see chapter 7) though this could not still settle the politics.

Protection and Expansion of Organizational Territory: To implement the MOU plans we needed to mobilize costs of implementation, including employment of more data clerks, training, data entry, and backlog data cleaning. But, while we were processing these, some stakeholders who learnt that the MOU was signed rushed to try and protect their territory. However, not only were their systems incomplete but also were implemented without the bureau's permission. Other stakeholders, who had already made some implementations in the region, started to expand their territory by further implementing their systems and invading more clinics. To do so, they took advantage of the lack of clarity in the allocation of clinics by the FMOH to the different stakeholders, and the fact that some clinics were directly governed by both the health bureau and the federal ministry with which the stakeholders have direct and strong relationships. So it was not clear who is responsible for those clinics in the region – the federal or the region – when it comes to supporting them with an IS. Still, we continued mobilizing costs to realize the MOU plans. To make matters worse, to cover the costs, the bureau depended on one of the very stakeholders, JHU, who were also trying to promote their own system.

However, JHU kept presenting different excuses. For example, they claimed that they had already entered a huge amount of data into their system and could not throw the system away before securing the data. Yet, even if we migrated the data into our system and showed them that the data can still be used, they did not volunteer to support the MOU. Rather, by introducing one precondition after another (for example, further system demonstration and evaluation) JHU systematically delayed decisions and subsequent actions, and left the MOU plans unrealized in time. Thus by diverting and withholding resources and deflecting goals they countered and undermined the project.

Evidently, this shows that the ISs that help to support HIV/AIDS management can become tactical and political pawns for the sake of protecting and expanding organizational territory. This argument, of course, reinforces the argument made by Keen (1981, p. 27-28) who observed that IS implementations may threaten the interests of individuals and groups by intruding on their territory, limiting their autonomy, reducing their influence. Similar patterns of behavior were experienced during the course of our empirical work. For example, commenting on the underlying reason that made such systems a political battleground in Ethiopia, the Plan and Programs Services head at the health bureau noted:

> *"Exceptionally quite a huge amount of money is involved in HIV/AIDS management. Really, the money routed is much beyond the capacity of the country to manage in time. It is one round of fund after another. The current system of the country can not in practice utilize such a huge amount of money. The area therefore is very much exposed to corruption. Everyone involved seeks to secure a pile of the money in one way or another. … I told you. The money being circulated around HIV/AIDS is a tide. That is why donors and health workers compete to work around HIV/AIDS. A number of donors want to involve themselves in some kind of effort around this program. They want areas where they can claim the money is being expended.… When you show them that a certain work can be done around this program, they want to make that work theirs and to stop your effort. They want to work it themselves. If you want to perform anything in this context, you should also come with a tide of money and be ready to drop a piece of it for individuals at each level. Give each one's share even to grass root level people… But you guys are giving merely software and support which can not be converted to money. No one wants that."*

Also, a staff member of the regional health bureau said:

> *"I suspect that JHU might have lied to its money provider [CDC] that it has worked around ART system project in the Addis region. It might have already withdrawn money by the name of the system."*

After learning the difficulty of realizing the MOU plans, the Professor who supervised us asked the Addis regional health bureau's HIV/AIDS program manager what he thought was the reason behind. Confused and tired of the situation, he replied:

> *"I don't really know what they get out of software. I am frustrated not just about this software thing but about the overall process. …They [JHU and others] want to prescribe software like the medicine a doctor does to his patient who can't argue why. We are autonomous. We must not be forced by external supporters. They are here just to support.*

> *…I am very sad that in this area whenever you try out something innovative they resist even to the level of the ministry. … I am trying to fight alone. At this position, I am just sacrificing myself. This is a lot of sacrifice…I am being hammered in every angle. I can continue at this position only if I can make a difference. It is very difficult to make new things and survive in this condition. In this situation, if you sit without doing anything you will be blessed. If not, cursed and hammered from every direction. A lot of traps. Too difficult to imagine. The struggle is not a simple one. This is one chapter, by the way. There are many other chapters with the same challenges. It is actually very difficult to manage such a health system in this country. A lot of people with many diverse interests. Some genuine and every combination. When too much money is involved there is always a problem. It is money that is manipulating. At the same time many people, for example, at home-based care are treated inhumanly. When you see some places in the country, say, rural area, you don't think that you are in the same world. It is as if you are taken from heaven to hell. How can one worship money so much in this situation?"*

Further, very annoyed about the situation, a clinic head in one of the biggest ART clinics who had been expecting our system to support her work immediately, asked JHU officials quite late in our project as they kept setting preconditions to realize the MOU saying:

> *"Why are you making issues about this software as complex as the current national politics?"*

No wonder, therefore, that when the regional health bureau invited an official from an American University to attend one of the repetitive evaluation meetings, she rejected the invitation saying:

> *I don't want to be involved in this dirty software politics.*

Clearly, while some of the motives around our project were clear, rational, logical, genuine, and put forth with our intentions, others were concealed, selfish, irrational, hostile, and incomprehensible. At any rate, as a result of the complicated terrain of political conditions, the systems become barraging chips.

By articulating the scope of politics in our project to embrace a combination of driving factors such as "concealed motives", "hidden ditches", and fear of "being blackmailed", we are emphasizing the complexity associated with the politics of introducing and making work ISs that support HIV/AIDS and ART management. This emphasis resonates with Bull's (2003, p. 2) assertion that that ISs have the potential to become political and tactical battleground. This assertion is magnified in the context of HISs to support HIV/AIDS and ART management in a developing country context due to particular conditions including the involvement multiple stakeholders and the accompanying diversity of interests. The sheer number of organizations involved in this domain makes the politics of making work the supporting systems a daunting task. True, socio-technical factors were important constraints in our project. But, as discussed previously, they themselves were also a function of the political conditions we experienced which were more prolonged and deterministic. Given this setting, without firstly addressing the political conditions around the intervention efforts in this area, practically making work such systems is next to impossible.

In summary, we have shown in this section that the scope of practically making work HISs that support HIV/AIDS and ART management in Ethiopia includes dealing with and addressing various socio-technical-political challenges. In the context of ART management in particular, we especially found technical and political conditions to be very demanding and shaping the processes of making work a supporting system. For example, since the ART systems provided by some of the influential stakeholders (e.g. JHU) were technically incompetent, the client organization and the end users rejected and categorized them as failures. Undoubtedly, given their financial strength and political backing especially from the federal level, these stakeholders would have won the game had they had a competent system and gained support from micro-levels. On the other hand, though the client organization and the end users significantly accepted our system in terms of technological features and fulfilling their requirements, we needed to keep dealing with the surrounding political conditions that hindered us from realizing the MOU plans.

The "making it work" perspective will help to address some of the heterogeneous socio-technical-political challenges that are embedded in the efforts to make work ISs that support HIV/AIDS management in Ethiopia. We now elaborate on this perspective.

8.3 The *"Making It Work"* Approach to Address the Challenges

As discussed in chapter 1, the perspective we take on "making it work" for ISs to support HIV/AIDS in the context of developing countries involves multiple issues. The scope of practically making work such systems includes continually and comprehensively addressing the various socio-technical-political challenges encountered, and also a prolonged effort to sustain the systems.

Theoretically, "making it work" has three key implications. Firstly, it emphasizes the need to look at system development and implementation as a set of activities that far transcends only the technical. This, of course, is not a new argument, and has been made by researchers working with web models (Kling & Scacchi, 1982), social theories like Structuration (Giddens, 1984) and Actor Network, (Latour, 1987; Callon, 1991; Monteiro, 1998) and also in recent years, with the information infrastructure perspective (Hanseth and Monteiro, 1998). However, what is especially emphasized by our notion is the need to also focus on the political and institutional conditions that have significant impact in shaping implementation outcomes. The second is the need to be deeply integrated and rooted with the local realities and micro-level practices on the ground – practices through which the more macro-level political structures are constituted – and also to deal with micro- and macro-level interconnected challenges. Lying within this is the focus on the opportunities (and challenges) that are created through political and institutional conditions, and how these can be used to embed new practices rather than impeding the system from providing real benefits to the stakeholders. This process of linking practices and political conditions lies at the heart of our approach. For example, in our effort to develop and implement the ART system, through our work in the ART clinics we gained political legitimacy at the regional level, and vice versa. Thirdly, the focus on "making it work" implied that the system and its outputs were seen useful by the actors themselves. This is of interest since, very often, IS projects in developing countries focus on the building of the software, conducting some training programs, but do not focus on the real challenge of how the system is made to work institutionally and become useful organizationally. With these three facets which have the potential to mutually support one another in a structurational logic, "making it work" emphasizes the building of a counter network (Castells, 2000) to try and perform the activities needed.

With this underlying principle of "making it work" at the backdrop, we focus on some key approaches and specific strategies employed by us to make our project work.

8.3.1 The Major Facets of *"Making It Work"*

In this subsection, we briefly present the major facets of "making it work" that helped us comprehensively address the socio-technical-political challenges we encountered, with a focus on how each of these facets was realized. In the subsequent subsection, we will describe the specific strategies we adopted in particular to make our project work politically, and also on how the different facets of "making it work" were exploited politically.

1. Gaining Entry

Access to the healthcare sector in general is very difficult since, by its very nature, the sector is intensely political (Braa et al., 2004b). However, as mentioned previously, we found the situation to be magnified in the politically charged case of HIV/AIDS due to the involvement of huge amount of money and the associated multiplicity of actors including donors. As a result, using various tactics (see section 8.3 and chapter 6), we needed to firstly penetrate the political and institutional conditions surrounding our effort. For instance, we approached the Addis regional health bureau HIV/AIDS program manager through a local HISP researcher with whom he had worked in another project under the HISP initiative whose reputations he acknowledges. Subsequently, through a series of presentations and discussions with him, we communicated ideas and discerned his concerns which we promised and addressed in short period of time unlike the other donors who disappointed him by failing to deliver what they promised. For example, after exerting effort vigorously, in two weeks time, we demonstrated to the bureau staff the prototype we developed which further boosted their confidence and paved the way for us to embark on subsequent efforts. In short, without infiltrating the politics and gaining entry which we found a mandatory condition, we could not be able to carry out the subsequent intervention actions.

2. Building Local Capacity

To address the various socio-technical-political challenges surrounding us and render the services the full range of the project demanded, our capacity needed to be built in various facets of the problem domain including understanding the structure of the HIV/AIDS program, and different public health issues such as the terminologies used in the ART paper formats. Given the absence of useful requirements document, building our capacity in this particular area was crucial since without it we would have been hard pressed to design the ART system. Our capacity also needed to be built with respect to the technologies we adopted to develop the system. Further, as we lacked previous experience around IS implementation, we needed to build the capability to develop social relationships with important health workers since, without it, it would be difficult to practically make the project work.

Figure 8.2: A fellow student who initially provided us with technical support

As discussed in chapter 3, though locally based, our being within the international HISP network where we enjoyed the company of various experts was very important in building our capacity in these areas (see chapter 6). For example, in the process of developing the prototype, we initially built our technological capacity with the support of a fellow student in the HISP framework (Figure 8.2). Moreover, with the help of the professor and one of the medical doctors (Figure 8.3), some of the research participants referred to in the methods chapter (3), we visualized the ART initiative in the context of the overall HIV/AIDS management and saw the existing interconnections. Further, since there were also public health specialists within our network, we were able to understand the medical terminologies used in the various formats, and also the information and analysis needs from the doctors' perspective and incorporated it in the system.

Figure 8.3: Discussion with the professor (middle) and the medical doctor (left)

Being local, it was also easier for us to be able to follow-up the system and provide support and maintenance services around the system. Altogether, these contributed for technical competence of the system unlike the systems from the competent providers. In general, the building of our own capacity being within such a diversified team, and the resulting useful features of the system which addresses the needs of the health workers at various levels including clerks, doctors, region level workers (see chapter 7), have altogether also helped us to secure political support successively in the course of the project.

3. Building Political Counter Networks

While infiltrating political conditions and gaining entry to initiate the project was one thing, maintaining the political backing was quite another. As Williams (2003, p. 13-14) noted "*political winds can change direction well after the IT project has left port. Political pressures can … cause funding to dry up, and simply crush a project in short order.*" In our case, as the development and implementation processes continued after the program manager granted us access to the field, we needed to continually face the severe resistance the project encountered particularly from competent donors who also challenged the program manager. To bear this unrelenting and lingering political condition, as an important facet of making the system work, we needed to gradually build a kind of counter-network (Castells, 2000) to try and counter the mainstream power dynamics originating through these donors.

In addition to ourselves and the research participants from the local and international HISP team (see chapter 3), this network included the various micro- and macro-level health workers we managed to progressively enroll into. The enrollment of macro-level officials like the program manager during the gaining entry process helped us to influence and also enroll those at the lower level including the health bureau's IT team and the staff at the clinics who also shaped the project. For example, as we involved these people in the project, we delivered a system the kind of which they could not find from previous efforts. The social circle created from their participation, and the resulting technically competent system that was considerably accepted by them, contributed to both build the confidence of macro-level officials, and also for them to resist other IS implementation efforts made by comparators which they categorized as impractical. Thus, had it not been through this network we could not have gradually cultivated political relationships and exploited these opportunities that are created through the political conditions. For instance, through this network, depending on the nature of the actor, we adopted political tactics like bargaining and negotiating with some actors, or eating around and overthrowing hostile and irreconcilable ones such as by making their efforts despised as compared to ours.

4. Adopting Suitable System Development and Implementation Approaches

As one of the key facets of making work our project, we focused on the adoption of appropriate development and implementation strategies that suited the specific application domain. Strong proponents of technology often argue for a radical change in producing software product. But, apart from a mere focus on the technology, this does not take into account complex contextual factors that affect IS projects. To yield to the complex socio-technical-political challenges surrounding our effort, we needed to make the various activities of our project to be steady processes. For example, since there was lack of well developed requirements documentation to discourage rapid system development, it was only gradually that we designed, developed, and implemented our system. Three distinct methods were adopted by us in these processes:

Evolutionary Prototyping: As the name itself is explanatory, evolutionary prototyping is a method of evolving software, and clarifying requirements (Sommerville, 2001). The method presupposes and depends on the participation of users to understand their requirements. “As users develop a better understanding of their problems, this can be reflected in the software system.” (Sommerville, 2001, p. 47). In our case, we rapidly developed an initial version (prototype) of the ART system from very abstract specifications (see chapter 6), exposed this to user comment and feedback, found out more about its problems and possible solutions, and then refined it through many versions until a reasonably adequate system that satisfied the users’ needs was developed. The prototype thus interleaved and served two major purposes – requirement elicitation and requirements validations (Sommerville, 2001, p. 172). The method also helped us to try out different design options, and also allowed to conduct early informal on-site training sessions to the users before the final version of the system could be delivered. These sessions helped us to manage the users’ expectations by gradually making their expectations more realistic, and also to establish a kind of social relationship with them that latter helped us politically.

Incremental Approach: Within the process of evolutionally prototyping, we adopted an incremental approach which is a strategy of choosing a priority area, developing the system, and handing in to the users (Sommerville, 2001). As our vision was to cultivate a system to support the Ethiopian HIV/AIDS management which comprises of multiple initiatives, we first consulted the Addis regional health bureau from where we understood ART management to be a priority area. As we involved particularly the data clerks and the physicians in the ART clinics, we discerned the need to give priority firstly to the putting in place of the basic functionalities even within ART, and incrementally provided other ‘luxury’ features with further comments from the users. As we have discussed in chapter 3, with the ongoing development of Debo we are also attempting to go incrementally towards an integrated HIV/AIDS management system.

Participatory Approach: The approach of participatory design helps facilitate the client’s learning of technology in the process of providing detailed information about their requirements and the surrounding practices. In our case, through the processes of evolutionary prototyping and incremental approach, we encouraged the participation of the public health specialists in our team, the health workers at the regional health bureau, and the clinic staff particularly the data clerks. We also used other methods of participation including formal and informal discussions, workshops, meetings, informal on-site training which are methods that have been also used by other HIS researchers (Byrne, 2004; Puri et al., 2004). The adoption of a participatory design approach in our project helped us in several ways.

First and clear, the contribution of the participants helped us develop a technically competent system. Secondly, it created a space for local participation and developing the capacity of the users to understand their requirements and to learn the technology in the mean time. Thirdly, taken as it is, the approach had political significance in that it helped us to progressively cultivate political relations with some of the most influential actors from the user community, and reduced the users' inherent tendency to resist (Markus, 2002) our effort. This is considerable given that the users were initially pessimistic about our effort since they were tired of such efforts based on their experience from previously failed efforts. But, most importantly, since the participation of the users helped us focus on the practices and address their real needs, their positive feedback about the system to the bureau's IT team and the regional health bureau's program manager helped us gain political backing from the more macro-level. We have thus seen that this approach had socio-technical-political significance in our project.

By and large, the development approach we adopted in our project to gradually cultivate the system and implement it enabled us to address several situation specific contextual challenges of socio-technical-political character. For instance, we addressed some of the various technical challenges that are specific to the Ethiopian ART management as mentioned above. For example, understanding the local reality, we kind of violated one of the basic principle of IS design and adjusting ourselves to loose our system with respect to unique record identifiers so as to make the entry of the backlog data possible with all the defects for a later cleaning, and also made possible "fuzzy search". Also, to fill the gap created from lack of database technology that accepts Ethiopian dates, we designed a date converter. As a byproduct of technical competence and user need satisfaction, we secured political support at different levels which was very important to take the effort forward. In short, the development and implementation approaches we adopted were suitable to the specific context we were working in that they provided us with flexibility, for example, with respect to the timing of training and ways of gathering requirements which can not get had we used procedural methods such as water fall.

<u>5. Institutionalization and Ensuring Sustainability</u>

Coming as other important areas of concern in the effort to make the project sensibly work are the interrelated issues of system institutionalization and sustainability – important factors contributing to failure when not addressed (Braa et al., 2004b). Sustainability refers to the tendency of the system to endure over a long span of time, and calls for the ability to identify and manage risks threatening its long-term viability (Korpela et al., 1998). On the other hand, institutionalization is the process by which ISs can be sustained over time (Braa et al., 2003). It was defined as "the process through which a social order or pattern becomes accepted as a social 'fact'" (Avgerou, 2000, p. 236). Regardless of their technical value, IS can be accepted through socio-technical-political processes as a social fact and be maintained because of their legitimacy.

In our case, having developed, implemented and scaled up the system, we had to also work around institutionalizing the system and sustaining it, especially given the political challenges that continued to surround us. With respect to institutionalization, we particularly focused on the local realities and micro-level practices in the ART clinics, and then accordingly incorporated in the system features which were seen very useful by the health workers at different levels (see chapter 7). As these functionalities were especially seen useful by the data managers, they started to use the system in their everyday work, and became locked-in to it for some of the basic issues in their routine work to the extent that the head in one of the bigger clinics felt that it is impossible to work without the system. With respect to sustaining the system, we kept to deal with the socio-technical-political issues that needed to be addressed. For example, by closely following up the system and continually upgrading it with the inclusion of features to serve the users emergent requirements, we attempted to provide it a distinctively competent character, and hence steadily changed the users' attitude towards the system and its acceptance. When the need arose, we also maintained the system, provided supervision services around data entry, and also built the capacity of the users through successive trainings. Thus, through the provision of continuous and practical technical support, and with the users as a political mouthpiece, we are attempting to successfully counter the sustained resistance originating from the competent donors.

Altogether, from the five facets of "making it work" mentioned above as applied in our project, we have seen that: (1) the development and implementation of such systems far transcends only the technical, and seeks to focus on the political and institutional conditions that the area presents, (2) a real attempt of making work such systems in the context of developing countries seeks to be deeply integrated and rooted with local realities and the micro-level practices on the ground, and also to deal with micro-and macro-level interconnected challenges, and (3) to make such systems practically work, focus should be made on the real challenge of how the systems and their outputs are made to be seen useful by the actors themselves and also organizationally.

In summary, as emphasized in chapter 1, we found from our project effort that the scope of practically making work the ISs to support HIV/AIDS management in Ethiopia includes the addressing of various socio-technical-political challenges comprehensively, systematically, steadily, and continuously. This calls for the need to be stretched and encompass all the activities that seek to be performed from initiating the IS to sustaining it, and hence is a prolonged effort. In the specific context of the system to support the Ethiopian ART management, we have seen the significance of five distinctive facets of "making it work", namely, gaining entry, building local capacity, building political counter networks, adopting suitable system development and implementation approaches, and institutionalization and ensuring sustainability. Within each of these activities, we have used distinct methods to make the system work. For example, with respect to system development and implementation, we have used the methods of evolutionary prototyping, incremental approach, and participatory approach, and have found them to be suitable to the application context. Clearly, yielding to all the activities constituted in the different facets of "making it work" is not trivial.

Following this, we describe the specific strategies we employed to make our project work politically since we found it more difficult and sustained, and necessarily needed to be dealt with continually. We also discuss the political relevance of the above mentioned facets of "making it work".

8.3.2 Strategies to *"Making It Work"* Politically

> *"[Politics is an issue] of fundamental importance to the effective exploration of computer technology."* –Keen (1981, p. 32)

While we have already presented in section 8.2 the political conditions created by the other actors involved in our project, we now discuss the various political roles we played from our side. We focus on the ten major strategies adopted by us to make work our project politically, both with respect to gaining entry, and also with regard to dealing with the political condition that sustained even after we gained entry. This will emphasize the roles of politics in "making it work". While it may be too early to judge the success of our strategies, we argue that a strong base has been established by our approach to navigation with the ongoing political issues. The signing of the MOU is a clear recognition of the confidence that the bureau has in our efforts and competence to make it a successful project. The main strategies used by us are:

1. Exploiting the Political Power of Qualitative Methods

Qualitative methods such as discussions, meetings, and presentations are often employed to find out facts in a study. In our case, these techniques also had political significance, for example in the process of gaining entry into the country's HIV/AIDS management. For instance, while we utilized the reputation of HISP and the link it already established with the Addis regional health bureau, it was importantly the discussions and presentations we made in the various meetings with the bureau staff that helped us penetrate the political condition that surrounded our effort in our attempt to gain entry. Using a series of such sessions, we communicated ideas in particular with the regional HIV/AIDS program manager. For example, from repeated discussions, we discerned his interests, concerns, the local needs, and made promises accordingly, and then revolved our efforts around relevant works. The meetings and discussions also helped us to emphasize our being locally based, the broad mix of our team – technical, public health, and HIS – and also its global dimension. Further, since the program manager told us in the discussions that some donors cancelled meetings and failed to deliver the systems they promised to him, we presented clear plans and scheduled deliverables. We also made Power-Point presentations of how we viewed things and communicated with the health workers the ways we wanted to approach them. Even later in the project, we used meetings and discussions to communicate with the program manager and others, for example we alerted them about our opponents' tactics of buying time and exposed their motives. In short, had it not been through these methods, it would have been hard to convince the regional health bureau staff and to gain entry, and also to deal with politics that continued after.

2. Buying Time: Promising the Future, but Addressing the Current Problems

As discussed in chapter 3, our vision was to integrate all the programs and services in the HIV/AIDS management, with the ART providing our point of entry. In our presentations to various groups, we deliberately called our system as IHAMS (Integrated HIV/AIDS Management System) and not ART as it presented a futuristic vision within the desired government agenda of integrating the different HIV/AIDS related interventions (see Figure 8.4). Current problems around the ART system, for example the manual load of data entry and the time taken to produce the reports, had been expressed in many forums and required immediate attention. Politically too, focusing on ART was desirable, since the policy makers were urgently trying to scale up the ART intake, for which we argued there was the accompanying need to strengthen the information systems. We thus tried to gain political support from both the field and bureau levels. Politically, since we were also competing under the American threat of an alternative system, it was important for us to position our system as something much superior to what a regular vendor could provide. Presenting this integrated vision of IHAMS that could be slowly expanded from the initial ART IS was one such way to compete. We also emphasized the superiority of the design approach we would adopt from other perspectives – patient specific, one that would meet existing needs and incorporate important functionalities. Further, in addition to integration we also promised flexibility, scalability and customizability of the system in the future. More importantly, the initial focus on developing an ART solution helped us to buy time to develop subsequently the other features. As the trust in us increased, the health staff were more willing to give us time, and also were content (for the moment) with the immediate solution to the problems in the ART management they were experiencing.

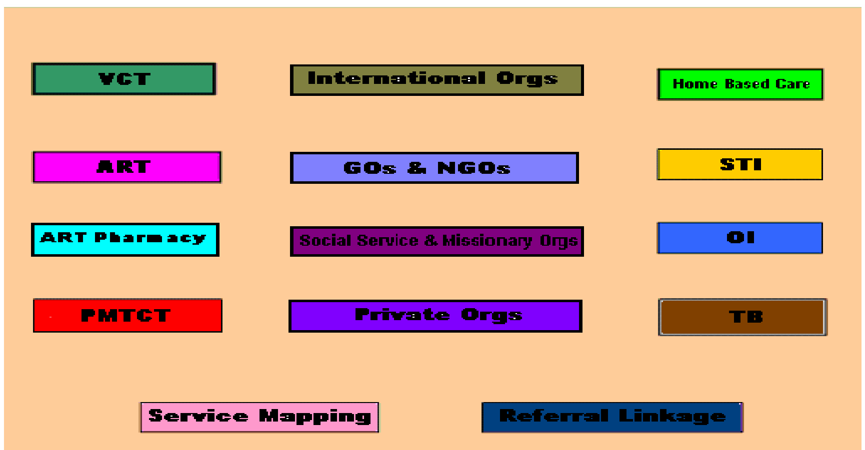


Figure 8.4: The IHAMS Vision

3. Exploiting "Windows of Opportunities"

The other important strategy we adopted to infiltrate and deal with the politics was through using the existing openings available, and also the various "windows of opportunities" created from political hesitancies. For instance, we exploited the opportunity created through the delays and the undelivered promises of the donors. For example, in March 2006, around the time when we had requested permission to begin our work, we were told that a system from a particular donor was already secured and that a person was assigned to train and introduce the system both at the regional and national levels. While this undelivered promise was disappointing especially to the program manager, it represented an opportunity for us to introduce our project, and we were successful in convincing the program manager to give us a chance. We persuaded the program manager telling him that "that systems are promised does not necessarily mean that they will come, and furthermore there is no guarantee that they will fulfill the requirements and succeed" at which point he concluded "let the best system win."

Moreover, although the past experiences with regard to system failures were disappointing to the health workers and initially created resistance in our effort to gain entry, we have seen later their usefulness since the health workers compared our system with the failed systems in previous efforts and appreciated it. Further, though negative in themselves, the lack of requirements documentation and the complex settings of some of the clinics we have been were useful opportunities since they served us as the base to motivate the health workers to participate in the project which, as discussed below, had significant political impact. Similarly, the national, regional, and clinic levels desperate crying for an ART system helped us to gain hearing ears. The decentralized governance structure in Ethiopia (see chapter 5) where there is a measure of autonomy to the regions to develop their own initiatives and support any useful effort, provided us with another window of opportunity. Despite federal level endorsement being not easily forthcoming to us because of the involvement of a variety of actors, the regions still were able to accord us permission to start the implementation process, which we did in two regions, and had direct requests from 3 other regions. However, this regional autonomy proved to be a stumbling block when we tried to scale up our system nationally because we still had not received federal endorsement.

4. Playing the Politically Charged "Free and Open Source Software" Card

We played the Free and Open Source Software (FOSS) card, ensuring the health department will not pay for licenses, to help gain entry and also in supporting the scaling process. In negotiating entry, the program manager did not need to take any permission from upper levels since there were no cost implications, and at his level could allow us access. The ready access to source code to fix bugs or to accommodate emergent requirements was very useful in supporting our rapid prototyping strategy, and with this building the user's trust in us. Scaling was also enabled as we could install the application on the machine of any user without having to worry about license requirements.

On the flip side, FOSS may also come with its disadvantages, particularly in the context of developing countries, as it closes out the room for passing favors often prevalent in software purchases from commercial vendors. A further downside is that managers often do not take FOSS providers seriously because the system is free and thus seen to be without value and unprofessional. On the positive side, FOSS provided a clear advantage to us when compared on a cost-benefit criterion with other commercial software. Avoiding vendor lock-ins is another advantage of the FOSS approach which we provided. For example, the ART program head of an American University felt that a prior system developed by an American developer did not work because, as she said, he was hiding all the code and documentation. By and large, the absence of risk with the zero cost experiment and free software, strengthened the regional program manager's exit strategy of "let the best system win [out of the system promised by us and the competitor donors]", and to grant us access to the field.

5. Igniting the Implementation Process

Once we gained entry into the field of HIV/AIDS management, we immediately developed a prototype with the basic functionalities in place, and installed it in the pilot sites where we were permitted to work with initially. However, due to the manual workload and limited number of data clerks, no one was willing to actually start using the system. Hence, from HISP funds, we employed assistant data clerks and made them to be supported by the regular clerks in the data entry process. Though trivial it might seem, the hiring of the assistant data clerks and the starting of data entry served as a jumping board to practically initiate the implementation process at an early stage of the project. Had we not started the process this way, it would have been very difficulty to get it started since permission and resources from the regional health bureau to hire more clerks was not easily forthcoming. Once we ignited the implementation process this way, however, people at different administrative levels started to take our project effort as a real one.

By and large, the installation of the prototype, the immediate hiring of the assistant data clerks, and practically initiating the data entry process, altogether proved to be a crucial turning point in the project in several aspects. For example, it helped us effectively elicit the requirements of the ART program including issues which we might not discover even if documentations were available given the messy conditions in the clinics. Moreover, it helped us to improve the system gradually, and also created the basis and led to the subsequent actual implementations.

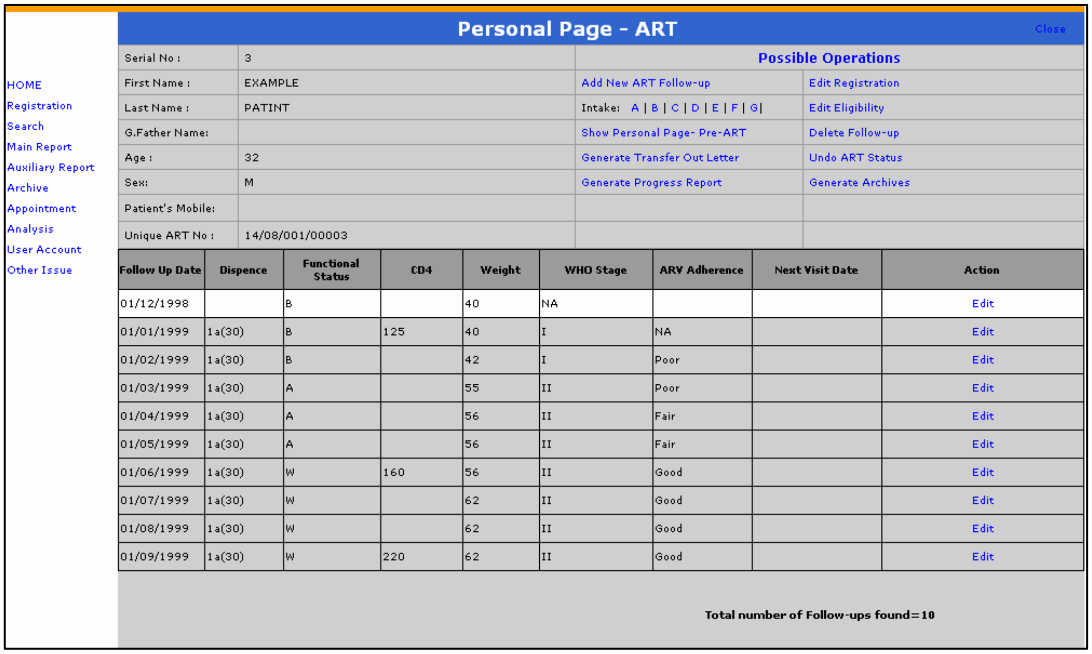
6. Grounding Efforts into Micro-level Practices and Local Realities

When cultivating the prototype, we started to adopt system development and implementation approaches that have intrinsically political character, and ones that were moldable to be. For example, rather than locking ourselves in a lab and delivering a finished product as it was with the efforts of the competitors, we encouraged the participation of the health workers and, in the process, we discovered what their real and immediate needs were, and then attempted to address them. When evolving the prototype and incrementally incorporating the different functionalities, we preferred to focus on the micro-level practices and local realities instead of sticking to certain hard and fast IS design and development rules. For instance, as mentioned above, the practice of registering patients without a proper unique identifier and the poor quality of the backlog data were some of the realities that forced us to loose our system and find practical but alterative ways to address such issues. Our being flexible this way to base our efforts on local realities when designing and developing the system, and the intensive participation of the health workers throughout these efforts mutually helped us to progress politically since they provided positive feed back to macro-level health workers which they did not do in the efforts of the competitors. Further, we provided informal on-site trainings to the users for each improvised version of the system, and since the data clerks who themselves were IT literate and saw the system from different perspectives, we found the comments obtained from these sessions to be particularly excellent methods of further improving the system both with respect to incorporating functionalities and fulfilling the requirements.

In addition to exploiting the political power of the above mentioned design issues and participatory approaches, we also benefited from some technological concerns. For example, since the health workers experienced technologies such as MS-Access in the failed systems, we emphasized the superiority of the technology we adopted – FOSS, web-based, and also the capacity of the database technology we used (MYSQL) as compared with the ones they have been experiencing. Repeatedly demonstrating the system with all these features to the program manager, who already liked our being local and the composition of the expertise in our team, boosted his confidence.

7. Exerting Marginal Effort and Yielding Value Added Features

While cultivating the prototype with the involvement of the health workers and the public health specialists in our team, we started to have a good database with real patient data. Given this and the capacity we have been building, entirely of our own volition we went beyond fulfilling the “official” requirements and provided various value added features by exerting only marginal efforts. For instance, without much deviation form the logic of the manual system, we improved the workflow of the system in such a way that data entry and navigation around the different corners of the system became shorter and not time taking. For example, we made each patient to have a personal page with all the possible operations to be performed and provided links to switch between functionalities and hence reduced journeys (see Figure 8.5). We also provided features that, when entering the patient’s current month data, would automatically replicate the data that was entered the previous month if it was logically replicable, and provided edit functionality to be used when replication was not of interest. These functionalities added high value to the system given the high volume of data that needed to be dealt with. In certain cases, by trying to replicate the logic and workflow of the manual system we attempted to the users feel easy to work with the system and kept the transition gradual.



Follow Up Date	Dispence	Functional Status	CD4	Weight	WHO Stage	ARV Adherence	Next Visit Date	Action
01/12/1998		B		40	NA			Edit
01/01/1999	1a(30)	B	125	40	I	NA		Edit
01/02/1999	1a(30)	B		42	I	Poor		Edit
01/03/1999	1a(30)	A		55	II	Poor		Edit
01/04/1999	1a(30)	A		56	II	Fair		Edit
01/05/1999	1a(30)	A		56	II	Fair		Edit
01/06/1999	1a(30)	W	160	56	II	Good		Edit
01/07/1999	1a(30)	W		62	II	Good		Edit
01/08/1999	1a(30)	W		62	II	Good		Edit
01/09/1999	1a(30)	W	220	62	II	Good		Edit

Total number of Follow-ups found=10

Figure 8.5: Screenshot– A Patient's Personal Page

Data Captured with Poor Quality

Error Types	Serial No	Unique ART No	ART Follow-up Date
ART patient without CD4 count	3	14/08/001/00003	01/03/1999
ART patient without CD4 count	3	14/08/001/00003	01/12/1998
ART patient without CD4 count	4	14/08/001/00004	03/09/1999
The weight of a patient is left 0	3	14/08/001/00003	01/12/1998
The weight of a patient is left 0	4	14/08/001/00004	03/09/1999
A patient is registered as Trasferred out without where to go	1	14/08/001/00001	03/01/2001
EDD not filled for a pregnant woman	1	14/08/001/00001	01/06/2000
You left functional status None for ART Patients	3	14/08/001/00003	01/12/1998
You left functional status None for ART Patients	4	14/08/001/00004	01/02/1999
You left functional status None for ART Patients	4	14/08/001/00004	03/09/1999

Figure 8.6: Screenshot – Data Quality Checker

Other valued added features we bestowed include: improved validation mechanisms that boosted the confidence of the data clerks with regard to the accuracy of the reports for example with respect to sex, ways to check the quality of the data in the system (see Figure 8.6), appointment scheduling, multiple searching and analysis mechanisms, and color codes to easily distinguish the status of patients (e.g. on Pre-ART or on ART). We also scaled up the system functionally by including features such as patient progress reports (see Figure 8.7). Thus the different features of the system were seen useful by the health workers at different levels – clerks, doctors, clinic head, and also at regional level – and were exploited for political success (see chapter 7).

Patient Progress Report

First Name	EXAMPLE	**Sex**	M
Last Name	PATINT	**Unique ART No**	14/08/001/00003
Age	32	**Card No**	

Follow up Date	CD4	Weight	Functional Status	Regimens	ARV Adherance
01/01/1999	125	40	B	1a(30)	NA
01/02/1999		42	B	1a(30)	Poor
01/03/1999		55	A	1a(30)	Poor
01/04/1999		56	A	1a(30)	Fair
01/05/1999		56	A	1a(30)	Fair
01/06/1999	160	56	W	1a(30)	Good
01/07/1999		62	W	1a(30)	Good
01/08/1999		62	W	1a(30)	Good
01/09/1999	220	62	W	1a(30)	Good

Number of Follow-ups = 9

Figure 8.7: Screenshot– Patient Progress Report

8. Enrolling the Political Champions, Developing Social Glue, and Building Trust

> *"That this system fails means I failed. Just keep working, forget the politics."* – A data clerk to the research team

Various actors that had significant political contributions in our effort needed to be enrolled into our network throughout the project processes. As mentioned previously, we started enrolling the political champions by enrolling the regional program manager in the process of gaining entry, the first champion who played vital roles in the overall process. Other important champions from the micro-level who played significant roles were also progressively and gradually enrolled during the system development and implementation processes (see Figure 8.8). We adopted a strategy of "enrollment based on addressing needs and meeting interests" where actors noted the usefulness of the system in which some features were incorporated based on their comments, and started to value it especially after we ignited the implementation process through the data entry process. For example, a clinic head who was initially indifferent about our effort started to better communicate with us on how to take the project forward once she observed that the system has eased the works in her clinic. Using the witnessing of the data clerks and other clinic staff about the system, we also made the regional health bureau's IT team part of our network by inviting them to see how the system is operating and what is going on around it.

Figure 8.8: Enrolling micro-level workers by meeting their interests

Apart from the mere enrollment of these actors, we needed to work more on developing social glue and building their trust in us so that they can make practical differences in wining the political conditions that surrounded our implementation effort. For instance, the clerks typically recommended the hiring of their friends when we wanted to employ assistant clerks for data entry. This helped us strengthen their favorable attitude towards us and developing social glue. The process of data entry was not only a means of cultivating the prototype but also created a very good atmosphere to develop social glue and secure the trust of the people in our network which was the basis for the successes achieved later. Since there was no requirements document, there were several things which we were unable to easily understand by analyzing the data capturing and reporting formats, and hence we necessarily depended on the actors explanations. As they helped us to understand things which we incorporated in the system, not only did the environment in this setting tied them up with us socially, but they were also developing trust in the work in which their contributions were continually and practically made intact in the system. Their confidence in the system was even boosted as we asked them detailed questions and, based on these, incorporated elegant features that they never thought of. As the system was shaped up in a good way with their being part of the overall process, they developed to it a sense of belongingness to the extent that one data clerk told us with confidence saying: "*that this system fails* *means I failed. Just keep working, forge the politics."* Comparing with her previous experience she also said:

> *"I have seen about four systems so far. …I just evaluated … using my little IT knowledge and discarded [them]. This system is not perfect too but you have always been working with us and I understand the system very well. …On this one …it is not only me, the doctor, you …all participated. That is why it reached here."*

The series of presentations and the discussions in the various meetings with the clinic and bureau staff, and also the informal gatherings we had with them were also other opportunities of developing social glue and building trust. Progressively demonstrated the various versions of the system with its newly added different features, helped us steadily build the trust of people at different levels all the more. Further, after data entry was carried out for one month particularly in two clinics, we compared and contrasted the reports generated from our system with the manual reports, and through a process of verification (see Figure 8.9) we attested nearly a 99% matching of figures the errors being mostly identified due to the problems in the manual system. The logic of the system was thus accepted to be correct, thus helping to build the users' sense of trust. So by providing a tangible product with practical support, we inspired confidence both on the technical and social fronts.

Figure 8.9: Verifying reports

In short, by enrolling the important actors gradually and then building social relations and trust, we were not only cultivating the system in such a way that it becomes technically competent but also building up a political counter network through which we developed political relationships that helped us make the system work politically.

9. Playing Multiple Roles and Institutionalizing the System

To make our project work politically, we needed to play multiple roles from initiating the project to sustaining it. The roles we played with respect to gaining entry and also with regard to system development and implementation may seem obvious ones. However, various activities sought to be performed within each of these that may sound unimportant, but were demanding. In the process of gaining entry, for example, we needed to provide many explanations to the bureau's IT about the workflow of ART management and the associated problems of the manual system which was new to them at that time. In the processes of system design and development, we needed to manage the expectations of the bureau staff by clarifying that these processes are gradual and that incorporating new functionalities will take time especially given the complex situations in the clinics and the lack of requirements documents. We also acted as consultants when providing in depth explanations, for example, about the pros and cons of different development technologies to both the IT team and the program manager. In the attempt to realize implementation, we had to help the regional health bureau by making presentations on their behalf to different stakeholders (such as donor agencies and federal authorities) to strengthen our political support and also to secure funds with which to get implementation expenses covered.

Figure 8.10: Providing support

Moreover, while the bureau staff had rather general ideas about the benefits of computer systems to support ART management, they did not fully understand some details very well such as how the problem of poor quality data is related to the deeper problem of the lack of a unique identifier and how this, in turn, affects data entry and the overall implementation process. Building this awareness and knowledge was an important part of our work. Further, for some aspects of the implementation process such as system walkthrough, report verification, informal-onsite trainings, data entry, and data cleaning, we needed to literarily work fulltime with the clinic and bureau staff continuously for several weeks. Besides these, we were also involved in bringing practical changes in the work procedures at the clinics when disagreements arose among the clinic staff that would affect the data entry process.

Furthermore, to make some features of the system practically utilized, we needed to discuss with the doctors and nurses, and enabled changes in the ways they filled the patient follow-up cards, for example with respect to next visit date which would affect the exploitation of the system's appointment scheduling feature. On top of these, we closely followed up the system while it was being used and provided sustained supervision and support services to clerks while data entry was going on (see Figure 8.10). In short, we played various roles including being developers, trainers, implementers, political dealers, consultants, supervisors, and maintainers.

With respect to institutionalizing the system, we benefited from grounding our efforts into the micro-level practices and the local realities, and also from yielding value added features. These features which gradually but continually scaled up the system served the interests of the health workers at different levels – clerks, case managers, nurses, doctors, clinic head, and also at the regional level. For example, given the significance of patient's adherence to treatment in ART management, finding out lost and dropped out patients with the important information to trace them was very essential. However, locating such information in the manual system was not easy for the staff especially in the bigger clinics, and case managers and the bureau staff were affected by the delays. Having the functionalities which addressed these issues, the system was seen very useful by the actors involved. Several other features were seen beneficial and made it exceptionally competent especially since they were incorporated based on the actors' suggestions which strengthened their sense of ownership and belongingness (see chapter 7). We believe that our ongoing attempts to institutionalize the system more and more, will contribute to sustaining it as has been the case so far. In short, the actions of incorporating important functionalities that were enjoyed everyday, and our playing of multiple roles such as providing support when needed were not only the gradual means to enroll the political champions in the process but also to institutionalize the system organizationally.

10. Building Coalition with Influential Actors and Overthrowing the "Bigger Empires"

Through the possesses of enrolling the champions and adopting the other strategies mentioned above, we were actually attempting to build coalitions with influential actors as much as possible and, when not, overthrowing the most hostile ones even if they appeared to us as "bigger empires". For instance, though it was not easy, it was very important that we cultivated political relationships and secured the support of macro-level officials from the health department such as the regional HIV/AIDS program manager, and also that of the micro-level health workers to succeed in our efforts. Accordingly, we have achieved this by using the various tactics mentioned above. Nevertheless, despite we recognized the significance of collaborating with some others in the HIV/AIDS management, their persistent hostility to the project forced us to prefer to systematically eat them around and overthrow them. For example, while the implementation process would have been facilitated if we had gained the support of JHU on which the bureau also heavily relied, such support was not forthcoming even if we attempted to collaborate (see chapter 7). Consequently, by using tactics such as providing informal on-site training, we succeeded to erode and loose the dependency of the bureau on JUH to the extent that the bureau eventually removed JHU from the list of supporting the scaling process as per the MOU. Therefore, in our process of building coalition with the influential stakeholders such as the bureau, there was a nested process of weakening the adversaries to overthrow them.

As discussed in chapter 7, such strategies we played around our project in Addis helped us better succeed politically in this region than in the other regions where inadequate effort was made to adopt such strategies by us and the other research participants involved in those regions. Yet, continued effort should still be exerted even in Addis to sustain the system since the political situation has not cooled off. Further, given the possibility of staff reshuffling at the regional health bureau that may result in evaporating the support we are currently enjoying (Braa et al., 2004a; Braa et al., 2004b), it may still be important to work out and mobilize further support.

In summary, while it was not trivial to deal with the socio-technical challenges we experienced, we found the politics around our project to be more prolonged, and needed to address it continually. Overall, in our project, we used several qualitative methods, build our own local capacity in various facets of the problem domain, and also gradually build a political counter network which consisted of people both from micro-and macro-level health workers whom we managed to enroll progressively. With these, we gradually: (1) gained entry into the field of HIV/AIDS management, (2) cultivated a technically competent system, (3) concurrently developed political relationships that helped us deal with micro-macro-level interconnected political challenges, and also (4) weakened and overthrew the hostile “bigger empires” that would impede the project.

Table 8.1 below summarizes the different facets of “making it work” discussed above, their significance, and the strategies by which they were actually realized in our project.

Facet of "Making It Work"	Significance of the facet	Some strategies of realization
1. Gaining Entry	▪ It was a mandatory condition to carry out the subsequent intervention actions in the politically charged case of HIV/AIDS management.	▪ Approaching health officials by making use of previously established links and reputations of HISP, and also our being locally based and the broad mix of the team composition. ▪ Through a series of discussions and presentations we promised close and long term support, an integrated system (IHAMS), and also to use FOSS tools. ▪ We exploited "windows of opportunities" such as the one created from regional autonym. ▪ Emphasizing the superiority of the technology and design techniques we adopt – patient specific and one that meets existing needs and incorporates important functionalities.
2. Building Local Capacity	▪ To be able to address the socio-technical-political challenges and render the services the full range of the project would require, and to become competent.	▪ Through the pubic health and IS specialist within the international HISP network, we built our capacity in various facets of the problem domain including the different public health issues and technologically and socio-politically.
3. Building Political Counter Networks	▪ To develop political relationships and be able to continuously deal with the particular political challenges surrounding our efforts.	▪ By progressively enrolling influential actors out of various micro- and macro-level health workers and also from the HISP network.
4. Adopting Suitable System Development and Implementation Approaches	▪ To be able to adapt the system to specific implementation environment, and make it technically, and hence politically, competent.	▪ Steady system development and implementation approach through the methods of evolutionary prototyping, incremental approach, and participatory design.
5. Institutionalization and Ensuring Sustainability	▪ To make the system seen organizationally useful and, through this, to sustain it.	▪ We focused on the local realities and micro-level practices and incorporated useful features to the users. ▪ Continually dealt with the socio-technical-political issues by closely following up the system, continually upgrading it, and also providing it a distinctively competent character. ▪ We also maintained the system, provided supervision services around data entry, and also built the capacity of the users through successive informal on-site trainings.

Table 8.1: Facets of "making it work" and the strategies to realizing them

Having shown the applications of "making it work" in our project, we now turn to describing the implications and positioning our analysis with respect to broader debates on related issues in IS literature, and draw more general conclusions.

8.4 Discussions: Implications of *"Making It Work"*

IS failures in the context of developing countries has been identified as one of the major issues by various researchers (Korac-Boisvert and Kouzmin, 1995; James, 1997; Heeks, 1999; Heeks and Davis, 1999). The failures of HIS in these countries are particularly reported to be rampant and with high rates

(Keen 1994; Rosenal et al., 1995; Anderson, 1997; Pare and Elam, 1998; Heeks et al., 1999; Avgerou and Walsham, 2000; Heeks, 2003b), and also with many undesirable consequences (Pare and Elam, 1998; Heeks, 2002). As a result, the challenges of averting failures and making the systems practically work has become a common theme in IS researches.

However, the attempt to investigate failure factors, an important step to averting the failures, was limited by various constraints. As Heeks (2002, p. 3) noted, *"the entire literature on IS and developing countries would struggle to fill a single bookshelf. The attention of writers – from researchers to consultants – has been focused elsewhere."* Further, when investigating the causes of system failures, researchers have often emphasized dominantly the various socio-technical factors, for example in the domain of the health structure (Bhatnagar, 1992; Korpela, 1996; Walsham et al., 1988; Heeks ea al., 1999; Kenny, 2000; Heeks et al., 2000; Lippeveld et al., 2000; Avgerou and Walsham, 2001; Heeks, 2002; Braa and Blobel, 2003; Kimaro and Nhampossa, 2005).

True, though from different angles, we have also seen the impacts of these classic factors in challenging ISs projects around HIV/AIDS management. For example, with respect to technical challenges, given the complex nature of our implementation context mentioned in section 8.2, we have identified that some design issues and the kind of technology to be adopted significantly affected the making work of a supporting IS. Also, with respect to social challenges, we have identified issues such as actors' exaggerated expectations, past IS failure experiences, workload, multiplicity of stakeholders and their allocation, and also scarcity of resources to have similar impact. Hence, we acknowledge that, without successfully addressing the interrelated socio-technical issues, it is difficult to make work systems in practice.

However, the political dimension of IS implementation, which we argue to be an essentially key issue in point, has been given inadequate attention in the IS literature (Keen, 1981; Markus, 1983; Sanunders and Scamell, 1986; Cavaye and Christianse, 1996). Granted, some researchers have described ISs to have a potential side (Bull, 2003), but these descriptions were more general in that they described ISs mainly in a sense that they can threaten the interests of actors by intruding territory and limiting their autonomy (Keen, 1981). Similarly, some aspects of politics have been described in the specific domain of HIS implementation in developing countries. Yet, these descriptions were made with a focus on macro-level issues such as national political arrangements and situations (Braa et al., 2004b; Mursu et al., 2000), and also with respect to the nature and structure of the healthcare sector itself in developing countries (Nhampossa et al., 2004; Williamson, 2001; Braa et al., 2004b; Alvarez, 2004).

Moreover, although certain strategies have been identified to make work systems, they focused on some specific socio-technical challenges, and little attention has been given to practical approaches to make the systems work politically. Even if they do, most researches in IS, especially in the domain of health, have often treated socio-technical and political issues independently, and have not explicitly analyzed the interrelation of these issues, and how they influence each other. Through our research, we argue that there are still some specific aspects of political phenomena that significantly influence HIS implementation. We also argue that there is a need to explicitly look at the interrelationship of socio-technical and political issues in implementation endeavors, as they are fundamentally related. Given this, we identify three sets of key and interrelated implications of "making it work".

The Significance of Political Conditions

As we have tried to emphasize based on our case, the development and implementation of ISs in developing countries is not a politically neutral process. The organizations into which the ISs are introduced are political orders with established distributions of power that may be disrupted by the introduction of the IS (Pettigrew, 1973; Newman and Noble 1990). Thus, political conditions can be one of the most important issues in an implementation endeavor that may also result in intense conflicts among the different actors, and can contribute to IS failures when left untreated. The pattern of politics described in our case resonates with the ones described especially in more recent HIS efforts in these countries (Chilundo and Aanestad, 2003; Braa et al., 2004a; Braa et al., 2004b; Puri et al., 2004; Mosse, 2004; Nhampossa, 2006). Yet, the sort of politics we have been experiencing in our project, and the way we viewed and treated them had some particularities both with respect to being challenges on the one hand, and also opportunities on the other.

In its challenging side, right from the inception of the project, we needed to deal with the problem of gaining entry into the field of HIV/AIDS management in Ethiopia which proved intensely political due to the involvement of multiple actors. We especially found the influence of the proliferating and divided donors around HIV/AIDS management to fuel and fan the politics. Being heavily engaged in politicking, they often acted in a manner that is detrimental both to us and to the interests of the recipients, thus leaving the system to be barging chips. The unfavorable political condition created from the various stakeholders also continued even after we managed to gain entry. The scope of the politics was complicated by the complex combination of the factors that drove it such as the "concealed motives" of the actors. It was also magnified by the schemes the actors manifested their politics including through hidden weapons such as deliberate delaying of decisions by introducing endless preconditions. While some of the motives that drive the politics were rational and put forth with our intentions, others were irrational and hostile. All these demanded us to exert prolonged effort to continually deal with and address the sustained politics which would otherwise have led to failure.

Nevertheless, as a particular facet of this research, we rather want to focus on the opportunity perspective of the politics – opportunities that are created from the political conditions that can put forth a project when effectively exploited – and also on the roles of politics in this sense. Given the inescapable nature of politics which is a reality intrinsically woven to implementation processes, we argue on the importance of searching out and seizing opportunities that would support these processes. For instance, in our case, we seized some opportunities that were created from political hesitancies. Exploiting the opportunity created through the delays and the undelivered promises the donors made to the HIV/AIDS program manager at the Addis regional health bureau, we managed to convince him grant us entry and then to introduce the project. The decentralized governance structure in Ethiopia where there was a measure of autonomy to the regions which was created from the political condition in the country was another opportunity we seized to gain entry. Further, since past failures disappointed the users and created political conditions, they also gave us room to enter through practical effort and a tangible product. The progressive effectiveness of the software was compared by the users with previous efforts, and helped us to enroll important actors that had considerable impact in the subsequent implementation process. Thus, rather than impeding our effort, the focus on such opportunities helped us to yield real benefits and to embed the new practices accompanying the system. Unless political conditions are exploited this way to play practical roles in favor of an implementation endeavor, we argue, it is difficult to introduce and make work particularly HISs. Hence, instead of condemning political situations as mere challenges, we should stretch to effectively seize "favorable winds of politics" and avert such conditions to be constructive ones. Yet, as also emphasized by Braa et al. (2004b), various approaches and strategies need to be adopted in order to be able to exploit political conditions. In this regard, we have particularly emphasized in this thesis the paramount importance of *developing political relationships through building a political counter network.*

Developing political relationships through building a political counter network: As we have shown with our case, such political counter networks can be built by progressively enrolling the political champions and aligning with them, and such negotiation should be made at different levels and with different people. Through the resulting network, firstly, it will be possible to gradually develop and strengthen political relationships that will smoothen and enable implementation. In our case, we initially developed a political relationship through the enrollment of the regional program manager in the process of gaining entry, and later with the bureau and clinic staff in the development process. This helped us to have strong political backing from all levels to effect implementation despite hostile conditions, and also to deal with the ongoing political condition. The point, therefore, is that when attempting to build the political network, focus should be made to negotiate and build coalition with some of the most inflectional actors in power who should necessarily be part of the network. Then, the support and actions of these actors should be secured by practically serving their interests. In our case, we did so by incorporating functionalities in the system that were sought and valued by the bureau and the clinic staff. Secondly, when negotiation is not possible with some actors that hinder progress, the political counter network will help to weaken and overthrow them by loosing the dependency of the most influential and decisive actors on these ones. For example, in our case, we worked together with the bureau and clinic staff to make the system training on-site and informal as the bureau relied on JHU for the training and the subsequent scaling process.

Clearly, this situation makes the roles and involvements of researches (developers and/or implementers) in developing countries, is far from being simplistic and singular. For example, given the political nature of the implementation process, they take the lead in enrolling the important actors and establishing and building up the necessary political counter network. This, in turn, requires them to take power into consideration, to establish a measure of alignment and secure the official mandate of the people in power, and also to try and mobilize support and resources. Then, they need to play the multiple roles required to make the system work from initiating the project to sustain it – engage in distinct networks yielding "a number of different forms and levels of participation" (Gustavsen 2001, p. 20, cited Braa et al., 2004b, p. 346). As shown in our case, this may include requirements elicitation, system design and development, dealing politically, mobilizing support, generating funds, training, implementation, consultancy, supervision, maintenance, and performing the various activities each of these constitutes. For example, with respect to development and implementation, we needed to deal with and avert the various difficulties such as the poor quality of backlog data that would hinder the project from working practically. We also needed to manage expectations and create awareness about various aspects of the project to the different actors involved. While playing each of the multiple roles, researchers need to keep an eye in looking for some opportunities that are created through political conditions and also in progressively enrolling political champions which helps to negotiate with influential stakeholders as much as possible, or to overthrow irreconcilable and hostile ones. The cumulative effect of all of these contributes to making the system work politically. Granted, IS researchers have in general been acknowledged to influence implementation (Braa et al., 2004b). But the significance of the nature of roles they play was not explicitly discussed with politics at the backdrop as emphasized in our notion of "making it wok".

In general, what we are emphasizing by the first implication of "making it work" is the need to look at system development and implementation as a set of activities that far transcends only the technical, and to understand the political nature of HIS introduction and also the role of politics in this effort. Further, like building up the technology, "selling" the technology should not be viewed as a trivial task, and it has to be done actively. Preferring to concentrate on the technical issues, and having a strong distaste for the politics does not enable to make the system work. Politics should not be viewed merely as manipulation and as evil. Exploited as opportunities, political conditions can be the processes of getting commitment, building coalition and support, creating momentum for change (Keen, 1981), and thus can play practical roles to make IS sensibly work. Yet, this requires being an astute politician in the field of implementation especially in overly political areas like HIV/AIDS management in developing countries where it seeks to develop and maintain a network of relationships with individuals and organizations plugged into the network. In short, if the politics does not fly, the system never will. It is dominantly the politics, and not the technology, that establishes the limits on what can be achieved in the effort to make work the IS.

The Need to Deal with Micro-Macro-Levels Interconnected Challenges

The second implication of "making it work" is the need to deal with and address micro-macro-levels interconnected challenges, and the political importance of this to make the system work. Primarily, this means to focus and be deeply integrated and rooted with micro-level practices and local realities on the ground. In this regard, we emphasize in this thesis the importance of *employing suitable system development and implementation approaches through building local capacity within a larger network of similar efforts.*

Employing suitable system development and implementation approaches through building local capacity within a larger network of similar efforts: Capacity building often refers to assistance provided to develop a certain skill or competence, or for general upgrading of performance ability, and has fast become a major topic among the developing societies. In the context of IS implementation in these countries, capacity building is often discussed with particular focus to user training and in relation to sustaining an already developed and implemented IS. However, in the actual effort to make work systems in developing countries which have various constraints including shortage of skilled manpower (Walsham et al, 1988; Kenny, 2000; Walsham, 2000; Braa et al., 2004b), capacity building seeks to include a broad range of activities that help to deal with the various challenges and avert failures. In the context of HIS efforts in Ethiopia, for example, low capacity of the people involved in the projects in various ways was identified to challenge the efforts (Damitew and Gebreyesus, 2005). Hence, capacity building efforts relate to almost any aspect of the efforts to make a system work. In fact, it is a process – the process of developing and strengthening the skills and capabilities that help an IS to thrive and survive in the fast-changing world. As an element that ensures the making work of an IS, capacity building traverses all the way right from the inception of the system to sustaining it, and is not an issue that comes only at the beginning or end of the system development process. When adopted for the different aspects of an IS project, it is an essential milestone in the move towards making work the IS.

An important area of concern is the understanding of the application domain itself where the system is to be adopted. For example, inadequate public health inputs (Mekonnen and Lagebo, 2005) were mentioned to be one of the major bottlenecks of HIS efforts in Ethiopia where well documented requirements are hard to find as was in our case. Moreover, all technology requires trained people to develop, implement and maintain the system, thus indicating the importance of building the technical capacity of the local people. Going otherwise can be problematic in low resource environments. For example, Braa et al (2004b, p. 355) pointed out that "an insufficient supply of technically competent people … made it difficult to sustain" their HIS effort in Ethiopia. Thus technology should be evaluated from the aspects of reliability and availability of support personnel and particular attention should be given to establishing an in-country support infrastructure that will become self sufficient since systems that rely on support from outside the country are less desirable. RHINO (2004c) sated: *"another crucial need is to develop country health information system expertise. Information systems require constant maintenance and upgrading as conditions change. Countries must be able to maintain and modify their HIS. In order to do this, they must develop in-country capacity"* (p. 3).

However, the mere building of technical capacity of people does not suffice to make IS practically work in this part of the world. For example, in relation to the kind of technical skill of professionals in Africa, Mursu et al. (2000, p. 5) noted that "IS professionals … are not educated in managing complex

ISD [Information System Development] processes. The education mostly emphasizes software engineering instead of information systems. Thus systems developers in Africa work under severe practical constraints but are less adequately trained to cope with them, compared to their colleagues in industrialized countries." Rather than focusing on users' needs and the micro-level practices and local realities, such approaches lead IT professionals to be technology-centered (Kimaro and Nhampossa, 2004), and this results in ineffective system design which leads to failures (Heeks, et al, 2000; Heeks 2002b). They also argue for "construction" and radical changes (Sommerville, 2001) which is often impractical in the context of HIS in developing countries, and does not enable to address the non-technological issues surrounding implementation attempts.

Yet, when donors initiate an IS in developing countries, the tradition is that they use "use of foreign expatriate who return to their home country as soon as the aid period ends" (Kimaro and Nhampossa, 2004, p. 4), rather than focusing on building local capacity. Lungo and Twaakyondo (2006, p. 2) also argued that "poor focus on the development of local expertise on the part of donor initiated projects and the tendencies of neglecting of social and organizational issues are cited as factors contributing to the problem of ineffective implementation of IS in developing countries." Further emphasizing the danger of neglecting the building of local capacity in the specific world of donors, Kimaro and Nhampossa (2004, p. 2, 5) argued:

> *"Donor support for health projects is relatively short term in nature. Given that HIS projects may take a long time to be fully institutionalized, sufficient resources are required to build local capacity … to support and sustain such projects after the withdrawal of donors. … Inadequate support contributes to a lack of human resource capacity, ineffective system design, and a dominant focus on technology rather than on the needs of the users. This contributes to the design and implementation of unsustainable HIS. … Strong donor dependence makes it difficult for planners in developing countries to cope with rapid changes of IT and the capacity to maintain them. In order to achieve appropriate IT design, collective efforts and resources are needed involving various actors… including …, developers and users."*

By and large, as also argued by Oyomno (1996), the sustainability of an IS project is heavily dependent upon and the availability of local capacity to sustain benefits achieved over time. Further, concerning the building of an effective local capacity, Braa et al. (2004b, p. 337, 341) stressed the pivotal importance of networks and the need to conceptualize and approach local interventions "as but one element in a larger network of action in order to ensure sustainability". They argued: "local interventions depend heavily on the support of similar action research efforts in other locations. This is essential for the necessary processes of learning. …Local interventions need to be part of a larger network to be robust. … Establishing networks creates opportunities for sharing of experience, knowledge, technology, and value between the various nodes of the experience." Hence, to generate local and self-sufficient capacity for the various aspects of an IS project, it is important to align with broader interventions with similar efforts which helps to share appropriately formatted experiences across sites.

In our case, as we have mentioned in section 8.3, being within the international HISP network, we built our capacity in the various facets of the problem domain. Most importantly, the building of our own capacity in these regards helped us with respect to the development and implementation approaches we adopted. True, the relevance of adopting appropriate development and implementation approaches has been underscored in various researches. What is specifically emphasized by us is the suitability to the specific context and the political significance of the kind of approaches adopted to make the system work. For example, through the help of the various experts in the local and global HISP network, we have well understood the application domain of HIV/AIDS and ART management, and the real needs of the health workers at different levels. Further, as this also enabled us to carefully note the practices and local realities such as the lack of unique patient identifier in the ART clinics, we needed to be flexible to fit our approaches and address such issues by providing suitable functionalities. This eventually provided political competence since, unlike our competitors, we managed to put the system practically in place in such a messy context. This shows that, when developing a system it is always important to return to the practical and to stay close to the practices and to what matters most. Allowing the development work to stray too far from local realities and immediate needs, and strictly adhering merely to the basic IS design principles may lead to ineffectiveness.

Further, by adopting evolutionary prototyping and incremental approach we encouraged the participation of the users which helped to develop social glue though gradually cultivating the system. This socio-technical competence contributed to the political competence and vice versa. For example, as we cultivated a technically competent system through the participation of the users, we managed to build the trust of more influential actors at the macro-level since the users provided positive feedback. This increased our circle of influence and helped to secure stronger political backing. As we attempted to address the interests of the health workers at different levels, this in turn helped us to make the system more competent, thus emphasizing the interrelation of socio-technical and political issues. True, participatory approach has been discussed with respect to contributing to the technical competence a system. However, its impact especially that of working closely with people at the micro-level has not been explicitly discussed in terms of political significance as we are attempting to emphasize in the notion of “making it work”. Really, there is a world of difference between merely acknowledging participatory approach as a factor of technical competence and exploiting it as a political weapon as well. In our case, we have also shown (see section 8.3) how it can be exploited in the comprehensive socio-technical-political framework at large, and not just to address an aspect of the issue independently.

In addition to the system development and implementation approaches, the technology itself, design issues, and the various functionalities of an IS can all have political implications as they have meanings to both micro- and macro-levels stakeholders. For example, as we have discussed previously, the FOSS and web-enabling nature of the technology we emphasized to the health department as adopted in our project (and then did) helped us in the process of gaining entry. Design issues such as the IHAMS vision we promised to the health department, and also the ones we actually put in place in our system such as loosing the system to accept dirty data had similar impacts. The complex practices and local realities such as lack of standards, variations of practices, and poor quality backlog data have proved to be particular bottlenecks for the competent system providers whose systems were declared and categorized as failures by the clerks. But by providing suitable solutions with our system, we exploited these realities to help us succeed politically. Similarly, the technical competence gained through the various functionalities we incorporated in the system such as the patient progress report and the data quality checker features which took into consideration the practices and local realities contributed politically. Clearly, all these issues testify to the fact that technology has material features that can enable political actions. Still, it should be noted that the best of technological solutions are not necessarily the best political solutions, and that design and technological excellence and organizational needs have to be balanced.

In most HIS efforts, there are dilemmas as to whether to deal with micro- or macro-level people. What is often emphasized to HIS practitioners is the need to understand the role of micro-level people especially in the development process. As a result, many HIS reform efforts focus at working solely with the lower levels (for example, health facilities). True, as discussed above, lower level health workers are far from having little or no say in HIS efforts. However, HISs are structured as a hierarchy of administration levels and neglecting to involve the higher administration levels (such as regions in our case) would create difficulty in putting the system in place. Thus, in an attempt to introduce and make work an HIS it is important to take both micro- and macro-level people together. What we are emphasizing in our study is that it is difficult to make work ISs in practice without using micro-level people as a jumping board. Further, we argue that the more macro-level political structures are implicitly constituted in the more micro-level practices and local realities on the ground, and that they are mutually interdependent. For example, through our work in the ART clinics we gained political legitimacy at the regional level and vice versa. Hence, it is through these practices that the more macro-level political structures are constituted, for example, the development of alliances with the national ministries and donor agencies. Without having a grounding in the practices on the ground, we argue, it is difficult to have a firm base to develop political legitimacy and make the systems work. Thus, this process of linking practices and local realities with political conditions is an important aspect of the "making it work" approach.

The Importance of Embedding an IS

The third implication of "making it work" emphasizes the importance of firmly embedding an IS into the surrounding mass so as to make it work politically. However, when introduced by donors, as is typically the case in developing countries, HIS projects typically follow a technical approach to facilitate their rapid installation and utilization, not very dissimilar to the approach used to transfer manufacturing technologies. Thus the projects end up with a prototype but never a routinely used institutionalized system. As a result, the problem of unsustainability continued to plague HIS projects in the developing world 'strikingly' (Braa et al., 2004b, p. 359). This is primarily because, very often, HIS projects in these countries focus on the building of the software, conducting some training programs, but do not focus on the real challenge of how the system is made to work institutionally and become useful organizationally. Kimaro and Nhampossa (2004, p. 4, 5) argued:

> *"Given the primarily technical focus adapted, after the withdrawal of the donors, projects are often left in the hands of local organizations without the necessary …capabilities to sustain the system over time. … Such projects cannot become fully institutionalized as they do not become part of the organizations work routines. Typically, there is no clear and explicit sustainability strategy … left in place to ensure that the benefits, if any, are sustained"*

Hence, "to make an information system work, in practice, over time, in a local setting …involves shaping and adapting the systems to a given context, …, and institutionalizing routines of use that persist over time (as well as when the researchers leave and external funding is over)" (Braa et al., 2004b, p. 338). To that end, it is very essential to make the system and its outputs seen useful by the actors themselves. This can be achieved by putting in place various functionalities in the system that can address the needs and interests of the actors. Surely, we can not make them want the system without tangibly incorporating in it what they want. In our case, through the participation of the users and by focusing on the micro-level practices and local realities mentioned above, we incorporated functionalities that addressed the needs of the health workers at different levels – clerks, data managers, case managers, doctor and nurses, and also of the regional health bureau staff. Further, we build the capacity of the users by provided on-site trainings at each new version of the system so that they can be introduce with, and keep using, the new feature. All these efforts thus helped us contain the system as essential characteristic of the health structure, and hence to sustain it thus far.

Finally, it is important to note that the above three key implications of "making it work" are interrelated and have the potential to mutually support one another in a structurational logic. For example, through addressing micro-macro-levels interconnected challenges, we embedded the system and vice versa. The overall process helped us to make the system work politically.

In summary, we have shown in the above section that, although political conditions have a challenging aspect, there are still possibilities to exploit such conditions as opportunities. In this regard, we have described the three key implications of making it work. Firstly, we have discussed the importance of developing political relationships with influential actors through building a political counter network, and also that of overthrowing the hostile ones where building alliance is not practical. In this context, we have emphasized that the natures of the multiple roles the researchers play can have significant political contributions. Secondly, we discussed the importance of building local capacity within a larger network of similar efforts and, with it, employing system development and implementation approaches that are suitable to the specific context, and are also politically yielding. Within this, we have emphasized the interrelation of socio-technical and political issues and that they are not independent. We have also shown the socio-technical-political significance of participatory approach, the political implications of the technology, design issues, and the various functionalities of an IS, and the fact that technology has material features which can enable political actions. Thirdly, we discussed the importance of embedding the system to make it work. In this regard, we have emphasized the need to focus on the adaptability of the development and implementation approaches employed so as to contain the system as essential characteristic of the organization and also to sustain it. Finally, we emphasized that the three key implications of "making it work" are interrelated and complementary.

In this chapter, we have presented the analysis and discussion of the research which we described in the *Research Methods* chapter (3) to represent the 'specifying learning' phase of the action research life cycle. Our main emphasis was to analyze and discuss the processes of making work ISs to support

HIV/AIDS and ART management in Ethiopia. The "making it work" perspective helped us deeply understand and address the various challenges around making work our project. Though, through our analysis, we have shown the socio-technical-political challenges associated with our efforts, we have especially emphasized the impact of political conditions and also the role of politics in making work the project. We have also discussed the three key implications of "making it work" and their interrelationship.

In the next chapter, we provide the conclusions of the research and identify some further research insights that we believe should be dealt with in future research endeavors.

9 Conclusions

In this chapter we present some brief conclusions arising from this study with respect to the research problems identified. We also describe the research contributions and identify some further research areas. Accordingly, we start our discussion in section 9.1 by exploring the essence and significance of the research aims and how they were met. In section 9.2 we present some concluding remarks which summarize key research issues and implications. After describing the research contributions and its limitations in sections 9.3, and 9.4 respectively, we conclude the chapter in section 9.5 by identifying some areas of further research.

9.1 Exploring the Research Aims

9.1.1 Significance of the Research Aims

IS failure stories are abundant in particular around HIS in developing countries (Heeks et al., 1999, p. 2), which remains to be an area requiring larger research focus (Heeks, 2002; Donaldson and Jenkins, 2000). More specifically, while failures have often been associated mainly with archetypical socio-technical factors, the political dimension of IS projects which we argued in this thesis to be significant and requiring greater attention (Keen, 1981; Bull, 2003; Gladwin et al., 2003), and has been a "hard to study" subject (Keen, 1981). Given this theoretical setting, we developed a theoretical framework which we conceptualized by the metaphor of "making it work", and helps to deeply understand and comprehensively address the issues that challenge the processes of practically making work HISs in developing countries (see chapters 1, 2, and 8). On the practical front, the empirical setting of HIV/AIDS and ART management in developing countries, our research domain, desperately seeks supporting HISs, and this issue is increasingly finding voice (RHINO, 2004a; RHINO, 2004b). In particular, in the specific developing country of Ethiopia, where this research was conducted, ART management, our specific application domain and analytical focus, was suffering from a number of information management problems. These problems, in turn, affected the overall management of HIV/AIDS in the country (see chapters 5 and 6). Thus, an HIS that could support this initiative was seen as *"a backbone for this program"* and was a national priority (FMOH, 2005, p. 23). Yet, the domain of HIV/AIDS and ART has some particularities (RHINO, 2004a), for example because ART is a lifelong treatment that requires exceptionally extremely high level of adherence, making its management very complex and requiring *a supporting HIS that should handle a longitudinal and lifelong treatment*. Further, the domain of HIV/AIDS is a strongly political field (Nega et al., 2007) because of the nature of the disease, its implications and strong donor interest.

Given this theoretical background and the practical situation of HIV/AIDS and ART management in Ethiopia, the research objectives were:

1. *To understand the workings of the ART initiative in Ethiopia and assess key information related challenges in its management,*
2. *To develop a patient-based ART management database system that helps alleviate these problems,*
3. *To implement the system in pilot clinics and attempt to then scale it up; and,*
4. *To develop an overall understanding of what is actually required to make HIV/AIDS management supporting ISs work in practice within the context of Ethiopia, and draw broader implications.*

These translated to the following specific questions:

1. ***What does "making it work" mean for ISs to support HIV/AIDS management in Ethiopia?***
2. ***What key conditions especially shape the processes of "making it work" in the context of ISs to support ART management in Ethiopia?***
3. ***Practically, what are some approaches and specific strategies of "making it work" around ISs to support ART management in Ethiopia?***

Having discussed the significance of the research aims, we review in the next subsection how we managed to meet them and address the research problems.

9.1.2 Answering the Research Questions

For the analysis of the research problems, we used the empirical setting of ART management in Ethiopia mentioned above (see also chapter 5 and 6). While we also attempted to exert our research effort in other regions, with a particular focus on Addis Ababa, we elicited the requirements of this initiative and designed, developed, and implemented a FOSS based supporting HIS (called IHAMS-ART). We then scaled up the system in the various ART clinics in Addis as per the MOU we signed with the regional health bureau, and are attempting to make it work in a sustainable manner given the ongoing nature of the research (see chapter 7). While meeting the research objectives this way, being in the HISP action research framework, we adopted a multi-site longitudinal action research design approach informed by multiple qualitative methods (see chapter 3). In addition to our development and implementation efforts around IHAMS-ART, we have been engaged, in parallel, with the development of a flexible, scalable, and customizable IHAMS (Integrated HIV/AIDS Management System) called Debo which we started in India and South Africa.

In the following section, we describe the conclusions that arise from the research investigation with respect to the research problems.

9.2 Concluding Remarks

Through our empirical work, we identified three key problems influencing the information management of HIV/AIDS and ART in the country which used to run manually. These are: (1) significant degree of fragmentation of different forms both within and across the various HIV/AIDS initiatives (ART, PMTCT, VCT etc.), (2) multiple work practices within a particular initiative (for example ART) which made it difficult to make things uniform and created problems, for example, when patients were transferred from one facility to another; and (3) high magnitude of workload on health workers and data clerks (see chapter 6 for the details). The manual work has resulted in a number of problems including lack of standards and huge amount of poor quality data, for example with respect to lack of unique identifiers. In our effort to introduce and make work an HIS that supports the management of HIV/AIDS and ART in this country, we identified three sets of key issues to have been challenging the processes to practically making work the system – social, technical, and political.

With regard to social issues, we found the following challenges: the users' ambitious expectations, their past system failures experience, high magnitude of workload, multiplicity of stakeholders and their allocation in the regions, and scarcity of resources both in our team and in client organization. In discussing these challenges, we identified such social issues to be very hard to deal with. For example, at the beginning of the project, the data clerks in the ART clinics went seriously against our efforts even if they recognized that they badly need a supporting IS and the benefits to be enjoyed from it. Given that they had ambitious expectations and also experienced several IS failure stories, it was not easy for us to deal with such problems. Further, the clinics were allocated to supporting donors in such a way that we needed to deal with several of these stakeholders at the same time in an attempt to implement our system in just one region. Such a social construction also injected political temperament to our project efforts.

Technical issues also constituted the challenges around our efforts. As mentioned previously, there are multiple initiatives in HIV/AIDS management that seek to work coordinated and the data collection needs in HIV/AIDS management is a moving target. Further, the longitudinal and lifelong nature of the treatment necessitated the collection and processing of immense data. Given this setting, we found some factors to have been challenging our system development and implementation efforts. We broadly categorized these factors into two as the kind of technology to be adopted (both hardware and software) and some design issues such as full spectrum integrations, flexibility, scalability, and customizability. Further, there exists lack of standards and variation of practice in different clinics, and also the backlog data is found in awful state, for example as it lacks unique identifiers, legacies from the manual system. Given this, we take the scope of the technical challenges around the efforts to provide an HISs that support the management of HIV/AIDS and ART in Ethiopia to include technical issues that challenge even some of the most fundamental principles of IS design and development. This actually surfaced in our development and implementation processes.

For instance, while theoretically a system should be designed in such a way that each patient registration has a unique identifier– the backbone of record storage and retrieval in electronic systems– the lack of unique patient identifiers in the backlog data forced us to break this rule and loose our system. Further, to *process huge amount of data in a longitudinal and lifelong treatment*, especially in the bigger ART clinics, with the available hardware technologies in developing country settings, we have seen, it seeks to develop efficient data models and algorithms. For example, the design limitation of our system was considerably complicated by the available computers of very poor and unsuitable specifications (e.g. RAM and CPU) which slowed down the system when processing some of the most complicated analysis reports such as cohort. This was especially so in the bigger clinics with significant number of patients each with huge amount of longitudinal follow-up information which consist of considerable amount of data elements. Such speed related technical issues also gave room for competitors to politicize our efforts. Further some country specific situations exasperate the technical challenges around the HIS that support HIV/AIDS and ART management. For example, Ethiopia uses a different calendar system, of for example 13 months, which we could not find to be supported by the database technologies we attempted to develop our system with, and needed to design an interfacing date converter which necessarily consumed additional execution time. Given the need to deal with considerable number of data elements of type date in ART management, this situation necessarily further slowed the system. Further, the various system features that were deemed important for HIV/AIDS and ART management and the challenges associated to meet them technically, especially given the complex nature of the implementation context in Ethiopia mentioned earlier, made issues even more complicated. By and large, for HISs that supports HIV/AIDS management, technology and design related issues seek important consideration.

Therefore, in many respects, HIV/AIDS and ART management exhibits certain particularities and over that of other diseases and their treatments. This is, in turn, reflected in the supporting HISs. The domain puts some demanding requirements which seek the consideration of various issues and scenarios in designing, developing and implementing such systems, for example in terms of the kind of technology to be adopted, and also the kind of data model and elegant algorithms to be implemented. Thus, technical issues are not to be taken for granted when it comes to systems that would support HIV/AIDS and ART management, and if not treated properly, may become causes for failures. Without addressing these issues, introducing and practically making work ART management systems will be an unattainable task in the context of Ethiopia.

When it comes to political phenomena, the major focus of this thesis, we found various issues to have been challenging our efforts to gain entry into the field of HIV/AIDS and ART management, and then carry out the subsequent intervention actions. Given the multiplicity of initiatives and stakeholders including various donors, we articulated the scope of politics around the systems in our project to embrace and be complicated by a combination of distinctive *driving factors or root causes.* These include: “concealed motives”, mistrust and skepticism, urgency for solutions, fear of “hidden ditches”, socio-technical problems, preservation and advancing of mandates, fear of “being blackmailed” and “hidden power”, and protection and expansion of organizational territory. The complexity of the political conditions around our efforts was further magnified by the distinctive and complex tactics and schemes through which the actors *manifested* and realized their politics. For example, the Addis regional health bureau depended on one of the partners to cover the implementation costs associated with the realization of regional scaling of our system as per the MOU plans. But this partner, which also competed with our effort claiming that it will bring a working HIS to support the area, introduced endless preconditions and delayed decisions that would lead to subsequent actions (both from our side and the bureau). Since the nature of the political weapons embedded in such intentional acts of influence was concealed and inexplicit one fired tactically, it was not easy for us to deal with and address. This resulted in *outcome* of the systems’ being contentious pieces. Thus, while some of the motives around our project such as the case of urgency for solutions were clear, rational, logical, genuine, and put forth with our intentions, others were concealed, selfish, irrational, hostile, and incomprehensible. At any rate, as a result of the political conditions created form the complicated terrain of various issues, the supporting information systems become barraging chips!

In general, the scope of practically making work the HISs that would support HIV/AIDS and ART management in Ethiopia includes dealing with and addressing the complex and multifaceted socio-technical-political challenges surrounding the different processes in that effort. In the specific context of ART management in this country, while social conditions are not to be taken for granted, technical and political issues prove to be the key conditions that especially shape the processes of making such systems work practically. Firstly, the multiplicity of initiatives that seek to be integrated with ART, the huge amount of data in the longitudinal and lifelong treatment, the poor quality backlog data, lack of standards, variation of work practices, lack of unique identifiers, and the available technological infrastructure, complicated the technical challenges and made the area a technical demanding domain one. Also given the messy situation, designing and developing a system by perfectly adhering to the established design principles of IT is not a trivial task. The design and development of an ART system that meets what are called the “ideal” requirements, a complete description of all possible functions of ART software (RHINO, 2004c), requires getting fundamentally beyond the basics of IT. Secondly, the involvement of multiple stakholders and competing donors who have various concealed motives and hidden agendas, and implement tactical weapons made the area to be a strongly political domain in such as way that supporting systems become fundamental political artifacts. To be a system provider in such a technically demanding and strongly political domain it requires distinctive competence and approaches.

The challenges in the various processes of our project were theoretically analyzed using concepts from the “making it work” perspective we developed. This perspective views IS projects, particularly HIS projects, in developing countries as efforts that involve various socio-technical-political issues which present challenges of multiple forms which may be too chronic and time taking to address easily and quickly. Accordingly, with the distinctive driving factor and root causes, the different ways of manifestations, and resulting outcomes, our project exhibited a political property. The political situations surrounding our project sustained throughout the project processes, from our attempt to gain entry into the politically charged domain of HIV/AIDS to the ongoing action intervention and research efforts. Yet, the systems studied in our project also importantly involve socio-technical issues. For example, we found some design issues, the kind of the technology adopted itself, and its features to have considerable implications in making the system work. We also identified issues such as exaggerated expectations of users and their past experience with IS, multiplicity of stakeholders involved, workload, and scarcity of resources to have similar impacts. The project, therefore, involved multifaceted socio-technical-political challenges which we needed to address.

The various socio-technical-political challenges in our project were also addressed using the approaches and strategies constituted in the “making it work” perspective. The perspective argues that socio-technical-political challenges should be addressed comprehensively, systematically, steadily, and continuously in the full spectrum of the project processes. Through our analysis, we identified five key approaches, facets of “making it work”, that helped us address in this manner the socio-technical-political challenges that surrounded our efforts. These are: gaining entry, building local capacity, building political counter networks, adopting suitable system development and implementation approaches, and institutionalization and ensuring sustainability. Within each of these, we have also identified various approaches. For example, with respect to system development and implementation, we have used the methods of evolutionary prototyping, incremental approach, and participatory approach, and have found them to be suitable to the application context.

More specifically, the “making it work” perspective takes into account the political nature of ISs and emphasizes the paramount importance of looking at implementation not just in the technical or socio-technical sense, but also the various political conditions that may impede or enable the system providing real benefits to the stakeholders. To that end, it underscores the importance of dealing with political conditions by effectively seizing and exploiting such conditions as opportunities. Through our analysis, we identified ten sets of key strategies specifically to address the political conditions that surrounded our efforts. These are: exploiting the political power of qualitative methods; buying time: promising the future, but addressing the current problems; exploiting “windows of opportunities”; playing the politically charged “free and open source software” card; igniting the implementation process; grounding efforts into micro-level practices and local realities; exerting marginal effort and yielding value added features; enrolling the political champions, developing social glue, and building trust; playing multiple roles and institutionalizing the system; and building coalition with influential actors and overthrowing the “bigger empires”.

As a point of departure of our conclusions, as compared to prior IS research on the topic of practically making work ISs in developing countries, our analysis helped to emphasize that the perspective of “making it work” helps to deeply understand and address the challenges of practically making work ISs in developing countries – the dual purposes of “making it work”. Earlier approaches on this topic, often discrete and procedural, focused merely on specific momentary socio-technical challenges to yield only partial and limited success in implementation efforts. Thus they lacked the strength to actually penetrate the numerous types of challenges that pop up in the course of the project, for example like the various political challenges that continued in the different processes of our project. In contrast, the “making it work” approach argues that practically making work ISs is not just a one shot event, should not be treated merely as a technical or even merely as a socio-technical exercise, but should be viewed as and effort that involves multiple and heterogeneous socio-technical-political processes. Thus ***the “making it work” paradigm thus stretches the scope of practically making work HISs in developing countries to include the addressing, with prolonged effort, of the complex and multifaceted socio-technical-political challenges comprehensively, systematically, steadily, and continuously in the full spectrum of the project processes.*** This is so especially in the specific context of the HIS to support ART management which is a life time or chronic treatment that requires a supporting HIS which seeks chronic support. Without taking socio-technical-political issues together and performing all the important activities required in the entire continuum of such projects, we argue, a form of failure will claim the system sooner or later at some point in the trajectory of the project, resulting in the wasting of the resources already invested.

Our analysis also helped to emphasize the roles of politics in “making it work”. Politics is a matter of serious concern and at most importance in IS project endeavors. In the effort to make ISs work practically, understanding it, and dealing with it, is crucial given especially the inherently political nature of HIS, in the context of these countries (Braa et al., 2004b). Our empirical work has shown that while socio-technical issues can not be taken for granted, it is much harder to address political challenges especially in the strongly political domain of HIV/AIDS and ART. In fact, some socio-technical issues were a function of the political conditions that sustained throughout the ongoing action research intervention processes. We thus significantly conceptualized ISs as political artifacts. This emphasis resonates with earlier arguments made by researchers broadly in relation to ISs, for example by Bull (2003, p. 2) who noted that IS have the potential to become political and tactical battleground. Yet, while not underestimating the glitch side of certain kinds of political conditions, “making it work” stresses the exploitation of ‘favorable winds of politics’ (Williams, 2003, p. 13) to introduce and make work ISs practically. In our case, the seizing and exploitation of several political conditions as opportunities helped us succeed in this regards.

Further, our analysis has shown the interrelation of some factors in the effort to make ISs work practically, Firstly, we have emphasized that, as seen in our project, socio-technical and political issues are not to be treated as independent elements in the effort to make ISs work practically. They should be treated as interrelated issues that influence each other since they are fundamentally related. Nevertheless, their relations should not be seen as in a linear form as they can be shaped by the particularities of the context. In any case, when these issues are taken up in conjunction, it is possible to clearly identify the actual factors that challenge IS projects and their interrelations, and also to devise working approaches that can comprehensively address the real issues involved. Thus, we have underscored in our research that while the ten sets of key strategies mentioned earlier were identified by us as methods primarily to address political conditions, they actually helped us to address socio-technical-political issues. Secondly, we have emphasized the interconnected nature of micro- and macro-level issues. As seen in our project, the more macro-level political structures, such as the building and development of alliances with national ministers and donor agencies, are implicitly constituted in the more micro-level practices and on the local realities on the ground, and thus are mutually interdependent and supportive. By fully understanding and being deeply integrated and rooted with local realities and micro-level practices of people on the ground who are engaged with the everyday work around the HIS, it is possible to cultivate the IS and also the political relations that enable to try and counter the mainstream power dynamics originating through donor funding and big money vendor interests. Further, a thorough diagnosis and understanding of the organizational settings to which the system seeks to be adopted, will shape the development and implementation approaches that need to be adopted to make the system work in practice.

In our study, we have summarized and especially emphasized the relevance of two key methods that help to comprehensively address socio-technical-political issues that surround HISs. The first is the significance of *gradually developing political relationships through establishing and building political counter networks*. In this regard, we emphasized the roles of researchers in progressively enrolling the political champions and gradually cultivating political relationships through the constituted political counter networks. We have also emphasized the importance of constituting this network both from researchers themselves, and also both from micro- and macro-level health workers. As discussed to be the case in our project, the second methods concerns the significance of *adopting suitable system development and implementation approaches through building local capacity within a larger network of similar efforts*. In this regard, we have emphasized the significance of evolutionary prototyping, incremental approach, and participatory approach. We have also emphasized the significance of the key actors involved and the nature of the roles they play; the various organizational conditions within which a system is implemented and needs to persevere in; and the material features of the system including the kind of technology adopted, the way it is designed, and the features it constitutes. While we described these two methods as importantly applied in our project to address political issues, they do of course help to also address socio-technical-political issues entirely, given that political and socio-technical issues are interrelated as per the "making it work" perspective. Yet, when it comes to politics, the focus of this thesis, the multiple facets of "making it work" – the above mentioned concepts, methods, approaches, and strategies constituted in it– serve two major purposes: that of building coalition with the most influential and important actors as much as possible, and, when not possible, that of weakening and overthrowing the hostile adversaries and "bigger empires" that would impede the project. Overall, this would help to successfully introduce and make work the HIS in a practical and sustainable manner.

In summary, through our analysis, we have identified three key implications of making it work that are interrelated and mutually supportive. The first concerns the significance of political conditions in IS projects in developing countries. The second is the need to deal with micro-macro-levels interconnected challenges. The third concerns the significance of embedding the IS organizationally. While our analysis has been developed based on empirical work carried out in some research sites around the management of HIV/AIDS and ART in Ethiopia, we believe that the study has broader implications for IS and HIS efforts in developing countries. For example, a general implication from our research investigation is to examine the processes of practically making work ISs as heterogeneous and interconnected socio-technical-political processes. While the nature of the socio-technical-political issues that challenge the processes of practically making work a particular system might be different in varying contexts, the analytical concepts of a socio-technical-political perspective is absolutely and essentially beneficial to understand such processes and the challenging issues associated to them.

9.3 The Research Contributions

The research has made contributions in three respects – theoretical, methodological, and practical.

Theoretical Contributions

Given the persistence and abundance of failure stories despite the move from the mere technical to a socio-technical perspective in IS project endeavors (Kling and Scacchi, 1982; Hanseth and Monteiro, 1998), the paradigm shift from mere socio-technical to socio-technical-political perspective is an important theoretical contribution. Since there has been limited understanding on the issue of politics (Keen, 1981; Bull, 2003; Gladwin et al., 2003) which is not easy to investigate (Keen, 1981) the discussion made in this thesis with regard to some driving factors and root causes, manifestations, and resulting outcomes of politics are significant theoretical contributions. The empirical findings of this study shed light on the multiplicity and complexity of the socio-technical-political that challenge IS projects in developing countries. In our study, unlike the management of other disease and their treatments and the HISs that support them, we have emphasized that the domain of HIV/AIDS and ART management in these countries is a technically demanding and strongly political field which is also reflected in the process of making work the supporting HISs. Thus, viewing HIS projects from the entire socio-technical-political perspective is far from seeing them merely as socio-technical, as often is the case, and implies the need to progressively and incessantly address these heterogeneous and longitudinal processes comprehensively, thoroughly and scientifically, and with anticipated prolonged efforts. The various processes and conditions around such systems in developing countries, such as the political ones, need to be addressed gradually and persistently while being understanding and sensitive to the difficulties and complexities inherent in them, and hence seek such a perspective.

The theoretical perspective of "making it work", with all its facets and constituting concepts, approaches, and strategies that theoretically help to practically make work particularly HIS in developing countries, is also a significant theoretical contribution of this research. This is considerable given the limited understanding on the full complexity of the failure phenomenon, the poor status of the understanding on the political conditions around IS projects and the difficulty to investigate them, and the subsequent lack of practical approaches that help to comprehensively address the issue that challenge the processes of making work such systems. With this perspective it is theoretically possible to deeply understand and practically address the issues that challenge IS project efforts in developing countries. More specifically, the roles of politics in making systems work practically as described in this thesis, that of seizing and exploiting political conditions and favorable winds of politics as opportunities (Williams, 2003, p. 13), are useful tools to address political conditions. Especially emphasized in this regard is the significance of *gradually developing political relationships through establishing and building political counter networks.*

The "making it work" paradigm stretches the scope of practically making work HISs in developing countries to include the addressing, with prolonged effort, of the complex and multifaceted socio-technical-political challenges comprehensively, systematically, steadily, and continuously in the full spectrum of the project processes.

In particular, the approaches and strategies proposed in this thesis for developing and implementing HISs, make a contribution to IS project endeavors in developing countries. In this regard, we have emphasized the roles of the researchers and micro-level health workers with politics at the backdrop. We have also emphasized that, to make the systems work practically in specific settings, system design and development should be so flexible even to the extent of breaking some established design principles of IS, may need to go fundamentally beyond the basics of IT. The importance of taking socio-technical and political issues in conjunction is also a contribution of this thesis since it helps to clearly understand the actual factors that challenge IS projects and their interrelations, and subsequently to devise appropriately working approaches that can comprehensively address the real issues involved. Another important contribution is our focus on, organizational settings, local realities, and the more micro-level practices of people on the ground, practices through which the more macro-level political structures are constituted, and the interconnected of micro-and macro-level issues.

Methodological Contributions

In this research, being in the HISP action research framework, we adopted a multi-site longitudinal action research design approach informed by multiple qualitative methods. Using this approach we have fretted out distinctive driving factors and root causes, manifestations, and resulting outcomes of the political phenomena surrounding our efforts. Since politics is known to be a "hard to study" subject that 'involves many hidden agenda' (Keen, 1981) and none of the actors involved in politicking would be keen to divulge their political secrets that help them to promote their interests, the approach we adopted can be seen as an important methodological contribution. Using this approach we have also explored various socio-technical-political issues.

The flexible development and implementation methodologies mentioned earlier that we adopted to develop a system in the technically demanding domain of ART management, and to suit it to the messy setting of the application area in Ethiopia are significant methodological contribution to the domain of IS development and implementation in developing countries. Further, the nested nature of our action research (see chapter 3) in which we accomplished the dual actions of addressing the political conditions while performing other intervention actions, and vice versa, is also a significant methodological contribution of this research to the approach of action research.

Practical Contributions

As is the objective of an action research, our study has made several practical constrictive contributions with which something new and tangible has been realized. By eliciting the requirements of the ART initiative, we have designed, developed, and made available an HIS that can support ART management in Ethiopia. Given the messy setting of the ART clinics in the region which made the design and development of the system technically demanding, the strongly political nature of the domain, and also the number of failure stories the users had experienced previously, the availability of such system was deemed considerable by the client organization. The system was initially implemented in some clinics in Addis and in SNNPR. Currently it is being scaled up in Addis as per the MOU we signed with the regional health bureau. Through informal on-site trainings we have enabled the data clerks in the region knowledgeable about the system and left them with a user manual. As data entry is ongoing, several clinics now have considerable amount of electronic data which they are using. While the system has not yet been used for reporting, it has considerably eased the works of the clinic staff and benefited them in several different ways.

9.4 Limitations of Research

As in any other research, ours also has its own limitations with respect to some unaccomplished tasks as a result of certain constraints including the constraints of time, other resources in our research team, and also due to the sustained political conditions that we needed to deal continually deal with in parallel with our intervention efforts. Firstly, with respect to development, we could not manage to complete the development of Debo to meet our IHAMS vision. With regard to the hard-coded system (IHAMS-ART) that we have already implemented in the various clinics in the country, we have not yet get it to be flexible. Given the fact that data requirement in HIV/AIDS and ART management is a moving target, it would have been good if it were made an easily adaptable system. Moreover, some design improvements should have been done to improve the speed of the system when generating the most complex analysis reports given the available hardware technologies in the clinics. Also features and functionalities like better analysis mechanisms such as graphs should have been incorporated in IHAMS-ART. Further, given that ART is a longitudinal treatment where patient follow-up information should be regularly captured, the system has to be designed in such a way that it automatically updates each patient’s information in a certain interval of time even if the patient does not show up to trigger transactions.

Secondly, with respect to implementation and scaling up IHAMS-ART, we could not move forward as per the MOU plans with the Addis regional health bureau. Due to lack of various constraints including computers, data clerks, and finance to cover implementation costs, formal training could not be provided, and backlog data cleaning and entry could not be completed. As a result, the system is currently being underutilized. Further, we have not yet build the capacity of the client organization in such a way that it can take full manage the works around the system.

Thirdly, with respect to the research aims, had it not been for time and other resource constraints, we could have intensively explored and compared the issues of making work the systems both within (across the various regions) and across countries (for example India and South Africa). This would have revealed more factors that challenge the processes of making the systems work, and also the approaches and strategies to address them.

9.5 Further Research Areas

Given the theoretical lens of "making it work" and the above mentioned unaccomplished tasks around IHAMS-ART and Debo, a further research area could be to explore the challenges of practically making work a flexible, scalable, and customizable IHAMS in the context of developing countries. This would help to discern more concepts, approaches, and strategies that would further expand the "making it work" paradigm. In addition, since failure stories around the IS in developing counties are still abundant, we need to take and practice a socio-technical-political approach in future HIS implementation endeavors in developing countries and further refine the approaches to make the systems practically work. Specifically, given that there are still limited researches on issues of politics around IS implementation, it will be worthwhile to conduct more researches concerning these issues. Further, taking the philosophy in the "making it work" theoretical framework as a point of departure, we still need to carefully examine what is actually wrong in the previous IS development and implementation research approaches that they could not practically contain the phenomenon of IS failure which is becoming rampant all the more.

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