Coordinating Patient Information in HIV/AIDS Care with Hybrid Health Information Systems

An ethnographic case study from South Africa

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Abstract

Patient records and integration of patient information in the research literature is often discussed related to hospitals and from a Western country setting. These discussions often focus on the complexity and problems with integration of patient information, and on redundancy related to a number of parallel existing systems in the organization. To achieve 'seamless' or 'shared care' of health records and reducing redundancy, ICT and electronic patient records have been suggested to solve the problems.

In low-income countries, different programs are established, and actions taken to manage and control diseases such as malaria, TB, and HIV/AIDS. There is need for systems to monitor development and effects of interventions, as well as coordinating patient information. To achieve this, it is claimed that, *"Computer-based data management systems offer the possibility of the multiple use of data recorded once to be used for different objectives and tasks"*, and the global vision for health IS are clearly prioritizing electronic systems. Despite clear potential benefits and high expectations, studies of health information systems in health work practices show that electronic patient records do not easily meet the expectations, and they bring new challenges. Human, physical and financial resources in HIS implementation also form special challenges in developing countries, where often the most essential resources are lacking.

This research has applied an interpretive research approach, and gives a rich description of the challenges in health work practices within HIV/AIDS care and treatment. The results describe how patient data are captured, stored and shared in clinic and across health service providers, in paper registers and ICT systems. The empirical data are collected through a longitudinal case study in South Africa, using ethnographic methods. The field data was collected over a 2-year period, with serial and/or periodic visits to the same sites.

The theoretical lens for analysis has been Computer Supported Cooperative Work and Information Systems Design. Based on the findings, I found the vision of integrated EPR less applicable in these settings, and I have suggested to conceptualise health information systems as *hybrid health information system*, seeing the hybrid collection of informational artefacts in use (paper and electronic) as *one* health information system.

This thesis contributes to the literature in CSCW and ISD discourses by suggesting principles for designing hybrid health information systems, to meet the challenges within health care work practices, in western- as well as developing country contexts. I have argued for, and have described how allowing a certain amount of redundancy in the system, creates a robust *hybrid health information system* to coordinating patient information over time and across space. In combining the positive affordances of paper and electronic artefacts I show how a hybrid system may provide outcomes that would mostly not be achieved in a 'pure' paper or a 'pure' electronic system. Robustness may refer to security in terms of *access* to information when needed, as well as *complete* clinical data in patient care and treatment.

I contend that hybrid health information systems would be satisfactory as vision; guiding plans to achieving the goals for health care delivery at higher managerial levels, with important implications for lower level planning, cost, design and implementation.

Acknowledgements

This PhD thesis comes as a result of a long journey with many twists and turns. My background before starting my studies at the University of Oslo is rather different from most of my fellow students. At the age of 16, I entered working life as a junior clerk in a Social Security Office. After three years of practice, I returned to high school, followed by, alternatingly work practices and education; including 7 years as an accountant in Germany and Norway, 10 years of managing a household with husband and three children, then a bachelor study to become a professional social worker. Several years of experience as a social worker followed, also serving as a deputy manager in a child welfare institution, before I went into an early retirement - all experiences, that might later have had an impact on my choice of research approach.

My studies at the University of Oslo started at the Faculty of Humanities, Department of Linguistics and Nordic studies in "Logic, language and information" (SLI), doing single semester courses over several years. When finally looking for a topic for a master thesis, my interests (among many), were decision making and evaluation in organizations as an integrated part of the planning processes. In this domain, collection and use of information plays an important role. I had to look outside SLI to find what I was looking for and I found it in the Systems Group at the Department of Informatics (IFI). My sincere thanks go my supervisor at SLI, Herman Ruge Jervell, for his advice to turn to informatics, and together with Jens Kaasbøll, for the generosity to accept my research proposal, as a cooperation between SLI and IFI.

Focus for the master thesis was on information use and information culture at health facility level, and the fieldwork was done in Cape Town, South Africa. From a position as a retired social worker, for several years studying for my own interest of it, I saw the possibility to applying my professional knowledge and practical experience on new ground, and suddenly I found myself being a part of an interesting international research. The master study was finalized 2007, but the interest in health information systems and the situation for primary health care in developing countries remained, and I applied for doing research as a PhD student at IFI, self-financed. This was accepted by the Department of Informatics and the Faculty of Mathematics and Natural Sciences, Jan 2008. A pre-study was initiated in Kerala 2008, and the final permission to do research in The Province of the Western Cape was given in Spring 2009.

Being able to complete this 'mission', would not have been possible without support and encouragement from many people, at IFI, family and friends. I wish to thank my supervisors at IFI, Sundeep Sahay (first year, when including India was an option), Jens Kaasbøll, and Margunn Aanestad, who never let me go when health problems emerged, and academic work went on low gear, but urged me to complete the project, giving valuable feedback in the process of analysing, writing and developing the final product. I will also thank the staff at the University of the Western Cape in Cape Town for facilitating my field visits, and to Dr.Gavin Reagon, who helped with the application process for ethical clearance, and getting permission to do research; acting as an 'on site' external advisor, which was required by the Department of Health in the Western Cape.

I am particularly indebted to the health personnel in the clinics, hospitals and health administrations in the Province of the Western Cape and the City of Cape Town, who accepted to participate in the study, and who took time to answering questions, showing me around, demonstrating use of their work, and how formal and informal information systems were used. Without these people, there would have been no thesis. Last, but not least, I want to thank my husband for support, encouragement and patience throughout my academic projects, and for going with me to Kerala and South Africa.

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Abbreviations and acronyms

AIDS	Acquired Immune Deficiency Syndrome
APP	Annual Performance Plans (WCDoH)
AR	Annual Reports (WCDoH)
ART	Antiretroviral therapy
CSCW	Computer Supported Cooperative Work
CSP	Comprehensive Service Plan (WCDoH)
DC	Developing Country
DHIS	District Health Information System
EHR	Electronic Health Record
EPR	Electronic Patient Record
GNI	Gross National Income
HCT	HIV counselling and testing
HDI	Human Development Index
HIS	Health Information Systems
HHIS	Hybrid Health Information Systems
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
HIV+	HIV positive
HDI	Human Development Index
ICT	Information and Communication Technology
IMF	The International Monetary Fund
IS	Information System
ISD	Information Systems Design
IT	Information Technology
MDR TB	Multidrug-resistant tuberculosis
MDG	Millennium Development Goals
MOU	Mid-wives Obstetrics Unit
NGO	Non-Governmental Organisation
NHISSA	National Health Information System of South Africa
NDoH	National Department of Health
NSP	National Strategic Plan
PEPFAR	The President's Emergency Plan for AIDS Relief
PFA	Patient Folder Application
PHC	Primary Health Care
PMTCT	Prevention of mother-to-child transmission of HIV
RDP	Reconstruction and Development Program
TB	Tuberculosis
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNDP	The United Nations Development Programme
UNGASS	United Nations General Assembly
UNICEF	United Nations International Children's Emergency Fund
VCT	Voluntary counselling and testing
WB	World Bank
WHO	World Health Organization

Chapter 1 Introduction

"The first level of care forms the core of most health information systems. It is the primary delivery point for services, the principal point of contact for patients, and the primary location for data" (RHINO Workshop 2006).

1.1 Patient-centred health information systems

Continuity of health care has in recent years received increased attention. To be able to provide quality health care, sharing and coordinating information about the patient is a central and important issue, and notions such as 'seamless' or 'shared care' and 'seamless integration' of health care records have been discussed and proposed as aims to achieve efficient and cost-effective quality of care (Grimson et al, 2000; Ellingsen & Monteiro, 2006; Mostert-Phipps et al, 2010). To meet the needs for information in the health care management, information systems are imperative, and according to Berg (2004, p.2), a system needs to provide three types of information:

1) information about an individual patient;
2) aggregated information about process and outcome of the organization ('management' information);
3) information about diagnostic and therapeutic decisions and procedures.

To meet these requirements, accurate and complete information, collected and documented at patient level is important. The overall aim for a patient record is to comprise all data and documents generated or received during the care of a patient (Knaup et al, 2007). Longitudinal patient records are furthermore important for the accumulation of data during the patient trajectory over a lifetime, in order to follow-up a person with a chronic disease. In creating this longitudinal record over time and across service providers, a number of health workers will be involved (hospital, clinic, pharmacy, laboratory). The different professions, clinics, and departments involved, will have different information needs, and in health work practices several information systems normally exist in parallel, comprising of various tools and technologies, leading to challenges with integration of information related to one person.

In line with the visions of 'seamless care' and integrated patient records, the debate within health information systems (HIS) and patient records in the discourses revolves around the theme of integration, and of replacing paper systems with electronic systems.

There are many terms in use to denote the computer-based patient record[1], and in different contexts they mean different things, as content and scope varies over time and across traditions (Greenhalgh et al, 2009). Without going in detail about the different definitions, and how they have been used in the different settings, I will use electronic patient records (EPR) in this thesis. EPR are seen as the key to meet the challenges in providing quality of care, by enabling integration of information from dispersed service providers, thereby

[1] Electronic patient record (Fitzpatrick, 2004; Jensen & Aanestad, 2007; Grisot, 2008; Greenhalgh et al, 2009);
Electronic medical record (Hartwood et al, 2003; Fraser et al, 2005; Berg, WHO);
Computer-based patient record (Detmer&Steen,1996; Dick&Steen, 1991);
Electronic health record (Fitzpatrick, 2004).

facilitating immediate access to information for health workers, and also to reducing information redundancy (Greenhalgh et al, 2009).

Although it is argued that information and communication technology (ICT) and EPR will reduce costs and improve health care, these claims have shown difficult to measure and confirm. Despite clear potential benefits and high expectations, studies of health information systems in health work practices show that EPR do not easily meet the expectations, and they bring new challenges (Hartswood et al, 2003; Ellingsen & Monteiro, 2003; Bend, 2004; Østerlund, 2004; Shekelle et al, 2006; Lucas, 2008; Coiera, 2009; Black et al, 2011).

> *"In almost all Western countries, concerted efforts are made to stimulate the use of information technology (IT) in health care. National, regional, and institutional projects abound to bring the shared Electronic Patient Record (EPR) into being, and to support the care process with order communication and decision support of health care delivery through optimizing communication. [...] Yet, there are only a few real success stories in health care IT, and the frustrations are many" (Berg, 2004).*

Black et al (2011), undertook a systematic review of review literature, assessing the effectiveness and consequences of various eHealth technologies on the quality and safety of care in order to inform policy decisions on eHealth deployments. They conclude that there is a large gap between the postulated and empirically demonstrated benefits of eHealth technologies, and there is also a lack of robust research on the risks of implementing these technologies and their cost-effectiveness.

HIS discourse tells stories of unsuccessful large projects in for example England, Denmark and Norway (Jensen, 2008; Avison and Young, 2007; Fitzpatrick and Ellingsen, 2012). Jensen (2008), has analysed two EPR in Danish hospitals and conclude that;

> *"The EPR system entails some clinical benefits in relation to the facilitation of certain work procedures and the improvement of certain patient centred aspects [….]. The analysis shows that representatives from the two health care groups find the EPR system constraining on a number of points, […]".*

In describing the history of the National development projects for an electronic patient record in the UK hospitals, Jones (2004) claim that:

> *"Despite the potentially important role of such records in visions for the modern NHS, however, their adoption is still restricted to a relatively small number of sites and limited progress has so far been made towards the achievement of national level electronic records."*

Although numerous accounts of problems and failures related to the implementation of complex electronic health information systems can be found in the literature, the vision itself seems not to be questioned. The underlying belief being that, once you understand the reasons for failures, or the complexity it creates when huge numbers of interests and (sets of) existing systems are sought to be integrated, you have the key to getting one step closer to the ultimate goal.

> *"The authors believe that with a heightened awareness of these issues, informaticians can educate, design systems, implement, and conduct research in such a way that they might be able to avoid the unintended consequences of these subtle silent errors"* (Ash et al 2004, p.104).

When discussing IS and ICT, and comparing the properties of paper versus IT, it is mostly the problems related to paper tools that are presented, problems that ICT will solve. The benefits of paper are rarely foregrounded in the HIS and EPR literature, but in an extensive literature review on electronic patient records, Greenhalgh et al (2009) find that: *"Paper records being flexible, portable, and tolerant of ambiguity, support the complex work of clinical practice remarkably well" (ibid p.754),* and they point to the flexibility paper may offer:

> *"The findings suggest that EPR use will always require human input to recontextualize knowledge; that even though secondary work (audit, research, billing) may be made more efficient by the EPR, primary clinical work may be made less efficient; that paper may offer a unique degree of ecological flexibility, […]"(ibid p.729).*

The important role that paper tools play within health care services, is also emphasized and presented in a number of cases within CSCW, Medical Informatics, and Health Information Management, when discussing health care work practices and coordination of patient information (Berg, 1996, 1997a, 2004; Berg and Goorman, 1999; Berg and Toussaint, 2003, Fitzpatrick, 2004).

1.2 Patient records in Primary Health Care in Developing Countries

Patient records and integration of patient information in the research literature is often discussed related to hospitals and from a Western country setting. These discussions focus on problems due to different requirements from a variety of professions with specific needs for clinical information, and on the complexity and problems with integration related to a number of parallel existing systems in the organization (Ellingsen & Monteiro, 2003).

In a developing country (DC) context, Primary Health Care (PHC) is responsible for providing health services to the community, and the setting differs from western countries in many respects, related to the organization of health services and available resources, but there will also be challenges of similar character, such as several service providers; dispersed in time and/or space, and parallel but not coordinated systems.

One of the main purposes of patient records is to help care providers to deliver health services to individuals in a facility or through outreach activities in the community, but will also serve other purposes and interests, such as programme monitoring, planning, and research (HMN/WHO, 2008).

In PHC in a DC, the paper folder has traditionally been the main artefact in keeping a patient record. During the last 20 years, electronic computer systems have been developed and implemented, also across DC's, primarily for capturing aggregated data, for keeping registers and generating reports for higher levels management, but the focus has also come to include electronic patient records, reinforced by the need for following up people with HIV/AIDS[2].

The optimism related to expected outcomes of EPR in high-income countries has also brought policy makers in developing countries to introduce EPR as a means to meet the

[2] human immunodeficiency virus/acquired immunodeficiency syndrome

challenges posed by the great burden of diseases such as TB and HIV/AIDS. Electronic health records are suggested to cope with the increasing numbers of HIV/AIDS patients, and to enable sharing of patient information across providers and over time, as well as meeting the requirements for keeping registers and reporting. Tierney et al (2010), claim that,

> "*With more and growing HIV treatment programs, EHR are becoming a necessity for managing and monitoring patients and health care systems while providing funders with data on the care provided and outcomes achieved".*

There are however researchers both in western countries and in DC's that are questioning the vision of integrated electronic solutions, stating that computer technology might not be 'the silver bullet' in achieving effectiveness and efficiency in health services (Skorve, 2006; Avison and Young, 2007; Sahay and Walsham, 2014). In DC's, the use of scarce resources in primary health care for computer systems and equipment is in particular brought to discussion (Lippeveld, 2001; Kreps & Richardson, 2007; Greenhalgh et al, 2009).

Wilson (in Lippeveld et al 2000, p. 198), discusses the use of computers in HIS in DC´s, and asks: "*What is the correct level at which to computerize?"* He lists some questions that should be taken into account when considering how to improve a manual system with computers, such as: how well the existing system functions, the availability of local resources, the volume of data to be processed, and the costs of technology vis-à-vis the cost and availability of skilled personnel. He also states that *"it is critical in the developing country setting to achieve the right mix of computer and manual systems, and to ensure that they are fully integrated"* (ibid p.201*).*

Implementing electronic HIS in a low-income country entails huge investments in infrastructure, hardware, software, and education. A major challenge within health care provision in developing countries today is the shortage of personnel in the public health sector, including doctors, nurses and pharmacists. There are also huge needs for more clinics, and infrastructure for transport, to mention some. I find there is not much discussion in the HIS in DC discourse about the use of resources and how to prioritize. It is mostly taken for granted that when replacing paper systems with electronic ones, the benefits will outweigh the costs, but there are few findings supporting this assumption. A few studies have provided cost estimates for developing infrastructure, implementation of EPR, training etc., but these studies are mostly done related to hospitals and in the US or other western settings. The reality in the healthcare work practices in both 'worlds' is mostly that, coordination of work and sharing of health information is performed using a number of technologies and information artefacts.

The South African National Department of Health mentions HIV and TB prevalence among the 'quadruple burden of diseases' in the country, (also including maternal mortality ratio and non-communicable diseases such as asthma and diabetes) (NDoH 2013). The biggest health challenge today in SA is the HIV/AIDS pandemic, being a human crisis as well as a challenge for the health authorities. In the next sections I will describe in more detail the background, challenges and responses related to the HIV/AIDS pandemic in developing countries, and the aim of integrated EMR in relation to this.

1.3 HIV/AIDS in Developing Countries

> *"The human immunodeficiency virus (HIV) is a retrovirus that infects cells of the immune system, destroying or impairing their function. As the infection progresses, the immune system becomes weaker, and the person becomes more susceptible to infections. The most advanced stage of HIV infection is acquired immunodeficiency syndrome (AIDS). It can take 10-15 years for an HIV-infected person to develop AIDS; antiretroviral drugs can slow down the process even further* "[3].

More people than ever are living with HIV due to fewer AIDS-related deaths and the continued large number of new infections (MDG's report 2012). In 2010, an estimated total of 2,7 million people in the world were newly infected with HIV. This is 15% fewer than in 2001, but due to better access to antiretroviral therapy (ARV/ART) in low- and middle-income countries, the population living with HIV increases as fewer individuals die from AIDS related causes.[4] This increases the pressure on the countries mostly affected. Since the start of the epidemic around 75 million have become infected with HIV. In 2012, there were approximately 35 million people living with HIV and the disease have claimed more than 36 million lives so far, from 2 mill in 2008 (UNAIDS epidemic update).[5]

As the HIV infection reduces the immune system in the human body, other infections, such as tuberculosis (TB) have increased significantly. Thus, coordinating the efforts to fight these diseases have been addressed by the World Health Organization (WHO) through guidelines for collaborative TB/HIV activities.

> *"The dramatic spread of the HIV epidemic throughout sub-Saharan Africa in the past decades has been accompanied by up to a fourfold increase in the number of TB cases registered by national TB programmes."* (WHO TB and HIV, 2003).

More than 30 million of the world's HIV/AIDS-infected population reside in sub-Saharan Africa (africa2015.org). The pandemic involves actors from a multitude of domains and organizational levels, from WHO, and National and Provincial health departments, to a large number of Non-Governmental Organisations (NGO's). In June 2001, the United Nations General Assembly (UNGASS) met in a special session on HIV/AIDS, "to review and address the problem of HIV/AIDS in all its aspects", and issued the "Declaration of Commitment on HIV/AIDS"[6]. The global aspect is also mirrored in the Millennium Development Goals (MDG)[7]. The MDG's are a United Nations (UN) initiative, and in the UNGASS[8] meeting 2001, a *"Road map towards the implementation of the United Nations Millennium Declaration"*[9] was issued. Eight goals were addressing poverty, education, and health, all with specific targets set. Goal no 6, is to "Combating HIV/AIDS, malaria and other diseases". This is further divided into MDG 6A where the target is to:

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[3] http://www.who.int/topics/hiv_aids

[4] WHO - World Health Statistics 2012

[5] http://www.who.int/mediacentre/factsheets/fs360/en/index.html

[6] http://www.un.org/ga/aids/coverage/FinalDeclarationHIVAIDS.html

[7] http://www.un.org/millenniumgoals/

[8] United Nations General Assembly

[9] http://www.un.org/millenniumgoals/reports.shtml

> "*[…] have halted by 2015 and begun to reverse the spread of HIV/AIDS"*, and of MDG 6B to:*"[…] achieve, by 2010, universal access to treatment for HIV/AIDS for all those who need it."*

These were ambitious and challenging targets and goals, as *"the greatest burden of disease exists in low-income countries that have the least resources"* (Were et al, 2010). Thus, major international donor agencies such as "The President's Emergency Plan for AIDS Relief" (PEPFAR), UNAIDS, The World Bank, The International Monetary Fund (IMF) and more, have invested heavily in poor countries, and thousands of NGO's, are involved in various ways to support with financial aid, or health care delivery projects (Oomman et al, 2007).

1.4 Coordinating patient information in HIV care and treatment

According to the "Patient monitoring guidelines for HIV care and antiretroviral therapy (ART)" developed by WHO/UNAIDS:

> *"Establishing good chronic HIV care including ART requires forming and preparing a clinical team to provide continuity of HIV care. A key element of continuity of care is keeping a record, which summarizes this care and allows each health worker or counsellor to understand what has happened before: the patient's HIV clinical stage, weight and functional status; what prophylaxis, other medications, education and psychosocial support have been provided on earlier visits; the patient's family, pregnancy, contraception and TB status (checked at each visit); and a summary of the patient's ART over time" (WHO/UNAIDS 2006, p 9).*

Once an HIV+ person is enrolled in the antiretroviral (ARV) program for medical treatment, strict adherence to the treatment is imperative, or else the person may develop drug resistance. Thus, systems to follow-up individual patients have become extremely important, both for individual care and for fighting the epidemic on a large scale.

HIV/AIDS was in the beginning of the pandemic categorized as a disease in need of specific clinical knowledge, and care and treatment was delegated to accredited HIV/AIDS (also called ARV) clinics. Since 2010, the disease has been categorized as any chronic disease, and is supposed to be treated in the ordinary PHC clinics. There are many service providers involved in addition to the PHC clinic (X-ray, TB section, laboratory, hospital, pharmacy), being located either geographically relatively close (sub-units in a large clinic), or they may also be situated in dispersed locations. To meet the information needs for each of the providers, and to satisfy the WHO/UNAIDS requirements for a patient record, is a challenge. The organization of the services varies from place to place, and the coordination of patient information is in all settings a crucial issue.

Patient records and follow-up of HIV/AIDS patients thus have become important to discuss for several reasons, such as:

a) The rapid spread of the HIV/AIDS pandemic, and the importance of adherence to medical treatment (health care /control);
b) The developing country (or low-income country) aspect (resources);
c) The increasing complexity within health care provision and health information systems (HIS, ICT, visions and reality).

These issues will be presented in more detail in the following sections.

a) The rapid spread and fight of the HIV/AIDS pandemic (control)

Information systems and statistics are important instruments to getting an overview of, and to fight the spread of the HIV/AIDS disease. As already mentioned, adherence to the ART medication is important, and this is strongly emphasized by the authorities in HIV/AIDS combat. To follow up HIV/AIDS patients within a developing country context is however not straightforward and comes with specific problems. The task of identification of an HIV+ person when he visits a clinic may alone be a problem, both technically, as names may be confusing (which is not unique for HIV/AIDS), and/or a person may also not want to be recognized, as he does not want to accept the diagnosis, due to the stigma related to being HIV+. To follow-up over time is another challenge as people may move around looking for work, which is particularly the case in the harvest season, or they drop out of the ARV program when feeling better. They may then be difficult to locate and to contact, as they often live in informal residential areas.

To share information across health service providers with many providers involved, from first positive HIV test to lifelong ARV treatment, (PHC clinic, ARV clinic, pharmacy, laboratory, X-ray, hospital) brings a number of coordination problems. In PHC in developing countries, paper based patient records are the most common artefacts used at clinic level. Electronic systems are mostly used for aggregated data for information management at higher levels, although computers and electronic systems are becoming more common in certain countries and in the big cities. The main disadvantage with paper folders is that they (mostly) can only be accessed locally, and makes sharing and coordination of patient information problematic. The question then is, how to coordinate and share important information about one patient across providers, and how to cope with reporting requirements to higher levels management, when the number of patients exceeds the capacity at local level, using manual systems. The recommended solution of introducing electronic patient centred systems will not always or everywhere be possible to implement, due to lack of resources, and, as I will argue in this thesis, may also not be the best solution under given circumstances.

Most ICT projects in developing countries' Public Health do in fact not describe comprehensive integrated electronic patient-centred systems. The ones reported in the literature are mostly single initiatives, often pilots, and with success related to one or two electronic components, such as for example an electronic patient register with unique patient identifiers and demographic data, or an appointment module, combined with encounter forms (paper) and patient cards (paper), within a larger hybrid health information system, i.e. about mixed systems in everyday work practices (Fraser et al, 2005; Tierney et al, 2010; Shidende, 2015).

These pragmatic hybrid solutions are not presented as systems or configurations that need to be studied closer from a design point of view, rather as ways of coping in various contexts, and as steps towards the goal of the complete, integrated electronic health records.

b) The developing country or low-income country aspect (resources)

> *"The word pair developing/developed countries became in the 1960s the more common way to characterize countries, especially in the context of policy*

discussions on transferring real resources from richer (developed) to poorer (developing) countries" (Pearson et al, 1969*).*

The notion 'developing country' is often not explicitly defined in IS literature, but will generally imply that a country is deprived when it comes to education, economy and infrastructure. International actors, such as the World Bank (WB), the United Nations Development Programme (UNDP), and the International Monetary Fund (IMF) use different metrics for classification, and classify the countries of the world as 'developed' vs 'developing' countries, or 'industrial countries' vs 'developing countries' (IMF), according to *"standards of living and levels of living"* (Lynge Nielsen, 2011). The World Bank's main criterion for classifying countries is 'gross national income' (GNI). Every economy is classified as low income, middle income (subdivided into lower middle and upper middle), or high income, while UNDP has introduced the Human Development Index (HDI), to emphasize that economic growth should not be the ultimate criteria for assessing the development of a country[10]. The HDI includes health and education in addition to income.

There are however large gaps within the developing country category. In Africa, Libya has a high HDI, no 55 in the world (of 187), and is ranked 1 in Africa, and on the GNI list classified an "Upper-middle-income" country. Among the Sub-Saharan countries, South Africa is ranked 118 in the world on the HDI index, and ranked 9 among the African countries, but with the same GNI classification as Libya, while for example Malawi is ranked 174 in the world and 39 in Africa (low HDI), and classified as "low-income" country (GNI-third last in the world). These gaps have of course great impact on the countries' capability to meet the needs within health care, and some countries depend to a large extent on the funding from the international community. Still, for convenience, I will use the 'developing country' (DC) concept when discussing the aspect of resources in relation to the challenges that follow in terms of meeting the burden of diseases, HIV/AIDS in particular, and the increasing needs for health services.

Information technologies are seen as a tool for development in many fields in developing countries, and ICT and electronic medical records have been recommended, as important tools for coping with the challenges within HIV/AIDS. One can easily understand that the visions of ICT and the expected benefits of EPR, have strong appeal. There are no doubts that introducing ICT in healthcare has enormous potential, but also that it might be a costly endeavour, and brings new problems (Berg, 2004). In a Working Paper on "The Role of ICT's in the Health Sector of Developing Countries", HealthLink Worldwide (2006) analyses and discusses various issues related to the ICT in the health sector. As part of "Constraints and Challenges", they also discuss the cost related to implementation of ICT in healthcare information systems, and claim that:

"The only justification for using a particular ICT intervention is that the benefits justify the costs (PAHO, 1999). Those benefits must be identified, not only in monetary terms but also in terms of improvements in access, quality of care, better return of resource utilization, better clinical end results, user satisfaction, and improvement of the overall community health status" (Chetley et al 2006, p. 35).

[10] http://hdr.undp.org/en/content/human-development-index-hdi

To decide where to invest, and to consider what will give the overall best outcome for the people; quality of care and expected gains has to be weighed against other needs in peoples' lives, which is very challenging. Fighting poverty, and diseases mentioned above, decision makers have to deal with the dilemma of where to invest scarce resources, such as infrastructure and unemployment in the larger perspective, and in healthcare: more clinics, personnel, medicines, infrastructure for transport, or for ICT and electronic health information systems.

The HIV/AIDS pandemic (and the MDG's) have for example brought extreme pressure on the primary health care to fulfil the goals for increased HIV testing and the provision of antiretroviral treatment (ART) to eligible HIV/AIDS patients, and the results should be monitored and reported to the international community. Although WHO has reservations on behalf of the low resource settings when it comes to 'full' monitoring system and use of ICT (WHO 2006, p.42), the overall 'drive' in the global effort to support health care in developing countries, is towards EPR. Use of ICT based information systems is also requested by the large donor agencies for their reporting requirements to control their efforts and investments.

The WHO report on "Management of patient information" (WHO 2012), has its focus on the informational part of health care only, and on the implementation of electronic systems. Although acknowledging the problems for low-income countries (ibid p.6), WHO sees the implementation of EHR/EMR as the only way forward. Issues, such as cost/benefit, and relation to other needs within health care provision (medicines, health personnel, more clinics) are not discussed.

IS design always involves political and economic issues that have to be taken into account, and an in-depth analysis is not within the boundaries of this thesis, I find however that these factors need to be mentioned, and should be considered when visions and goals are made.

c) The increasing complexity within health care provision and health information systems (HIS, ICT, visions and reality)

A health information system is supposed to provide an extensive amount of information to satisfy information needs at several levels of health care delivery and management. According to Hevner et al (2004, p.85), an information system or 'design artefact' is "*[…] complete and effective when it satisfies the requirements and constraints of the problem it was meant to solve"*.

From the examples mentioned previously, it has become evident that to develop a *'complete and effective'* patient centred HIS is not straightforward. Electronic information systems, or EPR are suggested to meet the requirements and aims described by Buckingham et al (1987, cited in Avison & Myers, 1995) and Berg et al (2004), but most EPR do not meet the claim of *"satisfying the requirements and problems they were meant to solve"* (Hevner et al 2004, p.85).

Complexity has been identified as a main challenge in the development of information systems supporting the health care sector in DC's. Braa et al (2007) refer to the large number of institutions involved in the care provision, geographical spread, vertical health programs, and services, and they point to the need for integration and standards for coordination. The

global involvement, international NGO's, and being dependant of their financial support, are also mentioned as factors that increase the complexity.

Hanseth et al (2006) discuss the socio-technical complexity related to IS standards and standardization efforts. They show:

> *"[…] how complexity may generate reflexive processes that undermine the initial aims of standardization"* and suggest, *"looking at the interdependencies and interactions between forms of complexities which can lead to reflexive processes".*

The *"complex world of (healthcare) information systems"* has also been discussed by Skorve (2013). His focus is on the management of complexity, and the need for a better understanding of the complexity involved in healthcare IS projects, to avoid the mismatch between the visions of integrated healthcare systems, and the experiences reported in the field of practice.

These examples of failures and obstacles mentioned are from western world settings, where ICT has a strong position, and in Norway, for example, 100% of public hospitals have electronic systems implemented. In the developing world, the preconditions for implementing ICT are different, although at different stages across the less developed countries and continents. Resources and knowledge, infrastructure and health challenges differ, and the promised benefits from introducing electronic health systems, have been difficult to identify and measure.

Along with the focus on patient level information systems, confidentiality and security are brought to front as important issues. Increasing emphasis has been put on the need for ensuring patients' right to privacy and confidentiality in the design of such systems, both related to technical design and availability of data (UNAIDS 2007). This brings to front the dilemma of competing interests between rapid development and implementation of EPR and easy access to information, vs security and privacy on the other hand, which is particularly important within HIV/AIDS.

Based on the experiences and challenges reported in existing literature on complexity and integration of information, and the role of EPR, I find it worthwhile considering if integrated EPR's might be the answer, and I would like to ask if there should be a re-vision of the policies and goals for health information systems and the role of ICT in DC; bearing in mind the implications that higher level visions and policy have for planning and implementation at lower levels.

1.5 Conceptualizing health information systems (HIS) as hybrid HIS

One aim of this study has been to understand the challenges in coordinating patient information in the context of HIV/AIDS in a DC, and the role of paper and electronic artefacts in this process. Based on the findings, I found the vision of integrated EPR less applicable in these settings, and worked on the idea of conceptualizing health information systems as *hybrid health information system* (HHIS), seeing the hybrid collection of informational artefacts in use (paper and electronic) as *one* HHIS.

For this introduction, I will briefly present the main concepts used for analysis, and for building a conceptual framework as a result of my study. Two theoretical strands have

proved the most useful for analysis of the findings and for building a conceptual framework, Computer Supported Cooperative Work (CSCW) and Information Systems design (ISD).

The research domain CSCW has a work practice-oriented approach. They have done extensive studies within health care on cooperation/coordination of health care and health information, both in situated and in dispersed settings, and CSCW projects use ethnography as a preferred method of investigation. The focus in their research is on how work practices in everyday life are done, and how ICT can support work practices, eventually with implications for design of information systems. From their rich conceptual framework, I have chosen '*collection of artefacts'* to denote the artefacts of different technologies involved in a health information system. To effectively coordinate health work both synchronous and asynchronous, different '*coordinative artefacts'* are in use, to convey information and connect components in an information system. When 'coordinative artefacts' is used in this thesis, there will be an emphasis on the artefacts used to link paper and electronic components of the HHIS. These concepts, together with '*affordances'* from this discipline emerged from the analysis of the empirical material. 'Affordances' is used to discuss the pros and cons of the paper and electronic technologies, respectively.

From the IS design domain, *'modularity'*, *'interface',* and *'standard'* are useful concepts for analysing an information system, and for discussing design of hybrid systems, i.e. about mixed technologies (paper and digital modules). Concepts used when talking about information systems design in the IS discourse, are normally applied to designing digital systems. As one result of this study, the idea is to combine paper and computer modules, and to apply parts of the conceptual framework from design theory in designing these hybrids. One of the main problems in paper-based systems, which ICT is supposed to solve, is the duplication of data. Suggesting a hybrid system with parallel paper and electronic records, although not identical, brings the need for including and discussing '*redundancy'* in detail, or maybe the concept *'robustness'* is a better word? (Currall, 2006; Ellingsen and Monteiro, 2008).

I will conclude this thesis by suggesting a different way of thinking about coordination of health information and development of health information systems. I propose a wider perspective, and suggest a hybrid health information system (HHIS) approach as an alternative to the integrated EPR vision. I introduce the idea of a hybrid systems construct not just as a temporary working solution, while striving towards the vision of an integrated electronic system, but I contend that HHIS in DC's would be satisfactory as vision; guiding plans to achieve the goals for health care delivery, also at higher managerial levels, with important implications for lower level planning, cost, design and implementation.

1.6 Research aim and research approach

My research will fall under the theoretical framework of an interpretive qualitative research, and according to Walsham (1993),

> *"Interpretive methods of research in IS tradition are aimed at producing an understanding of the context of information systems, and the process whereby the information system influences and are influenced by its context ".*

To learn about the HIV/AIDS patient care and treatment, and the associated information systems at the first level of care, this thesis presents a study of patient-centred information systems in Primary Health Care (PHC) in resource-constrained settings. A longitudinal case study was conducted in two Health Districts (urban and rural) in South Africa, using ethnographic methods of investigation.

The focus in the study has been on how a chronic HIV/AIDS patient is followed up over time and across dispersed service providers. The aim has been to study the technologies in use and the process of data collection and coordination, including the various information system configurations in the different contexts or levels in the health care system. What were the technologies and tools (paper and electronic in particular) applied by the health service providers to collect and share information about the patient in this process, while at the same time meeting the requirements for aggregated data and reporting to national and global health programs such as the ARV (and TB) program(s)? What was the core information needed at the different levels in the health care system, and how were the needs met by the collection of artefacts involved in these processes? How were data registered, stored, and transmitted/shared between the components in the system? How did the components of different technologies coordinate and cooperate? What was the role of ICT in this process?

During the research process, the scope of the study moved from the starting point of:

1) Understanding and giving a rich description of the particular setting and challenges of patient-centred health information systems within HIV/AIDS care and treatment, to also

2) Focusing on the design of such systems, and to contributing to the discourse around design of health information systems in developing countries.

3) Finally, the study came to include an interest in the visions and policies behind; reflecting on how they are guiding the choices made when it comes to development and implementation of information technologies intended to solve the challenges in health care delivery.

The interest and focus in this study is not on success or failure of the EPR, or primarily on identifying challenges in implementation of one (or many) integrated IS, but on how computer technology, *together with* the existing technologies (mostly paper tools) as hybrid systems, can be designed to meet the challenges when keeping a patient record related to a person with a chronic disease (the longitudinal record), in a resource-constrained setting.

The further **research aim** was then to contributing to a discussion whether hybrid health information systems may constitute satisfactory solutions, taking the DC context into account, which led to the following **research question**:

- *What are the principles for designing comprehensive hybrid health information systems in a developing country context?*

Sub-questions to guide the empirical fieldwork:

a) How is the information related to a patient with HIV/AIDS, registered, stored and retrieved over time within a health facility in PHC, and shared across dispersed health service providers?

b) What are the components and technologies (computer systems, paper forms, archives, etc) involved in this process, and how do they cooperate?
c) How do the users (doctors, nurses, data clerks, health managers) find the information and technological solutions?
d) What are the affordances of hybrid health information systems?
e) How have policies and visions influenced the current patient information systems?

1.7 Expected contribution

Fitzpatrick and Ellingsen (2012), conclude their review of CSCW research with four suggestions for how CSCW researchers can broaden their research:

1) To focus on multi-site workplace studies, to place work practices within their larges socio-technical context, such as political and policy-making context; and systems and workplace design.
2) Moving to a concern for change and larger-scale concerns: Only a few studies take into account how policies and wider institutional conditions shape ICT efforts;
3) The methodological challenge for studies; They ask: How to combine and relate workplace studies to policy making and technology selection? And how to conduct such studies over a substantial amount of time? One of the ways suggested is: "*to follow the patient trajectory around the multiple settings in which their care is provided, and to do this over more extended periods of time*".
4) They discuss the challenge of practical impact for CSCW studies, suggesting different ways of thinking and engaging on local issues. "*Once a CSCW researcher is in place, we argue that (s)he may shed light on the organizational consequences of new information systems" (ibid p. 41).*

The aim of this research has been to contributing to these calls by questioning the taken-for-granted view of integrated EPR as the solution to the challenges and problems within health care and health information systems in developing countries. Through the study of a health information system within HIV/AIDS care and treatment in Primary Health Care in a developing country context, the aim has been to contributing to our understanding of the conditions under which information systems in PHC in a DC works. The aim has been to describe how a hybrid HIS meets the information needs in different contexts; how visons and policy at higher levels in health management affect local plans and health work practices, and the role of ICT in the health information systems.

Methodologically, I have searched to meet the challenge for conducting case studies over a substantial amount of time, by using ethnographic methods investigation.

In the discussion, I reflect on, and suggest some principles for designing comprehensive, *hybrid health information systems* in a developing country context, from patient care and treatment to reporting requirements from national and global actors, with an emphasis on the affordances of the technologies involved, available resources, and the degree of redundancy appropriate to achieve robust systems.

1.8 Structure of thesis

The rest of the thesis is organized as follows:

Chapter two presents related research and the concepts that I have found useful for analysis and reflection on the empirical data collected; how they have been addressed in the discourses, drawing on the CSCW and HISD domains in particular. The focus is on patient-centred information systems, and coordination of patient information across dispersed service providers and over time, in a developing country setting.

In **Chapter three** I describe my research design, the process and choice of methodology.

Chapter four presents the wider historical, political and economic context of the chosen sites for the case and fieldwork, and the challenges in providing health care services in this environment;

while **Chapter five** gives a more detailed presentation of the Case, the locations, services, resources and work practices, with the focus on the patient record, the technologies in use, and the coordination of patient information.

Chapter six presents the research findings, and analysis of these findings, based on the chosen conceptual framework.

In **Chapter seven** I discuss the research findings in relation to the research aims and questions, and suggest some principles for designing hybrid health information systems in a resource-constrained setting. Finally, I present possible contributions from my case study.

Chapter 2 Related research and conceptual framework

This chapter presents the concepts that I have found useful for analysis and reflection on the empirical data collected, and how they have been addressed in the discourses. In the introduction and the secs 2.1-2.3, selected background and research literature related to patient records and the role of ICT are presented, while secs 2.4-2.6 introduce the theoretical resources used for analysis.

In discussing use of theory and generalization of results from interpretive case studies in IS research, Walsham (1995), presents three possible ways of using theory, referring to Eisenhardt (1989):

Use of theory
1. As an initial guide to design
2. As a part of an iterative process of data collection and analysis
3. As a final product of the research

Table 1: Use of theory in IS case studies (Walsham 1995, p.76)

I find that the points two and three in Table 1, describe my research process and the final conceptual framework presented in this chapter. The key interest through the empirical study has been on understanding the coordination of the health work practices related to a patient with a chronic disease, co-located as well as distributed in time and place, with the main focus on the information needs, and information system(s) and technologies in use to support those practices. How do the health information systems organize and coordinate information to follow the patient over time in one clinic and across health service providers, in a developing country context?

Coordination of health care services, and the health information systems to support them, relates to a multiplicity of research disciplines, and various aspects of the domain have been discussed extensively in the research literature; from health information management studies and medical informatics, to information systems development, and health information systems in developing countries. It will not be possible for this thesis to provide a complete review of relevant research domains, but I have chosen some of the existing perspectives that have informed my motivation, choice of empirical case, and theoretical framework.

In chapter 3 Methodology, I describe my search for theoretical framework(s) for this study in more detail; how I started my research without an initial theoretical approach guiding the design of the project, but with an interest in a field and a particular setting, and how I ended up selecting concepts from two different, but related research fields: Computer Supported Cooperative Work (CSCW), and information systems design (ISD).

In a *"Framework for action"* with the aim of *"Strengthening health systems to improve health outcomes"*, The World Health Organization (WHO) suggests a framework of six building blocks of a health system: 1) service delivery; 2) health workforce; 3) health information; 4) medical products, vaccines and technologies; 5) financing; 6) leadership and governance (stewardship) (WHO 2007). These building blocks are connected and influence one another. Although health information and technologies are the building blocks that I have studied in particular, I also find it important to bring in some aspects of the financing

and governance issues, because of their impact on the health care work practice at lower levels.

Section 2.1, presents how important issues within management of healthcare and health information, such as visions, goals and objectives, have been discussed in the literature, and their implications for practice, assuming a top-down view. This perspective also includes bringing in the role of ICT for management, and the issue of cost-benefit, including risk analysis when introducing electronic information systems, which I believe has a particular relevance in a developing country context.

The following sections will focus on the health care work practices, the patient centred perspective, and the need for information about the individual patient (patient records, coordination, and collaboration). There will be a focus on health information systems in developing countries, with a particular interest in the monitoring of HIV/AIDS. Some examples from developing countries are presented, showing how the issues of ICT and electronic patient records (EPR) have been taken into account within HIV/AIDS monitoring and health care. These sections serve as a background for literature reflecting on principles for design and development of hybrid health information systems in sections 2.5 - 2.7.

2.1 Health management and health information management

Health departments at all levels in a country are responsible for providing access to health care services for their population, and the common visions are to provide equal access of quality care to all citizens. WHO has recommended building on primary health care (PHC) and on a district health system, where each health district has a team responsible for the planning and management of all local health services for a defined population. Today's goals in health care provision are based on the declaration from the WHO international Conference on PHC in Alma Ata in 1978, where it is stated that:

> *"Governments have a responsibility for the health of their people which can be fulfilled only by the provision of adequate health and social measures. A main social target of governments, international organizations and the whole world community in the coming decades should be the attainment by all peoples of the world by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health care is the key to attaining this target as part of development in the spirit of social justice"* (WHO 1978).

Focus in organization and management studies is on quality and efficiency in health care delivery. To reach these goals, health information management for monitoring is of strategic importance to the organization (Berg 2004). Visions, plans and development of health information systems have traditionally been top-down and management oriented, with the emphasis on goals, standards and indicators for measurement of goal achievement, leading to development of systems to collect aggregated data to support higher level management.

For an organization there is normally the goal of achieving their targets in a cost-effective way. To measure whether the goal of quality health care has been met in a cost-effective way is however not an easy task, and within the HMIS discourse these goals are often stated, but there are not many studies that discuss or evaluate the experiences. In section 2.1.2, I will discuss the issue of cost-benefit in organizations in more detail.

2.1.1 Policy and visions – The role of ICT in management

In the introduction chapter I have described the wider context of the case; international engagement and responsibility taken, related to health care in terms of programs, guidelines and funding (WHO, UNAIDS, NGO's). To manage and control diseases such as malaria, TB, and HIV/AIDS, different programs are established and actions taken, and there is a need for systems to monitor development and effects of interventions. To achieve this, it is claimed that, *"Computer-based data management systems offer the possibility of the multiple use of data recorded once to be used for different objectives and tasks"*, and the global visions for health IS are clearly prioritizing electronic systems (Grimson et al 2000; Leiner et al, 2002).

Visions are important leadership strategies in organizations. One definition of 'vision' is *"an idealized goal to be achieved in the future* (Conger, 1999) *that involves both definition of goals and strategies for attaining these goals"* (Yukl, 1998 in Rawolle 2010). The motivational factor of visions has been discussed within literature on organizations, leadership and psychology, and it is way beyond this thesis to engage in these discourses. I think however that it is worthwhile reflecting on the expectations visions and plans at higher levels create, and on the impact they bear on the strategic choices and strategies for action, related to for example ICT in healthcare in low-resource settings (infrastructure, investments and priorities with scarce resources). Global visions and recommendations have great impact on important decisions to be made in the countries fighting the diseases:

> "*Health policy guides choices about which technologies to develop and use, how to organize and finance health services, or what drugs will be freely available."* (Buse et al 2005).

Visions act as inspiration and guidance for actions towards achieving them, but often visions sustain and become accepted as 'facts' that are no longer questioned despite problems and obstacles in attempts to reach the goals. One such vision, or rather pair of visions within health care and health information systems, are the goals of integrated (seamless) care (Grimson et al, 2000), and the integrated electronic patient record as a tool to achieve this. The vision seems sometime unchallenged:

> *"The advantages of the electronic health care record over its paper-based counterpart are clear—it is always available, information can be transferred, and it can support different views of the record for nurses, doctors, physiotherapists, and other users*" (ibid, 2000).

WHO also emphasizes the potential for ICT as the way to go to improve quality of service and reducing cost:

> *"Information and communication technologies (ICTs) have great potential to improve health in both developed and developing countries by enhancing access to health information and making health services more efficient; they can also contribute to improving the quality of services and reducing their cost. Patient information systems, for example, have the ability to track individual health problems and treatment over time, giving insight into optimal diagnosis and treatment of the individual as well as improving the delivery of services. This is particularly useful for chronic diseases, such as diabetes and cardiovascular diseases, and for maternal and child health services where a record of health and treatment over a period of time is required. Analysis of data in patient information*

systems can lead to new insight and understanding of health and disease, both chronic and acute" (WHO Report, 2012).

At the same time, WHO does acknowledge the problems ICT may cause for DC's, well aware of the specific character of funding within health care in most developing countries, as these countries are heavily dependent on donors and international agencies providing the resources required to meet the huge challenges in for example HIV/AIDS.

"While some low-income countries have been able to attract technical and financial resources to install patient information systems at some sites, these require significant investments for their successful implementation. In fact, these systems require abundant resources including skilled labour, technological, and financial means, all of which can be difficult to procure in low-income settings" (WHO 2012, p.6).

In the Report "Everybody's business", WHO (2007) mentions the competing objectives and demands within healthcare. They point for example to the fact that much of the increase in investment by external partners has focused on particular diseases or health conditions, and to the competition for resources:

"For example, the pressure to increase access to HIV/AIDS care and treatment, which has helped bring visibility to the human resources crisis in Africa, brings its own pressures on the capacity of the health system to handle other causes of ill-health. Progress in increasing staff retention in the public sector through better pay packages may mean compromise in containing costs. Competition for resources may be between hospitals and primary level care; between prevention and treatment; between professional groups; between public and private sectors; between those engaged in efforts to treat one condition versus another; between capital and recurrent expenditures. This means health system strengthening requires careful judgment and hard choices. It can be better informed by evidence and by the use of technical tools, but ultimately it is a political process and reflects societal values" (ibid p.7).

It may be that the strong focus on EPR to integrate information and systems, and to solve problems in health care provision, for example within HIV/AIDS care, puts too heavy pressure on the countries most affected by the disease.

2.1.2 Cost/benefit analysis

When discussing design and implementation of large information systems in any setting, the cost-benefit analysis (CBA) is important, but a CBA-model is based on a calculation of expected returns of investments (ROI) of new technology, where potential costs and income are stipulated. The CBA model is not easy to apply to health care organization, as the use of ICT in health care "*is not necessarily designed to produce a billable product*", and the benefits in terms of achieving the goals of improved quality of care and health for the population, are difficult to quantify and to measure progress (Menachemi and Brooks 2006; Blaya et al 2010).

In a report from The UK Institute for Public Policy Research, the authors examine the evidence that e-health is delivering real value, claiming that, *"clear benefits are yet to be shown in practice"* (Bend 2004, p.7). Shekelle et al (2006), have done a literature analysis and prepared a report for the Agency for Healthcare and Research and Quality, US Department of Health and Human Services, where they assessed the evidence base regarding

benefits and costs of health information technology systems. The majority of the publications included in their analysis are in the US, and many of these studies are in well-resourced US health systems. The authors state that an analysis of the usefulness of implementing health information technology (HIT) must take into consideration several factors, such as:

1) The potential of this technology to improve health care quality, safety, and patient satisfaction, and how this potential has been demonstrated;
2) The cost-effectiveness of the technology – the business case for adoption of the technology- including the cost savings that accrue […].

From their studies within Ambulatory Care, the findings reported were primarily related to implementation processes and to changes in clinical processes. They did not find much evidence for the ability of HIT systems to make health care more patient-centred. Using computerized reminders to patients was the best evidence of such a change. The authors conclude that,

> *"Using existing published evidence, it is not possible to draw firm conclusions about which HIT functionalities are most likely to achieve certain health benefits – and the assessment of costs is even more uncertain"*,

and further:

> *"[...] all cost-benefit analyses predicted substantial savings from EHR (and health care information exchange and interoperability) implementation: The quantifiable benefits are projected to outweigh the investment costs. However, the predicted time needed to break even varied from three to as many as 13 year"* (ibid, p. V).

Literature analysis by Uslu and Stausberg (2008), mainly representing large hospitals in the US, found that all the studies dealt with economic aspects, and only few considered additionally the impact of EPR on the quality of care. They conclude that: *"(….) concerning the influence of EPR on quality of care, the studies do not provide a clear answer to the question of benefits"* (ibid p. 680).

Human, physical and financial resources in HIS implementation form a special challenge in developing countries, where very often the most essential resources are lacking. Van Damme et al (2008) are concerned about the health system, and how to meet the need for increased ART treatment. They claim that, among challenges still underestimated, is the growing caseload of people to be maintained on ART in the long term, as ART treatment is scaling-up, and people live longer with the disease, while at the same time there is shortage of human resources to reach the estimated need for ART coverage. Although their main focus is on human resources and the health services delivery, the scenarios they present related to needs for resources all over, are also relevant for how or where to invest scarce resources.

As it is emphasized in health and health IS discourse, the use of ICT to support health-care services, has *the potential* to greatly improve patient outcomes (WHO 2005 – *58th World Health Assembly Report*). Blaya et al (2010), ask if there is any evidence that using ICT to manage patient care can have a positive impact in developing countries, looking for evidence and evaluations confirming *"that these systems are safe, beneficial, and not a waste of scant resources"*. The authors did a review of literature evaluating the impact on e-health worldwide, and found that most evaluations on electronic health records: "provided insights into *possible impacts* of the systems, but had limited scientific rigor". They underline however that:

"Evaluations in resource-poor environments face many challenges when compared to those in developed countries […]. With the rapid growth of e-health in DC, there is clearly an urgent need for solid evidence of its impact to justify and guide the investment of resources in such systems" (ibid p.249).

Overall, they conclude that,

"[…] *with the exception of PDA-based data collection, there are still few scientifically rigorous data on the effectiveness and cost-effectiveness of e-health systems in developing countries" (ibid, p.248).*

The next section will present some examples and initiatives on how the need for patient records have been met, and also the barriers to achieving the goal of a complete health record in primary health care practices.

2.2 Patient centred information systems

"The concept of integrated Primary Health Care is best viewed from the perspective of the individual: the aim being to develop service delivery mechanisms that encourage continuity of care for an individual across health conditions, across levels of care, and over a lifetime" (WHO 2007, p.5).

The importance of *"customizing information to users' needs"* is emphasized by many authors (Bodart and Shrestha 2000; Sauerborn 2000; Gurley and Rose 2004; Mamlin et al, 2006). Levels of information are often represented as a pyramid, illustrating the different managerial levels in the health care system, and also the needs for information at each level (figure 1).

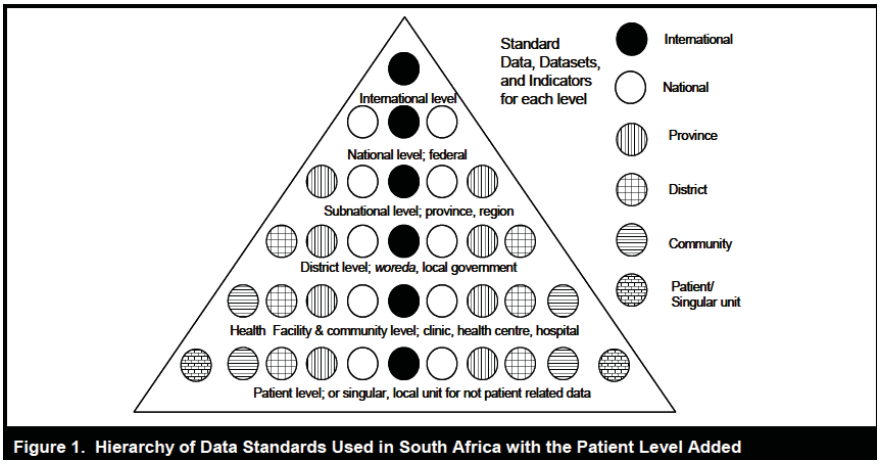


Figure 1: The information pyramid (Braa et al, 2007)

Following a model of managerial levels and management functions in health care organization, information needs for the health facility at primary level will mainly be information about patients, while at the same time they will need to meet the requirements for reports related to program management and disease surveillance at higher levels. Recently, the need for patient centred information systems, and a more 'bottom-up' and work practice-oriented system has received increased attention, and has been particularly relevant in fighting the HIV/AIDS pandemic.

WHO has engaged in the development of patient centred information systems, and claims that:

> *"The key to effective patient information systems is to retain the link between the individual and the data collected over time and to make those data available to multiple health care providers when needed. Following this 'data trail' that charts the health of an individual is both valuable and important: these data can be aggregated to provide data trails for communities, regions, and countries, upon which public health policy is shaped" (WHO 2012, p.9).*

2.2.1 The patient record – and the role of ICT in coordinating patient care

There is a general consensus in health care and management about the importance of keeping a patient record. The patient record and the role it plays have been discussed in various and partly overlapping discourses, such as Health Information Management, Medical Informatics, and Computer Supported Cooperative Work (CSCW). What actually constitutes a patient record, and the role it plays is however not unambiguous, and it will differ depending on the contexts. Different actors will have different information needs, depending on the role in the health service hierarchy, type of health facility (hospital vs primary health clinic), and the health professionals' need for clinical details.

For the health worker in a clinic or hospital, clinical information about the individual patient is crucial, to provide quality care and treatment, while for the data capturer in the reception, demographic information, date and type of visits, time and date for next consultation, is important to be able to identify the person, and to follow-up the patient over time. At higher managerial levels, data will mainly be interesting in aggregated format, useful for management of resources, and monitoring of a disease.

As there are many actors involved in personal health care, the need for sharing information about one person over time and across health service providers is emphasized in the literature. The concepts 'seamless care' and 'seamless integration' (of information) have been introduced as the visions for patient health care and sharing of information (Dick and Steen, 1991; Grimson et al, 2000; Ellingsen and Monteiro, 2006, 2008), bringing in the need for electronic records. There is then the question of what information is needed by the different service providers, i.e. what is needed to provide 'seamless' quality care?

With the technological development in the 20th century, computers are introduced in the health care and health information systems area, and the development of computerized information systems is claimed to be a key to meet the needs for information (Grimson et al, 2000; Hanseth et al, 2006; Shekelle et al, 2006). EPRs have repeatedly been identified as *'essential'* (Dick, and Steen, 1991*),* or *"at the heart of the application of IT in health care"* (Grimson, et al, 2000, p. 50).

In presenting "Medical Informatics: Past, present, and future", Haux (2010), describes the discipline to be "a cross-sectional or bridging discipline", that forms today one of the bases for medicine and health care. The author refers to the discipline to be:

> *"[...] dedicated to the systematic processing of data, information and knowledge in medicine and health care*" with the aim to: *"help achieving health of people throughout the world, both in contributing to the quality and efficiency of health care […]* (ibid, p. 600).

Cabitza et al, (2005, p. 164), also describes the optimism and the high expectations related to the effect of introducing EPR in health care:

> *"Expectations about the Patient Record (especially in its computer-based form) regard a wide spectrum of themes: e.g., a better decision making process, the achievement of better medication management, of an improved resource utilization and, in the case of Computer-Based Patient Record (CBPR) an almost total elimination of redundancy, especially of effort and data, in order to help people focus their attention on the most important tasks".*

It turns however out that, the aim of an integrated patient record that "*allows each health worker or counsellor to understand what has happened before"* is not easy to achieve in practice (Berg 2004; Bend 2004; Hanseth et al, 2006; Ellingsen and Monteiro 2006). Berg (2004) states that:

> *"In all Western countries, concerted efforts are undertaken to enhance the use of Information Technology (IT) in health care. […] Yet there are only a few real success stories in health care IT, and the frustrations many" (ibid p.1).*

The complexity and challenges are confirmed by Fitzpatrick and Ellingsen (2012): *"[…] despite significant investments and efforts, getting this right has proved to be a challenging task".* The causes for the problems are claimed to be complex and varied (ibid).

This is also acknowledged by the WHO:

> *"Many health information systems do not in fact retain data in the form of an individual patient record. Instead the data are aggregated into summary totals, which obscure the individual patient link, making it difficult to follow patients over time"* (WHO 2012, p.9).

The complexity involved in coordinating several systems from different service providers have been discussed extensively (Hanseth and Lundberg 2001; Hartswood et al 2003; Ellingsen and Monteiro 2003; 2006; Hanseth et al, 2006; Braa et al 2007, Gilson and Raphaely 2008), and the experiences described in literature so far, points to a number of problems arriving at the ultimate goal. Ellingsen and Monteiro (2006), claim that, the medical informatics literature has its focus mainly on technical and design issues, and not the work practice, while the CSCW literature is more attentive to the socio-technical aspects of integration.

The following experience is reported from a large Swedish hospital:

> *"The new system contained patient administration, clinical medical records and referral- and replies to referral information, but it was not an entirely paperless record: there were still many documents such as EKG and 'pictures' (e.g. radiology)" (Øvretveit et al, 2007, p.260).*

Instead of seeing the record as a 'container for information' (Greenhalg et al, 2009), or 'a passive information repository' keeping the past history, Berg (1996) shows how the patient record works as a processing tool, and Fitzpatrick (2004) introduces the concept of 'the working record', much with the same argument as Berg.

> *"In the practical delivery of care during the patient episode, the working patient record is centred on the contents of the official buff-coloured chart and its associated forms distributed to the folder hanging at the end of the patient's bed. Each member of the care team contributes to the information collected in the*

> *official patient chart through progress notes, examination notes or signatures signifying delivery of certain medication, procedures and so on. But **the working patient record** is also much more than this. While clinicians worked with the chart, they also worked with various other systems and pieces of paper reflecting their own view of the patient and their role in the care of that patient […]" (Fitzpatrick 2004, p.294).*

Berg (1997b), and Berg and Goorman (1999), focus in a number of papers on the contextual nature of medical information, and the need for knowledge about the patient, medical information, and the work practices, to be able to provide quality care. They use an example from a hospital Care Unit and how to measure the fluid balance to illustrate this, and point to problems when data from their primary contexts are 'translated' from one context to another. They conclude:

> *"Implemented in the name of 'efficiency' and 'improving quality of care', these tools lead to an additional burdening of the primary users and may actually diminish the quality of care by diluting the time available for actual patient care"* (ibid, p. 59).

Berg and Toussaint (2003) describe how the paper record, and the way the forms are designed actively, adds structure to the data inscribed in it, and thus contributes to coordinating activities at various locations and over time. They also emphasize that the patient record is only one element in accumulating knowledge and coordinating work processes. Doctors and nurses, for example, are people taking part in the processes and are also sources of knowledge, contributing to enhancing the information content of the written data (ibid, p. 339).

Knaup et al (2007), discuss the expectations and potential benefits of e-health and integrated electronic patient records: *"The expectation is that e-health will contribute to high quality information, data exchange and patient care"* (ibid p. 34), and they state that this *can* become reality. They point however to a list of barriers to be exceeded, among them the inherent complexity of the field, and the costs, together with ethical and legal requirements. Their main focus is the need for semantic interoperability, which they see as a major prerequisite for usability, and a necessity for interoperability. Sharing of information across institutions (called institution-wide patient record) is described to be at a different level of complexity, and important barriers mentioned for sharing of data, in addition to the semantic interoperability, are concerns about patient safety and privacy.

In their systematic literature review on tensions and paradoxes in EPR research, Greenhalgh et al (2009), arrive at a similar conclusion:

> *"[…] EPR use will always require human input to re-contextualize knowledge; that even though secondary work (audit, research, billing) may be made more efficient by the EPR, primary clinical work may be made less efficient; that paper may offer a unique degree of ecological flexibility; and that smaller EPR systems may sometimes be more efficient and effective than larger ones".*

With the focus on medical work in a hospital, Vikkelsø (2005), studied the way in which ICT affected work practices. Her results pointed to the way work practices were redistributed, and she claims that:

"[…] when new capabilities arise, so do new risks; when new competencies are produced, so are new incompetencies, and when a new order is established, so is also a new disorder", and claims that: *"this calls for a more careful use of normative claims such as improvement, optimal and smart when discussing ICT projects" (ibid p. 24).*

She suggests asking the following questions throughout the phases of design, implementation and daily operation of any ICT project:

- *The redistribution of work*: who will be relieved? Who must work harder?
- *The redistribution of attention*: what is brought into focus with what effect? What kind of blindness is made with that effect?
- *The redistribution of risk*: How is risk reduced for whom? How is risk heightened for whom?

2.2.2 The *complete* patient record

Leiner et al (2003) describe in detail what belongs in a patient record in a health care institution (hospital):

"The patient record is composed of ***all data*** *and* ***documents*** *generated or received during the care of a patient at a* ***health care institution****. […]. The patient record is composed of a number of partial documentation elements (patient history documentation, patient findings documentation, summarizing reports, overviews, etc.); all of them have different characteristics and suit different purposes […]"* (ibid p. 63, bold in original).

This definition and the requirements relate to *one* care provider, and one may easily imagine the complexity created when the complete records from different providers should be integrated.

In discussing integration of HIS as a potential remedy for problems in coordinating health information from dispersed health providers and systems, Ellingsen and Monteiro (2008), state that: *"Visions of integrated care are attractive because they promise a solution to these concerns including efficiency gains and improvements"*. Referring to a number of sources they claim that:

"An integrated solution is supposed to give physicians easy access to data from multiple information sources [13; 14, p. 1529; 15, p. 6], thus providing ***a complete*** *picture of the patient/client's medical history"* (ibid p.225 – bold added).

They also state that: *"It is by no means 'given' what constitutes relevant knowledge"* (ibid p.222)*;* which raises the question*,* what *exactly* constitutes a 'complete' patient record in a given situation, i.e. what information is needed to make it 'complete' and, what part of this complete picture is relevant for whom?

This question is of particular interest when discussing the transition from paper-based records to electronic systems. A complete health record for a chronic patient may over time contain a large number of documents. To meet the requirements for following a chronic patient over a lifetime, and to coordinate information about the person over time in a facility, and across dispersed health providers, is obviously a challenge.

Tough and Moss (2006), discuss recordkeeping in organizations. Although not from a health care context, they bring up the question of what elements do belong in a 'complete' record, stating that organizations differ in what constitutes the 'complete' record.

> *"In highly regulated industries it may be necessary to capture all the recorded information created or received as part of a business process".* They point to the fact that, "*in a paper-based system, users (people) of the record will need to make a decision to select a document (or piece of information) to be part of the record, and the action to include relevant papers in the correct file" (*ibid).

Further, they claim that electronic systems may influence the 'completeness' of the record in a number of ways, such as: record-keeping choices may be automated; record selection may be less narrow; and: *"particularly, if the capture of all business documents is mandatory or automated, this represent a potentially colossal increase in the volume of the formal corporate record over the traditional paper file".* This situation will occur in both low- and high- income countries, because of the many actors involved, and their specific information needs. Tough and Moss, conclude that: *"the completeness of the record would remain reliant on the behaviours and values of the organization"* (ibid p.29).

As the different health care providers and managers have different needs for detailed information, there will be a certain minimum of information needed. Some kind of 'core' patient journal has been suggested, with different types of content/data elements being included. In Norway, the core record - 'kjernejournal'[11], and in the UK, the 'Summary Care Record' are discussed, although, these projects have different agendas.

> *"The NHS Summary Care Record (SCR) is an electronic summary of key clinical information (including medicines, allergies and adverse reactions) about a patient, sourced from the GP record. It is used by authorised healthcare professionals, with the patient's consent"*[12].

The concept or idea of a summary record has materialized in different ways in a western setting and in a DC, depending on level of the electronic system development. A 'clinical summary' in a DC context could be a computer-generated record with patient demographics, diagnoses, drugs prescribed, and lab results, printed and placed in front of the paper chart the permanent medical record. (Were et al, 2010; Noormohammad et al, 2010; Whiting-O'Keefe et al).

A patient retained card or booklet, used in many clinics, may serve as a 'summary record', as also the referral letter. These examples are either pure paper forms, or computer-generated paper records. All in all, and depending on context (resources), the 'complete' record of a patient will be a combination of paper and digital components – i.e. some version of a hybrid system. More examples from patient record initiatives in DC's will be presented in sec 2.3.2.

2.3 Health information systems in Developing Countries - monitoring HIV/AIDS

As a part of the global scaling-up of HIV treatment, increasing emphasis is being placed on the information systems to improve patient management, to allow individuals to be tracked

[11] *https://helsenorge.no/kjernejournal/kjernejournal-for-safer-healthcare*
[12] *http://psnc.org.uk/contract-it/pharmacy-it/electronic-health-records*

over time and between places, and enable the development of longitudinal patient-level information for clinical management. HIV/AIDS is a lifelong disease and,

> "*[…] treatment of HIV/AIDS requires daily administration of three anti-retroviral drugs (ARVs) plus supplementary medicines, as well as careful monitoring of clinical progression, development of side-effects, and lab results"* (Jazayeri et al 2003).

It has become increasingly important to follow patient's adherence to the treatment to prevent multi-drug resistance, as ensuring adherence will delay emergence of resistant strains of the virus (Little et al 2002; Steel et al 2007).

This has led to several initiatives of development and implementation of computerized information systems both for aggregated and patient centred data. Potential expected advantages are significant labour-saving in reporting requirements, facilitating management of the increasing number of patients. Important is also the possibility to follow the patient trajectory across programme levels and facilities, and also to cross-check with information from different programmes, i.e. VCT[13], PMTCT[14], ANC[15] and opportunistic diseases like TB, which is strongly related to HIV/AIDS (WHO/UNAIDS 2003; Fraser et al 2005; 2006). As described in sec 2.3.2, a number of pilot projects in Africa and Asia have been reported in the research literature, arguing that these pilots demonstrate the advantages and feasibility of implementing ICT in developing countries (Hannan et al, 2001; Rotich et al, 2003; Fraser et al 2004, 2005, 2007; Siika et al 2005; Harries et al 2006, Were et al 2010).

In a WHO initiated "Workshop Electronic Medical Records & Knowledge Sharing for ART Scale Up in Sub-Saharan Africa" in Nairobi (WHO 2004), the need for electronic medical records related to the scaling up of HIV treatment was discussed. Participants were from WHO, Sub-Saharan countries' Departments of Health, and medical personnel from the US and UK. Examples from Kenya (AMPATH/PMTCT Plus Project), and Zambia (use of smart cards) were presented (ibid). The need for relevant information to monitor and evaluate scale-up of HIV treatment and care was emphasized, and The Meeting Conclusion 6.2 states that:

> *"[…] the information to be collected to be used for individual patient management and monitoring as well as clinical program monitoring and evaluation at health facility, sub-national and national levels […]"* (ibid p.12).

Key issues were the need for standards for sharing and integration of systems, and the need for guidelines, leading to the 'WHO Patient Monitoring Guidelines for HIV Care and ART' (WHO 2006). Although emphasizing the need for electronic systems, the meeting Conclusion 6.3, stated that: "*information systems to be used will include paper-based systems as well as electronic systems".* They list a number of requirements for the process and development of an HIV/ART monitoring system, that are in line with the characteristics listed by Clarke (ref sec 2.6, p.52), related to hybrid systems, such as: the need for flexibility to cope with differences in circumstances, and the need for capacity to change its elements

[13] Volontary Counselling and Testing
[14] Prevention of mother-to-child transmission
[15] Antenatal Care

over time, as its environments change (WHO 2004; Clarke 2005,). The following quote is from the minutes from the meeting:

> "**5.5 Discussion (***bold in original***),**
> 5.5.2 'Vertical versus General Health Information Systems':
> *A repeated wish from country representatives was that the information system should "ideally be one system". However, most countries will develop paper-based systems in combination with electronic based information systems. Even in countries with advanced information systems, combinations of paper- and electronic-based systems exist. It is arguable that even with a well-developed electronic system, one will need a paper back-up system" (ibid, p.10).*

The WHO Workshop (2004), and the "Guideline for Monitoring and Evaluation of ART" (WHO/UNAIDS 2006), both emphasize the need for patient information at all levels in the health management and services hierarchy. Monitoring at higher levels, seen as

> *"Systematic and sustained tracking and review of progress towards the MDGs - in terms of achievements, trends and shortfalls – using authoritative data, disaggregated, whenever possible, by gender, age and specific vulnerabilities, which will be identified through a consultative process with partner." (ibid p.9).*

On clinic level, individual patient information is needed.

Level of data collection	Monitoring tools	Purpose	Quantity
Global/Regional	Global/regional summary indicators	Summary indicators for global reporting	Less
National	National summary indicators	Summary indicators for national planning and reporting	
District	District summary indicators	Indicators for district and national reporting	
Facility	Facility registers, logbooks	Clinical team management of groups of patients, case review, audits, drug supply management	
Patient	Patient card/record	Individual patient management	More

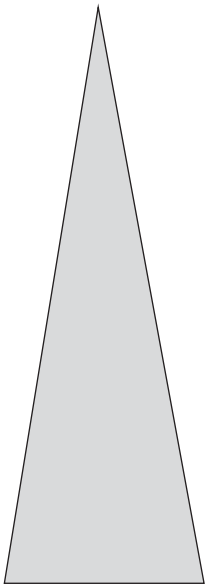


Figure 2: HIV/ART monitoring at different levels of the health care system – adapted from "Patient monitoring guidelines for HIV care and ART", (WHO 2006, p. 12)

2.3.1 Keeping a patient record in resource-constrained settings

In line with Leiner (2003), regarding the scope of a patient record, the WHO/UNAIDS "Workshop on Strategic information for ART programmes" (2003) gives this list of

> *"Unique characteristics of ART to keep in mind in monitoring processes and expected output:*
>
> *1) ART turns HIV into a chronic disease with lifelong continuous therapy [whose cost of poor adherence – the evolution drug resistant stain – is high.]*
>
> They also add challenges in keeping this record over time:
>
> *2) People (or patients with improved quality of life and health) do not remain in one place throughout their lives; economic, social and other factors cause people to move around.*
>
> *3) ART is comprised of a variety of treatments. Problems with toxicity will mean that first- or second-line treatments for some patients will have to be adjusted. Finally, over time, some patients will end up failing their treatment options but will then need palliative or terminal care."*[16]

Tierney et al (2006) report from the WHO workshop in Nairobi (2004), where a panel agreed on a minimum data set for HIV care in DC. The data set is intended for an electronic system, but indicates the overall needs for information related to one patient. Based on assumptions of who the users of HIV/AIDS data are, and what are their information needs, the panel suggests:

> *"The proposed minimum data set consists of data for registration and scheduling, monitoring and improving practice management, and describing clinical encounters and clinical care. Data should be numeric or coded using standard definitions and minimal free text.* ***To enhance accuracy, efficiency, and availability, data should be recorded electronically by those generating them.****"* (Tierney et al, 2006, bold added).

According to the WHO Nairobi meeting, these are the variables that should be in an HIV/AIDS reporting system: (Ref also Patient Monitoring Guidelines, WHO 2006, pp 16-19)

A) HIV/AIDS
i) opportunistic infections
ii) related comorbid conditions
(1) TB
(2) malaria
(3) STDs
(4) etc…
B) Pharmacy
i) ARVs
ii) OI drugs
iii) TB drugs
iv) OI prophylaxis
v) other…
C) Subjective findings
i) history

[16] WHO, Dep of HIV/AIDS, 2003 – Workshop on Strategic Information for Anti-Retroviral Therapy Programmes

ii) symptoms, etc.

D) Objective observations

i) vital signs
ii) physical examination findings
iii) laboratory investigations
(1) in laboratory
(2) point of care
iv) imaging investigations (e.g., X-ray)

E) ANC/pMCTC
F) VCT/CT
G) Risk/exposure/prevention
H) Outpatient visits
I) Inpatient (discharge)
J) Home-based care
K) Family planning
NL) Demographic/registration/identifiers
M) Provider

This list makes clear that a huge number of data has to be archived, which in a paper- based system will constitute a massive bulk of forms and notes contained in the patient folder/envelope. This fact, together with the problems of availability, retrievability, and more, has been behind the massive criticism of the paper medical record as information source, (Whiting-O'Keefe et al, 1985).

A complete electronic version of the EPR would clearly also contain a large number of data, which will require very high storage capacity in the system. Parts of the information will probably be stored in different sub-systems or modules, such as appointment-, administration-, and ARV and/or TB modules, that need to be integrated and/or accessed for a comprehensive view of an individual patient (Leiner et al, 2003; Were et al, 2010). The health care services and management in a DC will not easily meet these requirements for a patient record.

The legal requirement for keeping a record in South Africa was 6 years after they become dormant (MPS[17] 2012). Though, the advice in the "Retention of medical records" (MPS 2012) had this comment:

> *"The cost and space implication of keeping records indefinitely must be balanced against the possibility that record will be found useful in the defence of litigation or for academic or research purposes".*

Implementation of computerized systems in resource-poor settings has also been disputed in a DC context. Harries et al (2006) discuss ART in Malawi and state that *"Computerization of all the ART facilities might be possible (...) but we are not convinced that this is the answer"*. Among challenging issues mentioned in the discourse are: reliable patient identification, data quality management, data confidentiality and security (Boulle and Ford, 2008; Grimson et al, 2000; Hannan et al, 2001; Fraser et al, 2005). Other key issues to be considered and weighed against the expected benefits are limited financial and human resources, unstable infrastructures, such as electric power, and lack of computer skills. There is also a heavy pressure on the health workers and facility managers in terms of rendering

[17] Medical Protection Society

the ever-increasing demand for health services on the one hand and data collection and reporting requirements on the other hand (van Damme et al, 2008).

The idea of integrated and seamless care, and complete integrated patient records is however guiding the visions and goals in policy documents, standards and guidelines, although not easy to implement in low-income settings.

An EPR in the Primary Health Care work practices, in a DC setting, will mostly be a 'summary record', capturing selected data elements only, in terms of demographic information, date of visit and a few more data elements. Both paper folder and electronic information together are used to provide a complete and integrated patient record. For statistical purposes, there is a 'minimum dataset' to feed into monthly and quarterly reports for management.

2.3.2 Projects from Developing Country context: Initiatives and achievements

The global focus on scaling up of ART has not been for a very long time, and there are relatively few examples reporting from ICT projects in developing countries that have developed and implemented patient centred information systems for monitoring and evaluation of HIV/ART programs. A number of projects are however presented in the research literature: 'Partners in Health' has run projects in Haiti, Peru, Rwanda, Kenya and South Africa (Jazayeri et el, 2003; Fraser et al, 2005, 2007).

'AMPATH' started in Kenya in 2001, and has worked with combination of paper and electronic systems. They developed the Mosoriot Medical Record System, and have since 2004 worked with OpenMRS (Rothich et al, 2003; Tierney et al, 2006; Blaya et al, 2010). The system was focused on primary health care, consisting of paper-based encounter forms, and an electronic data base (Siika et al, 2005; Noormohammad et al, 2009), as most clinicians were not able to use computers directly during patient care. The encounter form had a mix of check boxes and blanks for free text entry. Free text entries were matched to know concepts in the database, assuring that patient data was entered in coded form. and They emphasize the need for balancing use of paper and electronic media, and the need for simplicity in design.

In Malawi, Ministry of Health in cooperation with Family Health International and London School of Hygiene and Tropical Medicine, has worked on scaling up ART and discuss patient information both paper-based and electronic. (Harris et al, 2006).

Were et al (2009) report on an EPR system in Uganda, which generated clinical summaries that covered patient demographics, diagnosis, drugs prescribed, and lab results (ibid, p.91). As the registration area was not connected to the data-entry room, the summaries were printed, and then placed in front of the paper chart, to be used by the health personnel.

These initiatives are projects in different stages of implementation. They are to some extent all presented as success-stories related to the use of ICT in resource-poor areas to support HIV and MDR-TB treatment, and important achievements are described. Emphasis is on identification, and tracking patients over time. The authors do however also acknowledge

the problem of limited resources, and see the cost of setting up IT systems in resource-poor areas as a barrier, that must be balanced against potential benefits (Fraser et al, 2004).

Since 2001, Western Cape Department of Health (WCDoH), has developed and run a pilot project in Cape Town, first as a paper-based monitoring system, later stepwise including and implementing electronic modules, becoming the Primary Health Care Information System (PHCIS), (Boulle et al, 2008) [will be elaborated in Ch 5.1.4, p 97].

Most important in any health information system is to identify the patient, and particularly when dealing with chronic patients, such as HIV/AIDS. Thus, information systems to create unique patient ID has been prioritized and developed in most of the developing country projects. It is also imperative to be able to follow a patient over time. Appointment modules are important and have been developed. These modules, also called tracking system, make it possible to keep track of the patient over time in a facility. The modules may print out list of patients due for consultation on a particular day or week, enabling the clinic to check if the person keeps the appointment, or else to contact the patients if they don't show up.

Blaya et al (2010), have searched and given a systematic review of e-health projects described. These projects all describe hybrid systems, or they are, at some level in the health services hierarchy, pure paper based. They find that, most large e-health implementations have little or no evaluation data, but that *"initial benefits were shown in systems that track patients through initiation, monitor adherence, and detect those at risk for loss to follow-up"* (ibid p 7).

In the following, I will first present some background on the CSCW domain and how the key concepts chosen from the field have been used and discussed, followed by the concepts that I have selected from the ISD frameworks.

2.4 Coordination and collaboration – Computer supported cooperative work

Computer Supported Cooperative Work (CSCW) is a research field that addresses how collaborative activities and their coordination can be supported by means of computer systems (Schmidt and Simone, 1996). There is a particular emphasis on the importance of understanding the nature of cooperative work to be able to inform the design of the systems to support cooperation, using ethnographic methods of investigation.

The research domain relates to and overlaps to other fields, such as Human Computer Interaction, Participatory design, and Information systems design, but as the name says: with a particular focus on, and interest in understanding cooperative work, and how computer-based technologies may support this. In their research, the CSCW projects focus on the workflow, cooperation and coordination in the work practices, and the artefacts in use, to be able to inform the design of the systems to support cooperation, using ethnographic methods of investigation, (Carstensen and Schmidt 1999; Fitzpatrick and Ellingsen, 2012).

The CSCW term dates back to 1984 and was coined by a group of people from different research fields, with a shared interest in how people work in groups, and the role of technology in the work environment (Grudin, 1994). As a research field, CSCW has been categorized differently in the literature. Some define it as a design discipline, some will

define Participatory Design as an aspect of CSCW, while others find this to rather confuse than define the CSCW field (Dourish, 2006). Early projects in CSCW were often revolving around office automation, where the studies were in co-located work environments and real-time, resulting in groupware systems aiming at supporting cooperation in the office. Early applications include for example: calendar systems and electronic mail, collaborative authorship applications, electronic meeting rooms and videoconferencing systems (Dourish and Bly, 1992).

Later, asynchronous coordination and cooperation in dispersed settings were also studied (Heath and Luff, 1998). In more recent literature, the complexity in today's cooperative work environments is emphasized, and the increased need for understanding the nature of cooperative work in 'virtual teams', i.e. cooperative work in dispersed settings and over time (Dourish and Bellotti 92).

CSCW has done extensive research within healthcare, and have done in-depth studies of healthcare work practices (Berg, 1999; Bardram and Bossen, 2005; Balka et al, 2008; Cabitza and Simone, 2007). The aim has been to understand cooperative work, with an objective to design information technology tools to support the work (Schmidt and Bannon 1992; Fitzpatrick and Ellingsen, 2012). In a review of 25 years of CSCW research in healthcare, Fitzpatrick and Ellingsen (2012), discuss the results of the research in terms of contributions, challenges and future agendas. They claim that, CSCW has provided *"a rich range of concepts and findings towards understanding the work of healthcare, but the work on the larger policy level is lacking".* In studying the CSCW research in more detail, related to the outcome of suggested design guidelines, they claim that the value of the studies is primarily their contribution to a rich understanding of situated practices; that

> *"[…] designing tended to be much less prevalent than understanding*" (ibid, p. 10), and that *"studies moving from understanding to design, as per this call for CSCW, have been less evident in the healthcare domain"* (ibid, p.30).

A second and interesting finding in Fitzpatrick and Ellingsen's review, is a note on *where* the studies of healthcare have been conducted. Of the 128 papers included in their review, 121 were from western settings, and "the rest of the world" was represented with only 7; the developing world especially under-represented in the accounts of healthcare work (ibid, p. 9). Thirdly, they also point to the fact that most of the papers dealt with hospital settings.

Smith et al (2008) discuss the implementation and experiences from a Health Management Information System in Tanzania and review the 'integration' concept from different angles, i.e. development administration, management and sociology. They propose a broader notion of integration, that: *"[…] includes not only integration of data, but also integration of administrative decision-making practices, policy imperatives local contingencies and health priorities "*(ibid, p.2).

Related to the challenges and discussion around integration is also the need for, and possible problems, with standardization, to be able to share across systems and technologies (Bowker and Star, 1999; Winthereik and Vikkelsø, 2005). This involves both the question of who have the power to defining standards, and the balance between local vs global needs (Cabitza and Simone, 2015; Hanseth et al, 2006; Ellingsen and Monteiro, 2006; Braa et al, 2007). This will be followed up in secs 2.4.1 and 2.5.2.

To be able to give a thick description of the cooperative work at a chosen site, the routines and processes, eventually with consequences for IS design, the preferred research method in CSCW is ethnography. One aim of this thesis is to contribute to the CSCW discourse in conducting the empirical study within a primary health care setting, within a developing country context, using a periodic and/or serial ethnographic method.

In providing a 'thick description' of the particular setting of HIV/AIDS care and treatment in a developing country setting, the aim is also to suggest a set of principles for designing hybrid health information systems, reflecting the actual situation in the field, and with implications for future planning. I will also briefly discuss more policy-related issues, such as costs/benefits and risk analysis when introducing ICT in sec 2.5.4.

2.4.1 CSCW – core concepts

Central concepts in the CSCW discourse, are 'coordination', 'awareness', artefacts, 'standardization', and 'ethnography' (Heath and Luff, 1992; Hughes et al, 1994; Schmidt, 2002; Blomberg and Karasti, 2013). 'Awareness' is related to ethnography and the ethnographic method of investigation, and is briefly defined as *"(...) an understanding of the activities of others, which provides a context for your own activity"* (Dourish and Bellotti, 1992). Although important in fieldwork, I will not include this concept in my theoretical framework, but I have discussed the ethnographic method of investigation and my choice in the methodology chapter.

Key concepts from the CSCW field, that I have found useful for analysis and ordering of the findings during the data collection process are: 'collection of artefacts' and 'coordinative artefacts (Star and Griesemer, 1989; Schmidt and Simone, 1996; Schmidt and Wagner, 2003).

Further, from this discourse, I also found the term 'affordances' important for analysis of the technological components in the system, in terms of both how and what they may provide of relevant information in the different settings (levels), and thus offer 'possibilities for action' as information carriers, as well as what are their limitations in providing this information. Thus, 'affordances' will also be an important element when designing the information system, and I will discuss this issue in more detail in section 2.4.2.

Coordination

Coordination, I see as an overarching theme in the CSCW literature. Many theoretical concepts are introduced in the literature to describe cooperative activities, such as:

- 'coordination mechanisms': denoting *"a generalization of phenomena described in other projects, such as classification schemes, standard operating procedures, time tables etc"* (Schmidt and Simone, 1996);
- 'coordinative practices'/ordering principles (Schmidt, 2011);
- 'ordering systems' *(sets of coordinative practices)* (Schmidt and Wagner, 2003);
- 'articulation work' (Strauss, 1988; Thoresen 1998), a concept introduced by Strauss to denote work to be done in 'real world' work flow, that is invisible within rational models of work, but central when describing how work is coordinated.

Important elements in studying coordination in work practices are *artefacts*, the coordination performed by artefacts, and the required standards to enable cooperation between the artefacts. In combination with artefacts, the concepts *'collection of artefacts'* and more specific *'coordinative artefacts'*, have been applied when work practice perspective has been key.

Collection of artefacts

An artefact is defined by Norman (1993, p.5) to be

> "*[…] anything invented by humans for the purpose of improving thought or actions (…), whether it has a physical presence and is constructed or manufactured, or whether it is mental and is taught".*

Norman mentions paper, calculators and computers as examples of physical artefacts; while reading, logic and language are mental artefacts, whose *"power lies in the rules and structures that they propose".* A collection of artefacts may thus be comprised of both physical and mental artefacts. Collections of artefacts are important in work practices. In CSCW studies it is important to identify the collection of artefacts, their role in ordering systems, and the relationships between them. The collection may comprise digital artefacts as well as paper and other tangible artefacts.

Bardram and Bossen (2005), studied a hospital ward, and how people coordinated work, using a wide range of non-digital artefacts, like whiteboards, plans, care records and post-it notes etc., visualized as a 'network of artefacts' (ibid, p. 170), to provide order and to coordinate work processes. The aim with the study was to better understand the coordination and collaborative work, to design computer support for such work. They show how these artefacts play multiple roles; how users had different views upon the same information, tailored to their needs, tasks and working context.

Hanseth and Lundberg (2001), look at 'collections of artefacts' as information infrastructures, and how these artefacts are linked together. They use the request form in a hospital as an example of a coordinative artefact. What they call 'a shared infrastructure' is also described as artefacts used to coordinating different activities, and the request form *"helps coordinating and keeping track of all main activities"* (ibid p. 357).

It is also important to identify the structures behind; what actually gets used and how. In one of the well-known projects in CSCW, the study of the UK air traffic control centre, the researchers observed how a paper strip, the flight progress strip, turned out to be of utmost importance for the control centre and work processes (Bentley et al, 1992; Hughes et al, 1994). Ethnographers, in cooperation with software engineers, worked on finding digital alternatives, but realized that they did not quite succeed in meeting the needs for immediate knowledge sharing in the work situation, where security and control in decision-making were imperative.

Though the interest of the CSCW field is on identifying functions and processes in the work practices that might be supported or replaced by computer systems, most of the work practices, and the supporting information systems described in the CSCW discourse are comprised of collections of artefacts, involving a number of different technologies. Thus, collections of artefacts in this thesis have been denoted 'hybrid information systems', and in this particular case, 'hybrid health information systems' (HHIS).

One aim in my fieldwork has been to identify this collection within my selected unit of analysis, to understand the structures behind, how the components were related, and how information was communicated between them. In studying the work practices, I aimed at understanding the logics in the existing information system (s), and to what extent they met the information needs, which they are meant to support.

Coordinative artefacts

'Coordinative artefacts' denotes a sub-set of collections of artefacts in use. The concept is relevant for designing systems in medical work. It may apply to a number of different artefacts, serving different functions and needs in coordinating information in medical work practices, coordinating information between artefacts in a system or between sub-systems. In health care, a coordinative artefact could be the patient folder, but also the patient held card, or the barcode sticker on these paper-based artefacts, providing access to an electronic database, and to link a patient held card and a patient folder.

A barcode label pasted on a blood or urine sample will work as a coordinative artefact, i.e. as a link between the clinic or hospital taking the sample, and the lab analysing it, and for return of the result. The barcode label may carry different types of information, depending on the level of the electronic database it is linked to: demographic information about the person who gave the blood, the referring clinic, the date the sample was taken, and more. A similar label will then be on the request form, which is also used by the lab to register the results and return to the ordering clinic. In my case, I will relate the 'coordinative artefact' concept to the coordination of information in terms of being an interface between the components in the health information system as a whole, conveying information between components being either electronic-electronic or electronic-paper based.

Standards in CSCW

To be able to communicate between and within systems you need agreed upon and shared protocols and standards. In the CSCW literature, the focus has been very much on politics involved in the standardization process, and the element of power inscribed in standards is central in the discourse (Bowker and Star, 1999; Bjørn and Balka, 2007). From this perspective, standards represent discipline and control over members' action. To understand the agenda embedded in the design can for example help explaining failure. In an early discussion in CSCW, Suchman (1993), argued that an application should not only be evaluated on its efficiency and productivity, but also in terms of how the application embodied specific forms of power and authority. Although I subscribe to the view of the power aspect as an important element in the standardization process, this will not be emphasized in my discussion. Standards and standardization are also key in the IS domain, and I will return to the issue of standards in relation to the information systems design framework in sec 2.5.2.

2.4.2 Affordances

The concept 'affordances' was first introduced by the ecological psychologist John J. Gibson (1979). Gibson viewed affordances as relational properties between an organism and its environment. Objects in the world offer different possibilities for action, and for different species, different affordances.

> *"An important fact about the affordances of the environment is that they are in a sense objective, real and physical, unlike values and meanings, which are often supposed to be subjective, phenomenal, and mental. But, actually, an affordance is neither an objective property nor a subjective property; or it is both if you like. […….] An affordance points both ways, to the environment and to the observer"* (Gibson, 1979, p. 129).

The concept is discussed across different disciplines, with questions such as: *"Does objects have objective affordances or are they only relational?"* or *"Must the affordances be 'recognized' by the observer?"* In the Human Computer Interaction (HCI) and Activity theory (AT) domains, the concept has been discussed with various added 'attributes' to the concept, such as: 'available information'; 'intuitive interface'; 'perceived affordances; 'real affordance'; 'objective affordances' (Gaver 1991; Albrechtsen et al, 2001; Kaptelinin,1996). These concepts are often discussed related to being properties or benefits available to the 'user', while some also emphasize the relational aspect and the importance of context.

Bloomfield et al (2010), give an account of the debate whether the concept 'affordance' refers to material properties of an artefact or if it is a relational concept where both the socio-(environment) and material (technological artefact) are involved. They claim that,

> *"Affordances cannot be separated from the arrangements through which they are realized in practice",* and*: "Accounts of 'affordances' often strip them of their relational character by identifying them as properties of the object and matching them to the 'effectivities' of the subject*" (ibid, p.417).

As one way of approaching the analysis of affordances, they suggest to ask*:*

> *"How, and under what circumstances are particular 'affordances' made present? How and when are different action possibilities made available – or unavailable – to specific actors in particular settings?"* (ibid p. 420).

Norman introduced the concept into design with his book "The psychology of everyday things" (POET, 2002) where he uses this definition: "*an affordance is the design aspect of an object which suggests how the object should be used"* (ibid). In 'POET', he claims to deviating from Gibson in that, *"affordances result from the mental interpretation of things, based on our past knowledge and experience applied to our perception of the things about us"* (ibid). Later, he emphasizes that the term is referring to *'perceived affordances'* and the *"actual properties of the thing, primarily those fundamental properties that determine just how the thing could possibly be used"* (ibid, p.9).

Gaver (1991), focuses on human-computer interaction, and the design of interface. He states that:

> *"Affordances per se are independent of perception. They exist whether the perceiver cares about them or not, whether they are perceived or not, (….)",* and: *"(...) affordances are properties of the world that make possible some action to an organism equipped to act in certain ways".*

He uses the concept: *"as a way of focussing on the strength and weaknesses of the technologies with respect to the possibilities they offer the people that might use them".* His conclusion concerns design and interface issues, and through examples, he describes a frame for the use of the concept in analysis of interface and artefacts.

Table 2, gives a comparison of how Gibson and Norman differ in their definition of the concept, with the main distinction being the observing object's potentials towards what the environment offers or affords:

Gibson's affordances	Norman's affordances
Offerings or action possibilities in the environment in relation to the action capabilities of an actor.	Perceived properties that may or may not actually exist. Suggestions or clues as to how to use the properties.
Independent of the actor's experience, knowledge, culture, or ability to perceive	Can be dependent on the experience, knowledge, or culture of the actor
Existence is binary – an affordance exists or it does not exist.	Can make an action difficult or easy
Perception – not manipulation	Design – manipulation so that properties (utility) can be perceived easily

Table 2: Comparison of affordances as defined by Gibson and Norman (categorized by McGrenere and Ho, 2000).

Kaptelinin and Nardi (2012), introduce the "mediated action perspective", and argue that HCI needs a *re-grounding* of the notion affordances. Their main claim is that, Gibson's affordances relate to interaction between animals and their environments, and that this is of limited relevance to HCI research. They propose understanding technology affordances as possibilities for *mediated human action*. Kaptelinin (2012), does however not question the general value of Gibson's fundamental insights, but claims that, the concept should be constructed on a theoretical foundation more suitable for analysis and support of *human* uses of technology. He points to the fact that *"Gibson's theory does not deal with the social and cultural aspects of the use and production of tools"* (Kaptelinin in lecture, Nov 2012).

Norman (1999) and Kaptelinin (2012) both, define the affordances of an artefact as action possibilities. They point to the human capabilities of learning and manipulation (design) in a certain context, and how to take advantage of this, when introducing new technologies, while Gaver (1991) and Bloomfield et al (2010) focus on the technologies in context, and ask when and how different action possibilities are available – or unavailable - to specific actors in particular settings, assuming that 'affordances' in a sense are objective, i.e. having properties that *"[…] exist whether the perceiver cares about them or not, whether they are perceived or not, […],* but only available to the user *'in particular settings'*.

	GIBSON'S THEORY vs. MEDIATED ACTION PERSPECTIVE		
	Similarities	**Differences**	
		Gibson's theory	**Mediated action perspective**
General notion *Affordances are understood as…*	action possibilities offered to the actor by objects in the environment	possibilities for animal actions in natural environment	possibilities for human actions in cultural environments
Relational property *Affordances emerge in interaction between …*	the actor and the world	the animal and natural environment	the person, tool(s), and cultural environment
Dynamics Action capabilities of the *actor are…*	a result of the development of a coupling between actor and the environment	relatively stable, formed by biological evolution, maturation, and long-term learning	dynamic, can quickly change as a result of tool switching
Role of perception *Quick extraction of information about affordances…*	is critically important for successful acting in the world	occurs as an immediate outcome of placing a certain animal in a certain environment	can be an outcome of learning
Needs *Affordances and actor's situational needs are…*		independent of one another	interrelated: tool affordances can be adjusted to situational needs

Table 3: Perspectives on affordances (Kaptelinin and Nardi 2012, p.973)

As I am not primarily looking at the discussion (pros and cons) of paper and manual systems versus computer systems in my analysis, but how to take into account both the benefits and limitations from both technologies, I find the relational perspective important, and the questions posed by Bloomfield et al (2010) useful, i.e.:

> "*How, and under what circumstances are the affordances made present? "How, and when are they made available or unavailable to specific actors in particular settings?*

– to be followed by the perspective of Kaptelinin:

> *"Affordances and actor's situational needs are interrelated, and the tool affordances can be adjusted to situational needs" (table 3).*

The context of HIS and HIV/AIDS in DC's is special, not only because of lack of resources, but also the need for flexibility and efficiency in using the HIS; factors that may also apply in other settings. In the next sub-sections I will give a more detailed description of the assumed affordances of the paper and electronic technologies, as described in the literature.

Affordances of electronic tools/technologies

The affordances of electronic systems are often presented as potential benefits, describing what the systems technically are capable of and how they may help medical practitioners in coordinating work related to one patient, enabling immediate access to patient information across time and space (Grimson et al 2000; Leiner et al, 2002; Fraser et al 2005; Bloomfield et al, 2010). Important is also the possibility of multiple uses of data, recorded once, to be used for different objectives and tasks, which will improve health, and reduce cost:

> *"Unlike paper records, computer systems offer the ability to decouple information from its representations to help smooth coordination. This decoupling opens up a rich design space for systems that allow people with different interests, concerns and work practices to work together effectively"* (Reddy et al, 2001).

Limitations are however also mentioned in literature when for example describing complex projects with limited success, and/or in day-to-day cooperative work in a hospital (Heath and Luff, 1996; Ellingsen and Monteiro, 2003; Hartswood et al, 2003), although these results are not so much taken into account when it comes to developing visions and plans.

On a more general level, Leiner et al (2002) mention:

> *"The use of computers* ***can have great advantages*** *over conventional documentation (e.g. the simultaneous availability of data at different places, fast and secure data processing, a decrease in work load) but* ***can have disadvantages*** *as well (e.g. more awkward use or higher expenses). Through the use of a computer, documentation often gets more abstracted and quite often inscrutable, so that incorrect data or mistakes in operating the program go unnoticed in many cases (black-box effect)* (ibid, p. 8, bold added).

Hutchby (2001), also suggests to include both benefits and constraints in HIS analysis. In a comment to the discussion about social shaping of technology versus technological shaping of society, he proposes a way of analysing the latter drawing on the concept of affordances, arguing for "*a recognition of the constraining, as well as enabling, materially artefacts"*.

As described in sec 2.1.2, the benefits related to costs, and to achieving the goals of improved quality of care and health for the population, are however difficult to quantify and measure (Menachemi and Brooks 2006; Shekelle et al 2006; Blaya et al 2010).

Affordances of paper tools/ technologies

HIS and ISD literature often focus on the limitations of paper-based information systems, such as: patient records are local accessible only; there is lack of information integration; multiple recording in paper tools leading to redundancy, and more, as elaborated in sec 2.2. The importance and particular value of paper records in health care are however also described when referring to case studies, often in combination with the need for 'articulation work' – i.e. professional 'reading' of patient information (Berg 1997b; Berg and Goorman, 1999; Berg and Toussaint, 2003; Hartswood et al 2003).

The concept of affordances, seen as pros and cons of the technologies, is applied in a number of projects within CSCW an HCI. Heath and Luff (1992), and Nygren and Henriksson (1992*),* document the importance of flexibility that paper documents offer in the work practices of medical personnel. Paper documents can, for instance, be moved around and showed to patients whatever positions they are in, physicians can browse through the paper based medical record extremely fast in the search for relevant information; important information can be derived from the thickness of the record and what kind of forms it contains, etc. Further, paper documents are flexible in the sense that whenever needed, physicians can, when it is relevant, put text into the document beyond what the document template specifies. This is important in complex cases. But it is also important because it enables the users to improvise and improve the technology when new needs appear or opportunities are discovered.

Braa and Sandahl (2000), describe the properties of paper artefacts and how they are organized in the physical environment: **'visibility'** and **'at a glance'** is important in cooperative work: *"the unnoticed resources of the documents that are shared by a community of practice"*. By taking into account the coordinating role of a form, a prototype was designed that partly extended the affordances of the new electronic system, but the existing system could not completely be replaced by electronic system. The project and study of the paper flight strip in the UK Air Traffic Control **(**Hughes et al, 1992), mentioned in section 2.4.1., is another example. Because of certain properties, such as flexibility, information at a glance, ease of manipulation, and cooperation at site, the strip was not easily replaced by an electronic system.

Affordances of a hybrid health information system

In studying the effect of introducing electronic systems in office work, Sellen and Harper (2002), seek to understand why there often seems to be an increase in paper use, despite the vision and plans for 'the paperless office'. The authors emphasize the importance of understanding the affordances of the different technologies, paper ***and*** electronic (ibid p.17), and ask: *"Are there any lessons to be learned about choosing or designing new technologies from looking at paper use?"*. They claim that, looking closely at paper use can be a resource for change rather than an obstacle to it. Building on Gibson´s theory, they relate the concept to peoples' perception (instead of animals) of the environment, and refer to affordance as, *"the fact that the physical properties of an object make possible different functions for the person perceiving or using that object"*. They emphasize the importance of studying the affordances of both types of components in its context, and argue that *"there is a lot to be gained if one no longer looks at paper as a problem in organizational life"*. Although acknowledging the usefulness of paper tools in the work processes in the office, the aim and purpose of this study was, being able to design appropriate electronic systems to be less dependent of paper tools.

Summing up Affordances:

There are mainly two reasons why I find the concept useful in the discussion about designing hybrid information systems:

1) Through the discourses, electronic and paper technologies are **both** described as possessing particular properties that cannot easily be replaced by the other. Electronic health records afford, i.e. enable, sharing of information across multiple users, while a paper system is only locally available. The electronic record also affords storing and accessing of large amounts of information useful for different objectives (Sellen and Harper 2002). Paper records will, on the other hand, provide a more complete patient record, and affords "visibility at a glance", and flexibility on site.

2) These qualities may only be perceived and utilized in a certain, relevant context (Gaver 1991; Sellen and Harper 2002; Bloomfield 2010).

Translated into a health information system's setting, the affordances of an artefact are objective properties in the sense of having potential benefits, but also having constraints. As affordances cannot be seen as having objective properties in situ, but only be assessed in relation to the current environment, the *"strengths and weaknesses of the technologies"* involved must be evaluated *"with respect to the possibilities they offer the people that might*

use them" (Gaver 1991). In other words, the 'action possibilities' of an artefact must be evaluated in relation to other entities in the *collection of artefacts*, and in relation to the *context*. The assumption in this thesis is that, the 'total' benefits of a *hybrid* health information system will exceed the benefits of a 'pure' electronic system, as well as a 'pure' paper system. Thus, a hybrid solution meets the functional requirement of "creating new potentials" as claimed by Clarke (2005). This will be elaborated in Sec 2.6 (table 7, p.53).

The findings from the initial phases in the case study and data collection, led to an interest in the health information system(s) as a whole; the design and different configurations, and the combination of technologies, ***the hybrid system***; at different health facilities, and at the different levels in the health management hierarchy.

In section 2.5, I will reflect on information system design, and important concepts in the field, such as, 'architecture', 'modularity', 'interface' and 'standards'. Important issues when discussing implementation of ICT are also how to reduce redundancy, and the question of security and risk involved. In sec 2.6, I discuss the term 'hybrid information systems'; how it has been applied in the discourses, and how I understand and use it in this thesis.

2.5 Information systems design

Definitions of systems, architecture and design vary in the literature. Although these definitions mostly are intended for IT artefacts and software engineering, I have selected some, that I find useful for the purpose of discussing hybrid systems. A hybrid system will, like electronic systems, be comprised of modules and collections of components, and the relationships between them, which implies that, modularity, interface, and standards between modules of different technologies, need to be taken into account.

A general definition of design is: *"The process of defining the architecture, components, interfaces, and other characteristics of a system or component"* (IEEE Stud 610.12-1990 (R2002)), with the aim to solving certain problems. In this case, quality health care and health information need to be met, and the result of the product is "*evaluated with respect to utility"* (Hevner et al, 2004, p.78).

The information system (IS) is designed according to a structure, or ***architecture***, i.e. *"a set of principles, guidelines and rules (....)"* (Boar 1994 in Bredemeyer and Malan 2001, p.8). The term 'architecture' is discussed and elaborated from different perspectives/views. Sowa and Zachmann (1992), introduce a comprehensive framework where different stakeholders (planner, owner, designer, builder, integrator, user) have different perspectives and interests related to the goals, function and design process.

'Enterprise architecture' (EA) is another conceptual framework introduced by Janssen and Hjort-Madsen (2007), aiming at filling the gap between policy and implementation.

> *"An EA identifies the main components of the enterprise, its information systems, the ways in which these components work together in order to achieve defined objectives and the way in which the systems support business processes"* (ibid).

Several dimensions and aspects are introduced for analysis on a meta-level, such as: policies, actors, and structures, governance and architecture principles, and standards. Among the

architecture principles (in total more than 160) are: *inter-operability, security, openness, flexibility, and scalability.*

I will however not embark upon an analysis using these comprehensive frameworks. For my purpose I will use the overall definition from IEEE[18], where software architecture is defined as *"the structure of the components of a program/system, their relationships, and principles and guidelines governing their design and evolution over time".*

A (general) ***system*** is defined to be: *"(...) a collection of components organized to accomplish a specific function or set of functions" (IEEE Std. 610.12-1990).*

An ***information system*** is then defined as:

> *"A system which assembles, stores, processes and delivers* ***information relevant to an organization*** *(or to society) in such a way that the information is accessible and useful to those who wish to use it, including managers, staff, clients and citizens. An information system is a human activity (social) system which* ***may or may not involve computer systems****" (Avison and Myers, 1995, bold added).*

What in a particular situation will be defined as 'relevant information', and how this information becomes useful for the users is not given, and there is no "one size fits all" but would need to be discussed in relation to context and resources, as discussed in sec 2.4.2 (Gaver 1991; Sellen and Harper, 2002; Bloomfield 2010).

2.5.1 Modularity

Modularity is a very general set of principles for managing complexity. A modular system is composed of units (or modules) that are designed independently, but still function as an integrated whole (Baldwin and Clark, 1997).

> *"By breaking up a complex system into discrete pieces, which can then communicate with one another only through standardized interfaces within a standardized architecture, one can eliminate what would otherwise be an unmanageable spaghetti tangle of systemic interconnections"* (Langlois 2002).

Compatibility among modules is ensured by 'design rules' that govern the architecture, the interfaces, and the standardized tests of the system (Baldwin and Clark, 2006, p. 180). The visible design rules, also called visible information, are decisions that determine how the modules will work together, and they fall into three categories:

- An architecture, which specifies what modules will be part of the system, and what their functions will be.
- Interfaces that describe in detail how the modules will interact, including how they will fit together, connect, and communicate.
- Standards for testing a module's conformity to the design rules (can module X function in the system?) and for measuring one module's performance relative to another (how good is module X versus module Y?).

Baldwin and Clark (1997, 1998), operates with three types of modularity: modularity-in-production (rationalizes a product into components), modularity-in-design (the product is decomposed into a set of independent subunits), and modularity-in-use (consumers can mix and match components). These theoretical framework and terminology are used in relation

[18] IEEE Std 610.12-1990 (R2002)

to building large complex digital systems, but seems to also be applicable in describing the configuration of a hybrid information system.

Ulrich (1995), introduce a conceptual model related to product architecture in a manufacturing firm. His aim is to create a vocabulary for discussing and addressing the decisions and issues linked to product architecture, where he is:

> "[…] *using and synthesizing fragments from several different disciplines, including software engineering, design theory, operations management and product development management" (ibid).*

Ulrich applies the common concepts in IS design, such as 'modularity', 'interface' and standards, applied in the production of physical products. He defines 'product architecture' to be *'the scheme by which the function of the product is allocated to physical components' (ibid p.419)*.

More precisely he defines product architecture as:

1) the arrangement of *functional elements;*
2) the mapping from *functional elements* to *physical components;*
3) the specification of the *interfaces* among interacting physical components".

He also states that, "***the function of a product is what it does*** *as opposed to what the physical characteristics of the product are"* (ibid p.420, bold added). Although this model of mapping is about product architecture and design, I find the idea of mapping from function to physical component interesting. [ref table 22, p 151, as an example for analysis]

Parnas et al (1985), discuss complexity in software design, and the importance of having a structural description of the system, that shows the program's decomposition into parts and the relations between those parts (ibid, p.259). The principle of information hiding, is presented as the most basic idea in their approach to a modular structure of complex They introduce 3 structures: a) the module structure; b) the uses structure; and c) the process structure, where

a) is the decomposition of the program into modules;
b) in the 'uses structure' the **components** are parts of the modules. The uses structure determines the executable subsets (of the software);
c) is a decomposition of the runtime activities, i.e. processes and not programs.

In this article, Parnas et al, discuss mainly point a), the module structure. I will include their a) and b), and 'borrow' this terminology for the hybrid solution. While they are looking at principles for modularisation, I want to focus on principles for *coordination* of the components *and* the modules.

Aanestad and Jensen (2011), build on Parnas (1972), when analysing a nation-wide information infrastructure in healthcare in Denmark. They propose to start with lower ambitions and more realistic visions for the project, and recommend the modular strategy for development of complex systems.

Ulrich (1995), claims to use fragments from a number of disciplines to arriving at his model for mapping functional elements to physical components. Combining Parnas et al's modular 'uses structure' concept, with Ulrich's model of mapping functional elements to physical components, I have suggested a simple table as an example for analysis of the case findings,

where the modules and components are roughly represented as paper and electronic technologies respectively.

Modules *Functional element (Ulrich)*	**Components (parts of modules)** *Uses structure (Parnas et al)*		
Module *Patient record in clinic*	*Paper* *Forms, folders, cards*	*Interface* *barcode label*	*Electronic* *EPR*
Interface *(standards/ gateways)*			
Module *lab system*	*Paper* *Referral form*	*Interface* *barcode label*	*Electronic* *NHLS*

Table 4: Hybrid HIS modular structure - Mapping from functions to hybrid components

2.5.2 Integration, standards and interface (gateways)

Information systems within healthcare are usually comprised of many parallel and/or sub-systems that need to communicate. The development of standards is thus crucial to enabling the transmission of data from one component to the other, to coordinating health information about one person, i.e. to create the patient record. Standards are important also in vertical systems, such as a country's health management hierarchy, and within large health institutions, e.g. a hospital, with a large number of sections or departments with separate information systems.

Standards have often been discussed related to integration of electronic systems, and/or information infrastructures, with different foci, such as complexity, global standards versus local practices, or the emphasis has been on rigid standards versus flexibility (Hanseth et al, 1996, 2006; Jacucci et al, 2006; Braa et al 2007; Mavimbe et al, 2007).

Hanseth et al (1996), discuss the increasing complexity in health information infrastructures, and the need for flexibility and standardization. Berg (2004), also claims that the notion 'Flexible standardization' is not a contradictory term, but 'flexibility' is an important characteristic of standards. Braa et al (2007), also relates this to information systems in DC's. The authors mention two forms of flexibility needed, i.e. in *use* and *change*. 'Use flexibility' refers to the ability to use a standard in a number of different environments, or for a number of different purposes. While 'change flexibility' is achieved through the classical principle of modularization.

Standards are also important in the design and development of paper-based tools, and will play an equally important role in the interface between paper and electronic systems. In most health care settings, the overall systems consist of both paper forms and electronic tools, in different configurations. This has also been emphasized by the WHO in their work on EMR. A number of paper forms are standardized both within national and international settings. In large health programs, such as TB and HIV/AIDS, forms for data collection and reporting are developed, defining the layout, the kind of information that should be included, and the format for representation (Hanseth and Lundberg 2001; WHO 2004; Mavimbe et al, 2007).

One of the conclusions in the Report from the WHO Electronic Medical Record Meeting (2004, p.13) states that:

> *"Participants thought it to be important and appropriate for the WHO to take*

the lead in organizing data standards. The information system environment will always be pluralistic with a plethora of paper and electronic systems. Information will be required for patient management, program management, planning, policy, and international reporting. This requires standard definitions of data elements and data sets."

In 2012, the Executive Summary of a Report on eHealth, WHO states:

> *"Electronic health systems must be built in a way to facilitate the exchange of data; disparate systems using separate disease definitions, for example, are of little value. Standards must be applied to the data and the systems themselves to allow for and facilitate the exchange of data between various sources. The adoption of standards is progressing well across most Member States including standards for eHealth architecture, data, interoperability, vocabulary, and messaging. These are important foundation blocks for the implementation of patient information systems because they facilitate clear communication."* (WHO 2012, p. 7).

The concept **'interface'** may have slightly different definition in different disciplines. In computer science the term usually means *"the point of interaction or communication between a computer and any other entity, such as a printer or a human operator*"[19], and is often thought of in terms of menu navigation, icon design etc. on a computer screen (Grudin, 1990). More generally, it is defined to be *"a point where two systems, subjects, organizations, etc. meet and interact"*[20].

In discussing modularity, Baldwin and Clark (2007) define 'interfaces' to be what: *"[...] describe in detail how the modules will interact, including how they will fit together, connect, and communicate"*. Braa et al (2007), use the concept **'gateway'** to describe an interface between standards, seen as *"a piece of software that links together different sub-infrastructures into an integrated one, by translating between data representations, formats, and protocols"*.

Gateways, they claim, may be of three general types: paper-to-paper, paper-to-computer, and computer-to-computer (ibid, p. 9). A typical gateway in the cases they present is between paper and computers, for example paper registers kept manually used to capture the numbers in computer programs.

> *"This gateway consists of a number of procedures for collating the paper forms received from the paper-based infrastructure and translating them to the required electronic format, so that it can be transmitted in the electronic infrastructure."* (ibid p. 17).

Investigating a PACS/RIS infrastructure in a hospital, Hanseth and Lundberg (2001), show how health practices in hospitals are heavily depending on paper, and:

> *"Accordingly, understanding all roles played by paper documents as well as designing computer systems that fits together with paper-based practices are important success criteria"* (ibid p. 369),

They define the interface to surrounding networks to be based on paper orders (ibid p.363), and the interface between two networks *"to be taken care of in terms of 'gateways'*

[19] thefreedictionary.com
[20] Oxford dictionary online

translating between them (italics added)". One such interface or gateway in their case, is a barcode reader to read a barcode generated by the Radiological Information System (RIS).

In Malawi, the Baobab EMR system has introduced a touch-screen as user interface to enable a 'Point of Care' information entering during clinical encounters (Chawani et al, 2014). They do however recognize that a paperless system is not possible, and the system is developed *"[…] such that patient visit summaries can be printed onto inexpensive adhesive labels and affixed to existing paper artefacts, such as the health passports"* (ibid).
I have applied the concept 'coordinative artefact' from the CSCW domain in my case study, when ordering the findings in the coordination of health data; artefacts functioning as interface between the components in the health information system as a whole, conveying information between components, being either electronic-electronic or electronic-paper based.

2.5.3 Redundancy and robustness

One of the main problems with paper-based systems, which ICT is claimed to solve, is duplication of data. Redundancy is generally defined as *"The state of being no longer needed or useful"*[21], and, *"Redundancy is said to exist whenever there is an excess or superfluity of anything"* (Landau 1969). 'Excess', then defined as *"more than the normal the required, the usual, the specified"* (ibid), and thus an unnecessary duplication, which is seen as a waste. In engineering the concept is more specifically defined to be;

> *"The inclusion of extra components, which are not strictly necessary to functioning, in case of failure in other components"* and, *"[…] a part in a machine, system, etc., that has the same function as another part and that exists so that the entire machine, system, etc., will not fail if the main part fails"*[22].

Landau (1969) elaborates on the meaning of the word 'redundancy'. He describes early visions (if not fully realizable) in information theory of '*zero redundancy',* but claims that "*Today, this goal is no longer entertained*" (ibid, p. 347). He then argues against the negative view of redundancy, and gives examples of redundancy, as repetition of a message in a text, and the use of more words than *"the absolute minimum"*, to illustrate intentional use of redundancy as a powerful source for suppressing error and lessen risk of misunderstanding.

The paper from Landau was written in 1969, but in the Health Information Systems, and Health Informatics literature, redundancy is still mostly considered inefficient and something to reduce (Grimson et al, 2000, Cabitza et al, 2005). In these discourses, redundancy in terms of duplication and overlapping data or functions, is defined a problem that needs to be solved. Redundancy occurs within paper systems, as well as across electronic systems when not integrated, and introducing integrated electronic systems is seen as a means to solve these problems. (Grimson et al, 2000).

There are however a number of authors, both in developing countries and high-income countries, discussing whether information redundancy plays a positive or negative role in health information systems. Strong arguments for certain types of redundancy playing a positive role, and even being a 'must' in some instances, are put forward (Ellingsen and

[21] Oxford dictionaries, online

[22] Merriam-Webster's Learner's Dictionary

Monteiro, 2003; Cabitza et al, 2005; de Vries and Nyemera, 2010). In a more recent study on spatial data in the public sector, de Vries and Nyemera (2010), more in line with Landau (1969), argue against the belief that *"data collection in the public sector should be collected once, and used multiple times".* They looked at perceived causes of redundancy: **technical**, i.e. inaccurate data, incomplete data, lack of uniform standards, or **institutional**, i.e. difficulties in access, lack of collaboration, lack of national sharing policy. Technical and institutional constraint in combination, led to duplication of data. They found that, redundancy at the same time was perceived as negative and positive. However, in the current situation in their study (i.e. public sector in Uganda), redundancy was perceived a necessary condition, and they stated that redundancy provided a reserve, which was crucial to maintain organizational knowledge in the system, and enhancement of system quality, which is also more in line with the engineering definition. They found that:

> *"[…] the dominant perceived reasons for redundancy are the possibility to increase data quality and access, the potential for back-up and ability to compare and check data",* and that "*The presence of duplicate data is especially relevant in a context where resources are scarce and dispersed"* (ibid*).*

The authors conclude that redundancy is vital for the development of public management; that redundancy should not be addressed from a purely information technological perspective, and that

> *[…] as long as the technological resources and the human capacity (in Uganda) are still limited, the presence of redundancy of spatial data in the public sector is vital for the public management for Uganda as a whole"*, The implication of their findings is that *"a shift in the thinking on data infrastructure policies in developing countries is necessary"* (ibid p. 12).

Redundancy is also discussed in health work practices, often related to hospitals (Ellingsen and Monteiro, 2003; Cabitza et al, 2005; Skorve, 2010). In a study of integration and cooperation in large-scale electronic patient record systems in 5 large hospitals in Norway, Ellingson and Monteiro (2003), discuss 'seamless integration' of a collection of information systems, and the role of redundant, fragmented and ambiguous information. The authors ask: "*Under what conditions is redundancy of information productive?"* They analyse integration of information in relation to contents and source (table 5). When information is identical in content but located in different sources, for example the same data reported in two different artefacts, it is denoted *duplicated* information, different from *replicated* data (reported at several points in the same artefact). If the sources of information contain non-integrated information and the information is identical, it is *redundant,* otherwise if related, but different, it is *supplementary*. The first category is the motivation for integrating systems.

		Source	
		Integrated information	*Non-integrated information in sources*
Contents	*Identical information*	**Compatibility**	**Redundancy**
	Related, but different	**Ambiguity**	**Supplementary**

Table 5: Redundancy in types of situations (Ellingsen and Monteiro, 2003)

The authors conclude that,

> *"[…] related but not identical information (dubbed supplementary and ambiguity) are the essential ones",* and they argue that this type of redundancy *"[…] facilitate robust, collaborative work configurations (establishing shared understanding, allowing local flexibility and performing consistence checks)"* (ibid).

Considering the volume of information accumulating for a chronic patient, they mention one important supplementary information source in particular, the record summaries; 'the abstract sheet'. In sum, they argue that, the benefits of supplementary information *"tend to override the costs associated with maintaining this supplementary information, […]"* (ibid, p. 88). Another example from the case led however to the conclusion that, *"the benefits (robustness) did not compensate for the amount of work involved in maintaining the redundancy […]"* (ibid*).*

They did also study how practitioners coped with the redundancy, and found that there was relatively modest level of problems actually caused by redundancy. Looking at the instance of redundancy between paper and electronic form, they found that

> "*[…] redundancy is not necessarily and automatically the kind of problem portrayed in traditional management of information systems. It is merely the argument that the pros (largely bypassed) and cons need to be assessed before judgement is passed"* (ibid, p. 86).

Similar to Ellingsen and Monteiro (2003), Cabitza et al (2005), also distinguish between different kinds of redundancy, using a different categorization. They describe health work practices in a hospital ward setting, where work is spatially and temporally distributed, focusing on how nurses operated in the ward to coordinate their activities among themselves. In focusing on the paper artefacts supporting health care, they discuss the role of redundancy, and identify three kinds of redundancy, i.e. redundancy of effort, functions and data. Redundancy of **effort** occurs when some task is accomplished either again, after the corresponding goal has been reached at least once, or by using more resources than necessary. Redundancy of **functions** describes when the capacity of different people creates an overlap of functions or skills, so that they could step in for one another. This type of redundancy may have a positive effect creating robustness and flexibility in the organization.

Redundancy of **data "***concerns the resources used to accomplish a task"*, and is described to happen:

> " *[…]* when *in an organization either the same or similar (i.e. pertaining to the same information) data are repeated in different places (artefacts, information systems, etc)* (ibid, p. 160).

Based on Ellingsen and Monteiro (2003), and their framework for differentiation of redundancy of data, Cabitza et al, develop their own version, and use the categories of data, as shown in the table 6:

	Same data	Correlated data
Same artefact	Redundancy by *replicated* data	Redundancy by *derived* data
Different artefacts	Redundancy by *duplicated* data	Redundancy by *supplementary* data

Table 6: Kinds of redundancy of data (Cabitza et al, 2005)

In studying these types of redundancy in the ward, they analysed how the different kinds of redundancy affected one another in the work "around the patients" in the hospital. Using examples from cooperation and coordination in health work practices in a hospital ward, they recognize the value of redundancy as 'supplementary' information recorded in different artefacts. Information identical in content but located in different sources is labelled 'duplicated data'. 'Duplication' they claim, may lead to different representations of the same information if this is represented in different mediums (paper and electronic), thus seen to be controversial. and also emphasize the importance of the design of technology:

> *"An insightful design of supportive technology must then be well aware of the ways coordination is made possible (and reified) by the whole net of artifacts as well as of the often-neglected function of data redundancy entangled within this net, so as not to end up by eliminating its beneficial effects in indiscriminately getting rid of effort redundancy from ward work" (ibid p. 162).*

The authors did however also point to risks with redundant information, *"as the information might become unsynchronized or inconsistent and lead to misconceptions or other human errors"* (ibid p.160). They conclude that: *"Redundancy plays a positive or negative role depending on various circumstances"* (ibid p. 158).

Despite the slightly different focus and conceptualization, Ellingsen and Monteiro, and Cabitza et al, seem to agree on the value of redundancy when data is supplementary and located in different artefacts, otherwise pointing to positive effects as well as problems under various conditions/circumstances, leading to a conclusion that, cases need to be analysed individually.

2.5.4 Security and risk analysis

Currall (2006), discusses information security and risk related to information systems, paper or electronic. He finds the concept 'redundancy' often used as a negative connotation, and suggests 'robustness' to be more adequate for analysis. His concern is in line with for example deVries and Nyemera's (2010) discussion of the information system in Uganda. Currall (2006), asks why protection of information is necessary, and what are we protecting it from?

In his discussion on security, related to confidentiality and availability in the digital domain, he claims that, the types of threat to information are in many ways the same in the digital and the physical world. *"The main differences are: how likely each of them* (the threats – my comment) *is, where the threat comes from, and how it may be reduced".* A problem with digital information is that it is only 'available' via the use of computer programs and not directly via the senses (ibid, p.53). He points to the fact that, information stored in a digital form can be very vulnerable to loss, unless managed very carefully. He then argues for the importance of conducting a risk analysis before making decisions, as *"security is about reducing risk",* and *"Security is also about controlling risk. We cannot control risk if we*

have not identified the risks and evaluated them in terms of impact and likelihood" (ibid p.49*).*

There are three elements of a risk that needs to be analysed (ibid, p. 61):

- a contingency
- a consequence or impact (with some measure of how big)
- a likelihood of occurrence

> "*You need to understand the threats, where they come from, what they mean and the effects they can have. In addition, you need to understand both the role that technology can play in providing solutions and also the problems that technology brings with it*" (ibid).

Software project risks have been discussed by Schmidt et al (2001), and risk management and sustainability within IS in DC's by Mursu (2002). Schmidt et al have to some extent the same point of departure as Currall (2006): "*The first step in the risk management process is to identify the risk itself, so that appropriate countermeasures can be taken".* They then have developed a detailed list of risk factor categories to consider, related to software project management.

Currall, conclude that: *"**Things will go wrong**. So, you need to plan on that basis and have appropriate tools to monitor the situation and to recover from the problems* (ibid)". Related to the threat to availability, Currall, emphasizes the importance of having a backup strategy *"[…] which ensures that there is an adequate number of copies stored securely in more than one location, […]".* This point can of course be applied in many settings, but may be particularly relevant in DC's?

The reason for giving this issue some attention here, is to get a more balanced view on these, otherwise so weighty arguments against paper tools in the development and implementation of electronic health information systems.

Summing up redundancy/robustness, security and risk analysis

Several authors point to the fact that redundancy, under various circumstances, may be positive and/or negative, and redundancy may be

> *"[…] playing a productive role as a principal reason for robustness of work";* because, if "*one component fails for lack of knowledge, the whole system does not grind to halt"* (Hutchins, 1995; Ellingsen and Monteiro 2003; Cabitza et al 2005; de Vries and Nyemera 2010).

Landau (1969), distinguishes between inefficient and constructive redundancy. Ellingsen and Monteiro (2003), ask *'when is redundancy productive?*' And they emphasize that: *"design decision regarding redundancy need to assess both costs and benefits"* (ibid p.86).

In their analysis of redundancy in HIS, Ellingsen and Monteiro (2003), and Cabitza et al (2005), introduce different types of information and categories of redundancy. They have to some extent a similar categorization of the concept (tables 5 and 6). Both models distinguish between data recorded in the same artefact or in different artefacts, and consider redundancy positive under certain conditions.

It seems reasonable to conclude that, redundancy should always be assessed in relation to context, taking into account both costs and benefits, as well as risk. In an HIV/AIDS context, and in a DC in particular, security and risk analysis are most important. The message from

Currall (2006) is clear: *"things will go wrong"*, and we cannot control risk if we have not identified the risks, and evaluated them in terms of impact and likelihood.

2.5.5 'Information system' or 'Information infrastructure'?

In contrast to information systems (IS), which are typically seen as independent or standalone systems, information infrastructures (II) is a concept being developed to describe large scale, complex, and networked technologies. These infrastructures include both the technical components, such as the technologies and standards, and also the interconnected social and organizational elements, such as work practices, human resource issues, politics and other institutional conditions (Hanseth et al, 1996). Health information infrastructure (HII) is then use of an information infrastructure within the health care sector (Hanseth and Monteiro 1997).

The II concept has been used to analyse large organizational structures, like in a hospital, comprising a wide range of systems and technologies. Grisot (2008), applies II to analyse the complex and distributed work practices related to heart transplant. This involves a large number of systems, people and artefacts to make the heart transplant possible, which the author denotes "hybrid distributed infrastructure" (ibid).

The two categories; 'information systems' and 'information structures', do however have a number of elements in common. There are certain characteristics that may be ascribed to both, such as: 'heterogeneity', i.e. "[…] *they contain components of multiple sorts – diverse technological components as well as multiple non-technological elements, (individual, social, organizational, institutional*)" (Hanseth and Lyytinen, 2003*).* Another important feature emphasized in II design is *'shared standards'* (Hanseth and Monteiro, (1998)*,* and strategies for developing '*flexible standards'* for sustainable II are discussed in Braa et al (2007).

Heterogeneity, in terms of multiple components, is also characteristic for IS, technological (paper and ICT), organizational, and social. Buckingham et al, (1987 in Avison and Myers,1995), define an information system to containing multiple elements:

> "*[...] An information system is* ***a human activity (social) system which may or may not involve computer systems"*** *(bold added).*

To be able to translate, integrate and share information from social and technical sub-systems into one IS, shared standards will also be important in any system.

Hanseth and Lundberg (2001), discuss the development of integrated and scalable information systems as developing **information infrastructures**. They discuss the problems and reasons for failures in existing information systems and suggest that failures often relate to existing technologies seen as separate and independent, rather than part of complex overlapping infrastructures (ibid). In order to understand how different artefacts and technologies are linked together, they introduce the concept 'work oriented information infrastructures' to denote collections of artefacts developed to support specific work tasks and practices for members of a community (ibid, p 365). They see for example the request form in the radiology department as a shared infrastructure for the personnel. *"We do not see an infrastructure as some kind of purified technology, but rather in a perspective where*

the technology cannot be separated from social and other non-technological elements, i.e. as an actor-network" (ibid, p.349).

According to Hanseth and Lyytinen (2005), an important difference between an IS and an II is whether the system or infrastructure has a specific purpose or goal to justify its existence. An information system they claim, is:

> "*[…] traditionally developed to serve dedicated organizational tasks. In contrast, information infrastructure has no specific purpose or goal that justifies its existence*, *other than a very general idea of offering information related services to community" (ibid p. 213).*

I have chosen to use the ***information system*** category, i.e. one system, many sub-systems, comprised of hybrid modules, to define the unit of analysis for my case, as the health information system(s) studied has a specific purpose and goal: i.e. to meet the challenges in health care service delivery, in providing quality health information.

Important elements and concepts in setting principles for designing hybrid information systems are: standards and interface between the modules, and how to find the balance between unwanted redundancy and robustness.

2.6 Hybrid information systems

The term 'hybrid' or 'hybrid systems' originate from biology: "the offspring of a cross between two different subspecies or species", but has also been applied in other disciplines such as social sciences and humanities, and in information systems (Clarke 2005, Jacob et al 2010). An information system is often defined to consisting of several components or modules. A hybrid system may be composed of many, and many *types* of components, social and technical. There is no consensus of the meaning of the term 'hybrid system' in systems science research, and the term is used with different meanings.

Clarke (2005), a consultant interested in policy aspects of e-Business, information infrastructure, and data surveillance and privacy, has studied a combination of business disciplines and professions, information technologies, and the strategic and policy implications of information technologies. He discusses various domains for potential application of the principles for hybridization, among them domains **involving human organizational forms**, including corporations, government agencies, formal associations, and informal associations including *"organisation with artefact(s), as is evident with technology-dependent and technology-centric organisations"* (Clarke 2005).

To illustrate the variety of use, he mentions examples of use of the concept within the Humanities and Social Sciences, such as "the creation of dynamic mixed cultures" in Sociology and Anthropology, and as *"the integration (or, mingling) of cultural signs and practices from the colonizing and the colonized cultures*", in the discipline of English. Clarke also refers to Yao (2003), who offers a taxonomy of hybridization strategies, introducing categories/concepts such as: mimicry, cross-fertilization and grafting, where grafting is:

> *"[...] the relatively superficial employment of an element from one entity in conjunction with another entity, with change to the element and/or the host only to the extent necessary to enable the connection to be achieved - comparable to 'interfacing' in information technology terms*" (Clarke, 2005, p.2).

Sanner et al (2014), applies the grafting concept in studying the complex processes in the evolvement of information infrastructures in m-Health, referring to horticultural grafting, where combining *"rootstocks that tolerate difficult environmental conditions with cultivars that would otherwise be unable to survive and yield desirable results"*.

Clarke conclude his discussion as follows:

> *"The term 'hybrid' has been generalized to refer to any recognizable entity that is made up of elements drawn from multiple sources. A hybrid is of particular interest where its elements are derived from heterogeneous sources, or it is composed of elements of a different or seemingly incongruous kind. The instrumentalist is naturally interested in combinations that are efficacious in some way, […]"* (Clarke, 2005).

He also suggests a range of definitional characteristics for a hybrid system (table 7), some of which, although directed towards the 'living species', may also be adapted to an information system case:

(Selected) Characteristics for hybrid systems	
A new instance	An entity which has existence distinct from its progenitors
Dual (or multiple) inheritance	The new entity must exhibit elements from two or more progenitors
Integration	Cannot just be a set of elements without inter-relationships
Optional characteristics	
Functionality	Creating new potentials
Flexibility	The new entity may or may not have sufficient flexibility to cope with differences in circumstances
Adaptability	May have the capacity to change its elements over time, as its environments change

Table 7: (Selected) Characteristics for hybrid systems (Clarke (2005)

I find the optional characteristics particularly interesting. Instead, for example, seeing hybrid systems, and the paper components in particular, as a problem, looking for possible digitizing of the paper tools, a more fertile approach might be to search for ways of exploiting the affordances of the different technologies *in combination*, thus 'creating new potentials', while also keeping a flexible and adaptable functionality.

Applied on a hybrid health information system: a paper-based patient retained card works as an information carrier, although limited in a 'pure' paper version. The card, extended with a barcode label on it, works however to conveying information from one component, i.e. the paper card and system, to the other, i.e. a central electronic patient database, and thus gives access to other systems, such as the electronic patient record, or to a pharmacy system.

It is emphasized that affordances must be assessed in relation to the context (Gibson 1979). An important question to ask when configuring a hybrid system would thus be: to what

extent do the different components afford what is needed in the different contexts, what are the benefits and the constraints?

Hybrid health record systems are not a novel concept or idea in information systems research. In 1992, Manchester et al, describe a hybrid electronic-paper medical record system within Primary Care. The arguments in the article relate to the deficiencies of paper medical records, and are in accordance with the ones mentioned in more recent literature, such as: lack of availability, incomplete data, poorly organized information and illegible, laboratory data get lost, and more. The case described, and the context in their paper are related to the current status of information technology in society more than 20 years ago, and show an optimistic view on electronic health records: *"It is anticipated that the electronic medical record will largely solve these problems"* (ibid, p. 13). The article is work practice oriented and claims to present an information system that utilizes the strengths of both the paper and the electronic record, without theorizing the design of the hybrid system as such.

Ten years later, Leiner et al (2003), describe the patient record in a health institution to still being a hybrid record:

> *"[….] the patient record comprises all data and documents generated or received during the care of the patient at a health institution. Document carriers may be conventional or electronic media. In its still most common form, the patient record is paper-based, contains a growing proportion of computer printouts, and is supplemented by an extra envelope or folder for x-ray images" (ibid, p.176).*

Today's status in high-income countries as well as in developing countries shows however that *'these problems'* (Manchester et al, 1992), by no means are solved. Even if this statement from Leiner et al, was written in 2003, a number of recent literatures show similar results. There are numerous articles describing how the expectations and potential benefits of EMR have not been met, and, on the contrary that new problems have emerged (Braa et al 2007; Ellingsen and Monteiro 2006; Gilson and Raphaely 2008).

In the CSCW discourse, most of the studies within health care describe work practices and information systems where the collection of artefacts carrying information is comprised of both paper and electronic components, although the hybrid entity as such is not their main focus, but on collaboration at the work place, and how to understand the work practices so that electronic systems can support and/or replace functions served by existing paper tools and systems. Bardram and Bossen (2005), describe how people in a hospital through "a web of coordinative artefacts" achieve coordination of work. They do not use the word 'hybrid systems', but talk about

> *"[…] linking and blending the digital and the physical world"*, and *"to link the digitalized artefact with the real-world ones and to even blend physical and digital 'material' into one artefact"* (ibid p.174).

By blending they mean *"that a combination of representations of data in both worlds together form a coherent whole*". As one example of *"linkage between the digital and the physical world",* they mention the use of barcodes to link physical artefacts to digital data. By focusing on the material characteristics of the non-electronic artefacts, they describe the affordances of the technologies, seen as the advantages of the different

artefacts, such as ***"at-a-distance-at-a-glance overview; easy change or adding information"***, and how these affordances support work in a hospital work setting.

Mikkelsen and Aasly (2001) evaluated the parallel use of paper based and electronic patient records in a transition period from paper to electronic systems in a hospital, with the ultimate goal of replacing the paper system to using completely electronic patient records. Their hypothesis was that, keeping two parallel systems up to date requires maintenance of both, being at risk of becoming inconsistent, thus causing failure. They conclude that the parallel use in this period resulted in inconsistencies between the records, and documentation was missing in both the electronic and the paper-based records. The precondition was to, at all times, have complete parallel records, paper based **and** electronic, and the strategy was to gradually replace the paper records with the electronic version. In this process the paper records would be kept as backup.

The assumption in the case discussed by Mikkelsen and Aasly, was that both patient records should provide all necessary clinical information about a patient, and the evaluation of the parallel systems was in relation to this requirement. The electronic patient record systems in DC's that are described in the literature do only cover small parts of these requirements. Still the lessons learned in this case may be useful to keep in mind, in a setting where the hybrid components partly overlap and partly complement one another. The important question(s) to ask will be: how can a hybrid system (comprising electronic and paper artefacts) best cooperate and coordinate information to meet the info needs, and eventually: how to design for flexible changes in the hybrid model over time?

2.6.1 Hybrid systems in HIV/AIDS monitoring

In this thesis, I use the concept 'hybrid information systems' to refer to the general definition of *"systems having two kinds of components that produce the same or similar results"*[23]. The previous sections describe patient records and monitoring systems that are all hybrid systems in different configurations. I will specifically focus on the combination of paper and electronic modules and systems within health care, with the assumption that, in line with Clarke (table 7, p.53), a hybrid system *"cannot just be a set of elements without inter-relationships"* and that it has the functionality to "*creating new potentials"*, thus providing a more complete result than the single technology and components alone. "The patient's fluid balance", as described by Berg (1997b, p.146) would be an example from the CSCW and health informatics discourses. Berg discusses the combination of paper forms and electronic systems when nurses calculate a patient's fluid balance in an intensive care unit. He describes a situation with a hybrid system of tools, where the computer-based record performs a fragment of the total calculation, and he argues that "*the organization of the hybrid produces the net effect: the fluid balance*". Although Berg's 'hybrid' is composed by more and different entities than electronic and paper technologies only, the point is that, different artefacts together, and their organization, produce *"the net effect"*.

[23] www.thefreedictionary.com

The focus on hybrid systems has a work practice orientation, i.e. how to ensure that the service providers have the key information needed, to be able to give quality care and treatment, while also acknowledging the need for monitoring the disease at managerial levels. Important in designing hybrid systems to achieve this, are standards and interfaces to secure transfer and sharing of information between components, between health service providers as well as across managerial levels.

WHO (2006) emphasizes the importance of keeping a patient record as a key element of continuity of care. The guidelines acknowledge that data collection will be done by paper based and electronic systems in combination, and that *"systems vary as to where the paper to electronic transition occurs",* as illustrated in table 8. They underline however the importance of the definition of essential data elements being standardized, so that each system, whether paper or electronic, reports in a uniform way (WHO 2006, p. 41).

System type	Patient record and patient retained card	Registers	Quarterly cross-sectional and cohort reports	(Sub-) Districts or regional and up
1) Paper based system with electronic entry of reports	Paper	Paper	Paper	Paper → electronic
2) Paper based system with electronic entry of registers	Paper	Paper → electronic	Electronic	Electronic
3) Electronic patient record (EPR) with electronic entry of paper records	Paper → electronic	Electronic		
4) EPR with direct electronic entry without paper when managing patients	Electronic	Electronic	Electronic	Electronic

Legend:

	data collected and aggregated manually at facility level
	data collected and entered into EPR at facility level

Table 8: Paper- based and electronic patient monitoring systems (WHO 2006, p. 41)

2.7 Hybrid information systems – design principles

Literature related to design principles covers a wide range of perspectives, from focusing on architecture and design on a metalevel, to discussing one particular issue, or presenting detailed lists of what the author(s) see(s) as the basic principles related to a number of factors. In a study related to Integrated Child Health IS, Hinman et al (2004), present 19 principles regarding issues such as availability, security and confidentiality, cost and flexibility. Krickeberg (2007), discusses eleven basic design principles of a more technical character, but emphasizes that "*HIS is not only a tool for collecting indicators; it is intimately tied to clinical and preventive practice, as well as to health management and health economy".*

In a case study of an EPR in a hospital, Ellingsen and Monteiro, (2003), suggest design principles for the integration of collaborative systems, with the focus on "*the productive role of redundant, fragmented and ambiguous information"*. The authors claim that the ideal of 'seamlessly' integrated systems relies on unwarranted purifications, and state that,

> *"Design and intervention strategies for EPR need to balance on a tightrope: on the one hand, to avoid promoting unrealistic, futuristic aspirations, overly emphasising the potential of the technology, and on the other hand, to move beyond a description of the immense richness of medical practice that may easily infuse the impression that any intervention would necessarily upset this elaborate and delicate play"* (ibid, p.92).

A panel of medical informatics specialists, clinical HIV specialists, and program managers, suggested a pragmatic approach to constructing a minimum data set, based on their experience in managing HIV clinics in developing countries (WHO Workshop, 2004; Tierney et al, 2006). This work was work practice oriented, and had the focus on the users of information and their information needs. A Patient Summary Report was created, suggesting a minimum dataset for EPR, containing identifying data, diagnosis (HIV-related and others), drug allergies, HIV-relevant lab test results, and HIV/AIDS treatment data. The report was printed for clinicians before the patient visit (Tierney et al, 2006, p.373).

Hanseth and Lyytinen (2010) discuss design related to complexity and information infrastructures. They describe design theories to be

> "*[…] about 'how to' principles and rules of form and function"*, and *"Design principles state broad guidelines how the design can be carried out, […]"* (ibid, p.5).
>
> They also state that, *"Each design theory applies in a certain context […], and the design context is determined by the nature of the system, its size, the design phase, the type of technology, the type of users or designers"* (ibid).

Based on the fact that, design of information systems needs to take into account the wider context of people, knowledge and resources, I suggest to change the vision of integrated electronic patient records to be the solution for achieving quality of health care, to recommending and developing design principles for **hybrid** health information systems - building on the knowledge from CSCW projects, IS design, and the reality in the HIS in DC's field. This opens up for the introduction of concepts such as redundancy and affordances in suggesting how hybrid systems may function, being flexible and robust enough.

Chapter 3 Methodology

This chapter presents my research process, the philosophical assumptions that have guided the methodological approach, and data collection strategies.

3.1 Interpretive research

To study certain phenomena in the world, researchers have developed different methods for collecting data and achieving new insights, guided by certain philosophical assumptions about society, human action and knowledge creation. Myers (1997), divides these underlying

assumptions into 3 categories: positivist, interpretive and critical. He describes positivists as generally assuming that reality is objectively given and can be described by measurable properties, which are independent of the observer and his/her instruments, while critical researchers assume that social reality is historically constituted and that it is produced and reproduced by people. Interpretive researchers believe that social reality can only be interpreted, and that access to reality is only through social constructions such as language, consciousness and shared meanings (Orlikowsky and Baroudi, 1991; Myers 1997).

Alvesson and Skölberg (2000), claim that: *"Reality is always already interpreted"*. Even if the researcher presents data directly from field notes, as for example quotes from interview, they are only parts of a total, chosen by the writer, and detached from the context. My research will fall under the theoretical framework of an interpretive qualitative research, with a critical element. According to Walsham (2005), research can be both interpretive and critical and that stronger critical emphasis comes from:

- *Motivation* – what is wrong in the world rather than right
- *Focus* – on issues such as asymmetries of power relations
- *Theory* – with a critical edge e.g. Frankfurt school, Bourdieu, post-colonialism

To study information systems interpretively requires certain strategies for collecting data, and ways of analysing them. Walsham (1995), claims that, an in-depth case study is the most appropriate method for conducting empirical research interpretively. He also emphasizes that

> "*Such studies will often be carried out longitudinally, namely over a reasonably long period with the opportunity to directly observe the unfolding events over time" (ibid).*

Yin (2003), proposes case study as the strategy for data collection in exploratory studies where research questions such as 'how' or 'why' are being posed, and Geertz (1973), recommend 'thick' descriptions as a way of presenting the collected data,

> *"As data collection and analysis in the interpretive tradition will be the researcher's subjective interpretation of the participants' interpretation, 'thick' descriptions, i.e. rich accounts of what is seen, understood and interpreted, are sought".*

Orlikowsky and Baroudi (1991), point to the fact that, the researcher will never be able to observe and describe field observations objectively.

> *"Retelling the actor's story is never fully possible, as the interpretive schemes of the researcher always intervene, and hence the researcher in part creates the reality she is studying through the constructs used to view the world" (ibid, p.15).*

"Stories we tell", is a Canadian documentary film, written and directed by Sarah Polley. Through interviews with family members, and other persons involved in their family life, she creates the story of her family, in particular her mother (Diane), and the relationship between her parents. The director (Polley) lets everyone tell their version as they saw and remember it. In the process of making the film, she is noticing that the 'truth' depends on who is telling it. Often the participants give contradictory answers to the same question. Towards the end of the film, some of the characters question Sarah's way of doing this, i.e.

how she creates *her* story about her mother's life. One person claims that: *"The reality essentially is that, the story of Diane, I regret to say, is only mine to tell". He* only knows and can tell *the truth* of what happened in a certain period of time in their life. Another person contend that Sarah does not at all capture what *really* had happened, *the* truth as he sees it. He claims that, the different stories told by the people involved, are only narratives of what they remember, and are shaped by their relationship to the person, and their loyalty to her. He questions the director's right to collect these narratives, and then to select, edit and present her version of the family story.

I find that this gives a good description of an interpretive research approach, and how it is performed. Translating the making of this film into the case study of my research, this is how I did it:

Following an interest (motivation), I have, within a certain research area (patient related Health Information Systems in DC's), selected people and units (sampling) that I thought might shed light on the interest and questions I had. With my personal and professional background (professional social worker; accounting, management, informatics), guided by my pre-understanding of this research field (collected through previous research; reading the discourses and secondary documents), and my wish to know more about it, I conducted (semi-structured) interviews, asking people about their view on selected matters, and made them tell their stories from their work; what they did, how they did it, and what they thought about it. During my visits in the field I also observed (non-participant) the environment. From my collected data, recordings and notes, my understanding and interpretation of the interviewees' narratives and my observations (analysis), I created my story – this thesis – to inform the questions and objectives that I brought with me in the beginning, and with results that hopefully will contribute to, and bring new insights into the HIS in DC field.

In the sections 3.2 – 3.4, I will present the chosen research design, described as a longitudinal case study, using an ethnographic strategy for data collection, or seen as a 'serial and/or periodic ethnography' (ref Ch 1.7, p.14), or a combination of these strategies for data collection. I will briefly describe various types of ethnography discussed in the literature, many of which deviate from the 'classic' ethnography as described by Myers (1999), and argue for my choice of method for doing research.

3.2 Research design - ethnography

> *"[…] if you want to understand what a science is, you should look in the first instance not at its theories or its findings, and certainly not at what its apologists say about it; you should look at what the practitioners of it do" (Clifford Geertz 1973, p.5).*

Key characteristics of ethnographic research are described to be 1) taking place in natural settings, 2) descriptive, 3) holistic i.e. the case has to be understood in a larger context, and 4) it strives to consider the participants' own perspective (Sandhu et al 2007). Hammersley (2006), defines ethnography to be: "[...] a form of social and educational research that emphasises the importance of studying *at first-hand* what people do and say in particular contexts. This usually involves fairly lengthy contact, through participant observation in relevant settings, and/or through relatively open-ended interviews designed to understand people's perspectives, […]" (ibid, italics in original).

According to Geertz (1973), doing ethnography is not all the techniques the researcher uses (selecting informants, transcribing, mapping fields, keeping a diary, ...), but to give a 'thick description'.

> *"A practice perspective, like the one a fieldworker can obtain during ethnographic fieldwork, it has been argued, helps surface users' assumptions about the information systems they work with, and as a result can be used to inform information systems design"* (Blomberg et al, 1993; Button and Harper 1996; Luff et al. 2000).

Knoblauch (2005), also mentions other ways of doing ethnographic research that deviates from the 'classic' way, such as various work-place studies within the CSCW domain (Heath and Luff, 1992; Hughes et al, 1994).

A number of authors have added a descriptive connotation to the ethnography concept, such as:

- 'rapid ethnography' (Millen 2000; Sandhu et al 2007),
- 'evaluative' or 'periodic' ethnography (Crang and Cook, 1995; Rodden, 2006; Rouncefield 2006;),
- 'focused' ethnography (Knoblauch, 2005),
- 'quick and dirty' or 'lightweight' ethnography (Martin and Somerville, 2006,
- 'micro-ethnography' (Streeck and Mehus, 2005).

Millen (2000) introduces the term '*rapid ethnography'*, to be:

> *"[…] a collection of field methods used as, a way of providing 'a reasonable understanding of users and their activities, given significant time pressures and limited time in the field".*

'Serial hanging out' (SHO) is another term used within 'rapid ethnography', i.e. sequential, short-term (2-4 days), participant observation with multiple, independent informants. The concept is used by Sandhu et al (2007) in human-computer interaction (HCI), to describe a method for rapid assessment of user needs in rural settings. The core field method in SHO is participant observation rather than interviewing. The authors claim that rapid methods are necessary *"[…] because projects operate under severe time and budgetary constraints".* Operating within these constraints may, however, lead to sacrificing the holism and members' perspective (ibid). Their focus is specifically on rural communities in the context of international development.

'Focused ethnography' (Knoblauch 2005), is characterized by short term field visits, and visits in various intervals; data collection and analysis deviate from 'conventional' ethnography by intensity, use of audio-visual technology, and presupposes an intimate knowledge of the fields to be studied.

'Quick and dirty': provides knowledge of large organisations' work setting in relatively short space of time (Martin & Sommerville 2006).

'Evaluative' or 'periodic' ethnography is described as a more focused version of 'quick & dirty' that does not involve a prolonged period of fieldwork. *"Modest redesign through* ***periodic*** *ethnographic field studies of system use may have considerable benefits* " (Crang and Cook, 2008, bold added).

In my case, to stay over a long time period would not be appropriate for various reasons, and a strategy more in line with the serial and/or periodic types of ethnography seemed to be a useful solution. I have chosen to do the in-depth field study over a 2-year period, with multiple visits at the same sites, interviewing the same people each time (if possible), and with observation at the sites. This would provide an opportunity to investigate and follow the process of collecting and sharing patient information without being present all the time. It would give me time to reflect over the findings between visits, to discuss findings with the participants, and to follow up with additional questions at the next visit, in accordance with the hermeneutic principle of doing research.

3.3 Research process – hermeneutics

Collection and analysis of data in interpretive research is a process of hermeneutic nature, and according to Klein and Myers (1999), the most fundamental principle of hermeneutics is that of the hermeneutic circle, a meta-principle upon which other principles expand (ibid p.71). The hermeneutic process describes a process of data collection and analysis in interpretive studies, where there is an interplay between the part (single interviews and/or observations) and the whole (final interpretation/story).

> *"The research process constitutes a (re-) construction of the social reality in which researchers both interact with the agents researched and, actively interpreting, continually create images for themselves and for others: images which selectively highlight certain claims as to how conditions and processes – experiences, situations, relations – can be understood, thus suppressing alternative interpretations" (Geertz 1973, p. 6).*

Myers (1999), distinguish between case study and ethnographic research. To study phenomena in their social and cultural context, he claims that an ethnographer is required to spend a significant amount of time in the field, and

> "[…] *to immerse himself or herself in the life of the social group under study. In a case study, the primary source of data is interviews, supplemented by documentary evidence such as annual reports, minutes of meetings and so forth. In ethnography, these data sources are supplemented by data collected through participant observation* (Myers in Yin, 1994)."

Van Maanen (1979), claims however that,

> *"Assuming an ethnographic stance is by no means a guarantee that one will collect accurate and theoretically useful data how long one remains in the field"* (ibid p.539).

In accordance with Geertz, Walsham (1995), also claims that, to understand what is happening in connection with a complex computer-based information system, there is a need for 'thick' descriptions. Grills (1998), states that:

> *"Ethnography provides a researcher with the opportunity to get close to 'where the action is'*, and the approach *"[…] remains close to the ways people experience and make sense of themselves and others"* (van Maanen, 1979).

Thus, it seemed reasonable to me, that a longitudinal case study, using ethnographic data collection techniques, would be an appropriate strategy for doing the research.

Klein and Meyers (1999), suggest 7 principles for conducting interpretive field research of hermeneutic nature, but emphasize that "*not all of the principles may apply in every situation".* In table 9, I give a brief account of how I met the principles:

Principles for interpretive field research	Description	Data collection and analysis
1. The fundamental principle of the hermeneutic circle	All human understanding is achieved by iterating between considering the interdependent meaning of parts and the whole that they form.	Repeated visits at the sites, and interview with the same people, (or other person) in same clinic, discussing my findings from last visit and bringing new questions
2. The principle of contextualization	Critical reflection of the social and historical background of the research setting, so that the intended audience can see how the current situation under investigation emerged	Extensive studies of literature related to historical, political, and ICT development and background related to current situation, before and during case study.
3. The principle of interaction between the researcher and the subjects	Critical reflection on how the research materials (or 'data') were socially constructed through the interaction between the researchers and the participants	My role and involvement with people included in the study, is described in sec 3.7
4. The principle of abstraction and generalization	Relating the idiographic details revealed by the data interpretation through the application of principles one and two to theoretical, general concepts that describe the nature of human understanding and social action	This principle will be discussed in Sec 3.8
5. The principle of dialogical reasoning	Sensitivity to possible contradictions between the theoretical preconceptions guiding the research design and actual findings, with subsequent cycles of revision	In sec 3.6, I describe my theoretical path, starting out with GT, then switching to Sensemaking, and returning to GT, for ordering, selecting key themes/issues, and analysis of the collected data
6. The principle of multiple interpretations	Sensitivity to possible differences in interpretations among the participants	In Ch 6.1, I present how the interviewees brought deviating views on the need for, and use of ICT in data collection, and on information needs, relating both to context and personal views/interest
7. The principle of suspicion	Sensitivity to possible 'biases' and systematic 'distortions' in the narratives collected from the participants	Will be discussed in sec 3.8

Table 9: Principles for conducting interpretive field research of hermeneutic nature (Klein and Myers,1999)

3.4 My research process – sampling and getting access

To learn about the health work practice in resource-poor settings, a literature research was conducted before starting the case study. Data was collected from reports on projects related

to development of HIV/AIDS/ART information systems, and pilots being carried out in developing countries. The literature was selected through online search in journals within Medical research, Medical informatics, Information systems & management, Social science & medicine, Conference proceedings (IFIPwg9.4), Bulletin of the WHO, and literature from the HISP global project[24].

My original intention when starting the PhD study was to apply Grounded Theory (GT). GT is a qualitative approach that generates theory from observation (Calloway and Knapp 1995).

> *"Grounded theory is both a theory and a methodology. As a theory, it is the result when one's empirical material is analysed and structured according to grounded theory procedures and techniques. As a methodology, it is the procedures and techniques that help generate grounded theory from one's data."* (Thoresen, 1998).

I wanted to *"let the empirical data tell the story"*, i.e. let issues and concepts emerge from the data collection, as it unfolded, without using the 'full' GT in terms of the explicit coding techniques. Thus, I did not have a conceptual framework in mind when designing the study and doing the first phase of data collection.

Through analysis of field reports, the policy documents, standards and guidelines before going into the field, concepts and issues that emerged in front, were: 'the patient record' and 'sharing of information', 'patient identification', 'continuity of care' and 'adherence to treatment'. The reports from the field emphasized the importance and difficulties in identifying, and keeping track of patients, for following up of treatment. The reports analysed and discussed to what extent the computerized systems that had been developed and tested in their projects, succeeded in supporting their work.

To be able to give a 'thick description' of the health work practices and information systems in play within HIV/AIDS care and treatment, I would need to get close to the people at ground level, thus, I found the ethnographic methods relevant, i.e. the 'focused' and 'periodic' variant as described in section 3.2.

3.4.1 Sampling

For the field study I was primarily interested in the situation for the health workers (doctors, nurses), and data clerks at clinic level; their information needs, and tools in use for data collection. The idea was to include representatives from both urban and rural areas, assuming that context in terms of HIV prevalence, headcount, and resources would differ. As I had done research within PHC in Cape Town for my Master thesis, I wanted to include some of these clinics in the sample, to take advantage of the previous acquired local knowledge. To some extent, that is, as there had of course been a certain development in the time since my last research period (2003), but I did meet with some of the persons from earlier visits related to the Master study.

Trying to mirror the wide range of stakeholders involved in HIV/AIDS prevention care and treatment (PHC clinic, ARV clinic, hospital, lab, x-ray, TB), the clinics chosen span from one big ARV clinic, to a small primary health care clinic. The smaller clinic did not provide ART at the time of selection, but they provided TB services and they did HIV counselling

[24] www.hisp.org/www.hispindia.org

and testing. During the research process, recommendations from the selected respondents also led to including IT and Program managers at City Health and Provincial Departments.

The plan for empirical fieldwork was to be done in the Province of the Western Cape, South Africa, and the data collection to span a time period of 2-4 years, with 1 pre-study of 2 weeks (2008), 4 field visits (2009-10), each of one-month duration. Later in the analysis, to follow-up with e-mails with interviewees, and document studies.

7 health clinics with sub-units (ARV, MOU, TB, Pharmacy) was included in application for permission to doing the planned study. Three of the clinics were situated in the townships of Cape Town with a high HIV prevalence, one in a more mixed, industrial part of the City, while three sites were in the rural districts with lower prevalence and caseload.

3.4.2 Getting access

The next phase was the process of getting access to the research site. Winthereik et al (2002), argue that getting access to a research site *"[…] must be seen as a process of negotiation in which researchers deal with resistances made by the object of study".* Crang & Cook (2008), also describes various scenarios and problems one may encounter when establishing contact and start an investigation. In getting access, there were also in this case, some obstacles to be passed.

Initially, the idea for the research was to do a comparative case study, doing fieldwork in Kerala, India, and in the Western Cape, South Africa. This led, in addition to reading up on the health system and HIV/AIDS in India, to a five-weeks pre-study in Trivandrum, Kerala. My application for doing research there was however not accepted by the health authorities, and after discussing the situation with my supervisor, it was decided to concentrate on the South African case.

The experience from Kerala, and a pre-study in Cape Town, led to a thorough preparation for permission to do research in South Africa (SA), and getting access to the research site in SA was not a straightforward task. A prerequisite for getting this permission, and before applying for permission to doing research in the chosen sites, formal procedures had to be followed. In addition to more general and overarching ethical obligations when conducting research, (human rights, sustainable development, promote peace, development of democracy)[25], a project involves particular ethical challenges when dealing with people working in the field of health care, and the stigmatised HIV/AIDS disease in particular. The Department of Health, Western Cape (SA) for example, states that:

> *"There is a frequent misconception amongst some researchers that research that does not involve patients does not require ethical approval. In reality however, research that involves service providers, both clinical and managerial, often has the largest impact on health service delivery" (WCDoH, 2007).*

Although there would be no patients participating in the study, and no personal information about the participants would be collected, this issue was of particular importance. All actors involved in planning and provision of health care emphasize the right of people for privacy,

[25] NENT: National Committee for Research Ethics in Science and Technology (Norway)
NESH: National Committee for Research Ethics in Social Sciences and the Humanities (Norway)
VC: Vancouver convention

security and confidentiality. The Vancouver Convention (ICMJE 1979) emphasizes that identifying information should not be published in written descriptions unless written informed consent is given. This is also underlined in the NENT guidelines, as a sub-section of the Precautionary Principle. There are guidelines for protection of research subjects, the demand for informed consent and to secure the privacy of the research subjects.

The research project had thus to be reported to the Norwegian Social Science Data Services (NSD), which is the Privacy Ombudsman for all Norwegian research. Once the project was registered at the NSD, ethical clearance by an accredited Research Ethics Committee in South Africa was required. Ethical approval for the research study was received from The University of the Western Cape (UWC) in January 2009, and an application for permission to do the field study was sent to the Western Cape Department of Health (WCDoH). In their research application form, WCDoH required detailed information about the research aim, objectives, methodology and sites for the research.

The rationale for selecting research sites was motivated by the idea of following a person's trajectory from the first HIV test, to the person being eligible for antiretroviral treatment (ART), thus becoming a chronic patient. I wanted to understand how the health care system captured, stored, and retrieved data related to this person, and how this information was shared across health service providers within PHC, while at the same time meeting the requirements from higher level management and health programmes.

The first answer to my application had detailed comments to the planned research with useful information about today's status of the health and health information system in the Province. The WCDoH did however not accept my initial selection of sites, and argued that only three of them were ART sites. They also questioned the value of interviewing staff on the ground level related to some of the issues I had listed in my interview guide (appendix), attached to the research application. In my response, I explained the rationale for the sampling, i.e. being able to study the patient trajectory from first HIV test to receiving ART, and how information in this process was coordinated, but the response from the Department was as follows:

> *"This would be a very challenging, if not an impossible task for the following reasons: VCT (voluntary counseling and testing) and ART data are collected in separate paper-based registers. Patients may move between different sites, and thus be recorded in registers at different sites. Data is reported in aggregate format for both ART and VCT, thus there is no way of linking VCT at one site with patient enrolment to ART at the ART site. A suggestion would be to focus just on ART sites, those using eKapa II, and those without eKapa II*[26] *"(e-mail WCDoH, May 2009).*

The Department recommended including information managers, based in the Health Department Administration, and not in the clinics. After a few rounds with negotiations around the sites, we agreed on the selection, more in accordance with my intentions, as described in the previous section, and I received the permission in May 2009. The permission letter listed the selected clinics and a contact person for each clinic, mostly the clinic managers. It turned out later that one of my wanted sites was a 'combined facility' (managed by Cape Town City Health and Province together), but administratively run by City Health, and a second round of application for permission to the City Health Directorate was required.

[26] The HIV/TB module of PHCIS

City Health showed no interest in my research project, but after arriving in Cape Town, May 2009, I took personal contact with the City Health administration (Specialized Health and HIV/AIDS program), explained my interest and methods, and finally, in June 2009, I got the permission from City Health orally, and the permission letter end of July 2009.

I realised later that this process had taken place at a higher administrative level in the City and Provincial Health Departments, without the facility managers being asked for acceptance. The process and result so far were however of utmost importance for getting access, and to conduct the field research. To have the permission letter when contacting the clinics, the first time was crucial. Before even listening to my introduction on the phone, all contact persons (facility managers) asked if I had been in contact with the Health Department, and if I had a permission letter. With this letter, however, the doors were opened, although not everyone were happy to accommodate me, and their question was often: "what is in it for us?" - a question that is difficult to answer at the beginning of a project like this. The fact that I did not represent Health Management, an NGO or financial interests, was met with superstition by some of the respondents in the first place, but might in the end have worked as a benefit, as it was believed that I had no personal agenda but for the interest in, and outcome of the research.

3.5 Data collection and methods

The objective of the study was to understand today's situation, to get insights in information needs, and information systems in use related to HIV/AIDS patient care and treatment. I also had an interest in studying processes related to the implementation of global standards and guidelines for HIV/AIDS data collection and reporting at PHC clinic level in a DC. Considering the overall focus on ICT for development, this included an interest in the preconditions necessary for use of ICT as a tool in data collection, integration and use of data, with a particular focus on following up HIV/AIDS patients in a life-long perspective.

To be able to give a thick description, a longitudinal case study, interview, and observation are the methods recommended. According to Yin (1989, 2003), evidence from case studies may come from six sources:

1) Documents: written reports, minutes of meetings, user manuals, policy documents;
2) Archival records;
3) Interviews; one of the most important sources in case study. May take several forms: open-ended in nature; focused (semi-structured): may be open-ended, but the interview follows a certain set of questions;
4) Observation; direct (in meetings, waiting room etc, demonstration of data program in use); formal observational protocol, or casual data collection (photo, drawings); participant observation: the researcher participating in the events being studied (pro and cons);
5) Physical or cultural artefacts (tools, technologies, physical evidence).

The strategy I have chosen for data collection, may be labelled a case study using ethnographic strategies for data collection; or a periodic ethnographic study (Crang and Cook, 2003; Rodden, 2006), i.e. doing serial interviews, visiting the same clinics, and the

same persons, if possible, over an extended period of time. The interviews would be semi-structured, and followed up by e-mail exchange later during the analysis period.

In combination with the interview visits, I would have the opportunity to make observations, such as sitting in the waiting room by the reception, and/or joining personnel behind the counter. Document analysis, including review of organizational documents and artefacts (reports, data collection forms, plans, software user guidelines), and demonstration of tools and technologies in use, were included in the data collection. The data collection was conducted in five phases, ref sec 3.6 and table 12, p.74.

The case study was finally conducted over a time period of four years. Within this timespan some of the clinics involved in the study, went from mostly paper-based systems and offline computers in the reception, to implementation of a web-based Primary Health Care Information system (PHCIS).

3.5.1 Interview

Interview is seen as the most important technique for data collection in case studies. Crang & Cook (2003), also emphasize the importance of interviewing as a primary source of information in ethnographic research, and introduce 'serial interviews', with the same persons, as an ethnographic strategy. The interviews may be structured (asking pre-determined questions in a specific order), or semi-structured, where the researcher has selected some themes to be discussed, no pre-determined order, and this may develop more like a conversation, depending on the response from the interviewee.

> *"The main difference between arranging a series of multiple interviews with the same people, and a range of single interviews with many more is that, after repeated visits with the same person at the same site over a period of time, the quite formal interviewing style discussed above may/should dissolve. Here, interactions, which are much more like informal conversations can usually be developed in which both parties feel more able both to reveal their often undecided, ambiguous, and contradictory feelings about the matter in hand, and to challenge each other about these in an atmosphere of mutual respect and trust. And, it is this 'atmosphere', which is the most valuable product of this approach to interviewing"* (Crang and Cook, 2003, p. 46).

I found this strategy suitable for my purpose, as staying over a longer time period for doing fieldwork was not an alternative, but still being able to establish contact with the participant over time, and the possibility to study the field in more depth. The plan was then to conduct a series of semi-structured interviews with the same people, with themes formulated in accordance with my interest at the moment, i.e. starting out with themes obtained from reviewed literature. After each interview, themes that emerged from last interview, were followed up at the next visit. The interviews were either tape-recorded, to be transcribed verbatim later, and/or notes were made on site. Immediately after an interview, I wrote a short summary of the visits, while still fresh in mind, and later, analysed in more depth, related to the themes in focus. From this analysis, next interview was planned. 38 people were interviewed, some several times, a few only once. In total 66 interviews were conducted. Most interviews lasted on average 45 minutes (range 20 minutes to 2,5 hours), and they took place at the work place of the interviewees (table 10, p.68).

Type of unit	Participants / professions	Informants	Interviews
Health directorate, IT-management, Program management	IT director ARV program manager ARV doctor/researcher Business analyst	4	8
Sub-District management	Sub-District/ARV clinic doctor and manager; Information officer	2	6
PHC clinics (+TB)	Clinic manager, nurse (TB), HIV counsellor	3	4
CHC's with sub-units (MOU, Pharmacy, Reception, TB section)	Clinic managers, information manager, nurses, data capturers, pharmacist	18	27
ARV-clinics (one HIV/TB combined)	Clinic managers, ARV doctors, nurses, pharmacists, data capturers	11	21
Total		38	66

Table 10: Data collection – interviews

3.5.2 Observation

Observations can be participant, or direct but non-participant, covering events in real-time, and the context of event. This may be useful for instance for observing technology at work, and understanding potential problems as they occur. Photographs from the site may add valuable insights (Yin 2003). In my case, meeting people at their work places provided an opportunity to seeing how they organized their work, i.e. how they identified a person, searching for and creating patients' folders, and archiving etc. in the office (computer, shelves, fax, phone, archives), often interrupted by people entering the office, or incoming phone calls during interview.

Mostly, I did non-participant observation; sometimes intervening by asking clarifying questions. In some of the facilities, I spent time sitting in waiting rooms together with patients, observing how reception/registration was done at the counter, and at times health information related to HIV/AIDS and TB was communicated from nurses to the waiting patients in public. In some clinics, I had the opportunity to sit behind the counter (reception), observing from this view how patients' folders were searched for, electronic on the computer, the use of computer systems related to registering patient information, creating barcode labels and use of hand-scanners, and/or how they were retrieving and archiving paper folders. I also participated in one Sub-District meeting (CityHealth), together with information officers and clinic managers, where the developers demonstrated a new IT system (patient data).

Walking between health service units in the larger clinics was useful. This provided the opportunity to observe the physical environment and context in which the health services were performed. With a combination of interview and observation, I had data clerks demonstrating how they used the data systems more exhaustive, without patients present (register patients' data, fill in forms, compile reports and statistics, and more), and I had copies of various forms printed.

My focus by and large when observing, was both to get an idea of the various tools and technologies involved in the processes, to understand what was actually documented in the electronic system, compared to the paper versions, and how information needs were met. To spend time together with the people doing their jobs, does give a rich variety of information. To document what I was observing, I wrote notes during these sessions, and subsequently tried to analyse and fit in the broader perspective.

3.5.3 Document analysis

Document analysis included literature research as a preparation to designing the research, and later, a study of the different documents collected during the data collection period, with a shifting focus, as described in the research process. Before embarking on the case study, literature research was conducted and data had been collected from reports on projects related to development of HIV/AIDS/ART information systems and pilots being carried out in developing countries.

This was supplemented by studying policy and strategy documents, white papers etc. from global and national key stakeholders (WHO, UNAIDS, National Department of Health, South Africa, Provincial Department of Health, Western Cape, and City of Cape Town Directorate), to learn about the visions, policies, standards, guidelines, information and reporting requirements issued by higher levels authorities. Relevant for this thesis have been policy documents, standards and guidelines, covering two main areas: programmes for HIV/AIDS related prevention, treatment and care, and frameworks for monitoring and evaluation (M&E) of progress within these programs; accordingly adopted by leaders at national and provincial levels. Within both areas there are specific guidelines and standards for ARV patient care and management.

Figure 3: Examples of documents reviewed (Global, National, Provincial)

Document category	*Selected documents*
Policy documents	United Nations Millennium Declaration (UNGASS 2000)
HIV/AIDS strategy	"Treating 3 Million by 2005" Making it happen. The WHO Strategy (WHO 2003)
HIV/AIDS/TB Guidelines	Guidelines for implementing collaborative TB and HIV programme activities (WHO 2003) Treat 3 million by 2005 – Scaling up antiretroviral therapy in resource-limited settings: Treatment guidelines for a public health approach – 2003 Revision (WHO 2004) Patient monitoring guidelines for HIV care and antiretroviral therapy (ART) (WHO 2006) Interim guidelines on protecting the confidentiality and security of HIV information (WHO 2007)
HIV/AIDS – ART Standards for treatment	Standards for quality HIV care: a tool for quality assessment, improvement, and accreditation (WHO 2004)
Monitoring and Evalution	A guide to monitoring and evaluating HIV/AIDS care and support (WHO) 2004)
User Manuals – EPR	ekapa II PHCIS Tier.NET iDart

Table 11: WHO/UNAIDS policy documents and standards for HIV/AIDS care and treatment

3.6 Data analysis and the use of theory

During the study and data collection, I followed the model of an interpretive, longitudinal case study as an on-going iterative process, from initial interest and focus, to analysing the results from data collection. Through the initial document search in the pre-studies and process of getting access for this study, concepts and issues that emerged were: 'the patient record', 'sharing of information', 'patient identification', 'continuity of care' and 'adherence to treatment'. As I initially had chosen to use a Grounded theory approach, I started my fieldwork with semi-structured interviews, guided by the themes that had emerged from reading literature about health information systems in DC's, and health care related to HIV/AIDS, as described in sec 3.4. An interview guide for the first visit was designed, with key questions, and with a few specific questions for the various professions (health care providers, data capturers, managers etc) (appendix). In the following sections, I will describe in more detail how organizing the findings, and how the progress of making sense of the collected data was performed, in line with the principles of the hermeneutic interpretive research.

Phase 1-2: Preparations – identifying information systems and stakeholders

The first field-visit in South Africa took place in May-June 2009, and aimed at getting an overview of the health care services and information systems in use related to HIV/AIDS

and patient monitoring, from HIV voluntary counselling and testing (VCT, later HCT)[27], done 'everywhere' in the health care facilities, to medical treatment of AIDS, antiretroviral therapy (ART), in ARV clinics. I was focusing on how the routines in the day-to-day work practices were, from receiving a person for VCT the first time, to giving ART over time. How did they identify and register the person, how was data stored and retrieved, how were the referring procedures, what were the stakeholders involved, and what were their information needs.

From analysis of the tape recordings and notes after interviews. I did not apply the 'full' grounded theory, i.e. coding the findings, but the results were sorted (data reduction) according to themes such as: 'type of HIV/AIDS services', 'case load', 'patient identification', 'routines', 'follow-up', 'equipment', 'patient card', 'patient folder', and 'staffing'; themes that were followed up in the next visits. The crucial role of the patient record became a central issue. The concept of integration came very much in focus, as I got a picture of the number of stakeholders involved in HIV/AIDS care and treatment; from blood banks and pharmacy, to primary health care clinics and mobile clinics in the rural areas, and ART clinics in the larger communities and within hospitals. Integration, seen as sharing of information related to one patient, involves both technical and clinical issues and forms a complex domain, and I made this simple sketch to try to get an overview of the involved parties at ground level (fig 4).

The figure 5, is an example of notes made after visiting a large clinic (2009), with several sub-units, to get a grasp of the organisation of the clinic, followed by fieldnote after interview with the information manager.

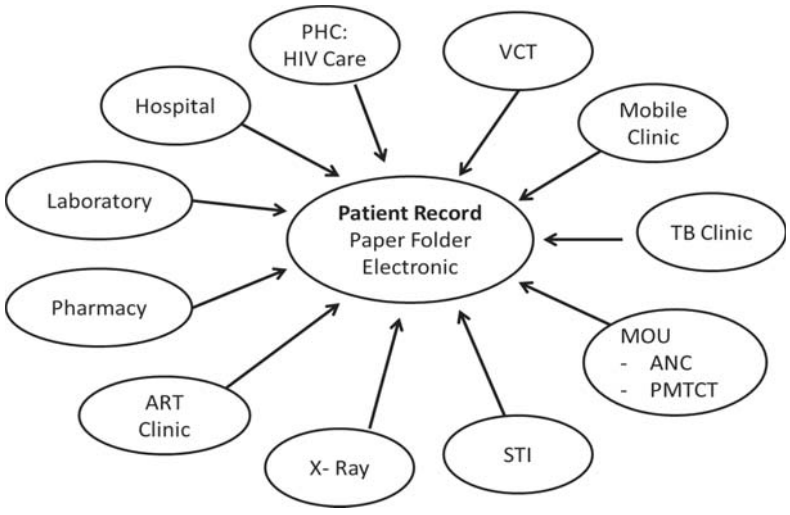


Figure 4: Preliminary analysis: services and providers involved in HIV/AIDS

[27] VCT: voluntary counseling and testing; HCT stands for HIV counseling and testing and is the new term launched in April 2010 (South Africa)

Administration	CoCT/ PGWC	PGWC (prev CoCT)	PGWC	CoCT	CoCT?	CoCT
Unit	ARV/TB clinic	MOU	Day hospital/ health centre	Pharmacy	X-ray	Clinic
Health services/ Programs	ARV – PGWC TB - CoCT	ANC, PMTCT (report to CoCT)	Children >5 Emergency Chronic			Children <5 VCT – run by Lifeline HIV test HIV care stage 1&2 STI
Electronic systems	eKapaII ETR.net?	Cradle	PHCIS in reception (only one patient record)	iDart?	??	PHCIS (and Clinicom)
Comments Reports/ registers (programs)	eKapaII to PGWC TB directly to CoCT, not via Information Manager (IM). eKapaII exports to ETR.net?	Reports go to CoCT from MOU (MOU claims it goes to IM)		Pharmacy does monthly RMR; Stocks of medicine goes to Metro DHS		EPI goes to IM STI goes to IM In combined clinics PREHMIS is not used

Legend	***CoCT***	City of Cape Town/ City Health	***VCT***	Voluntary counselling and testing
	PGWC	Provincial Government Western Cape	***STI***	Sexually Transmitted Infection
	MDHS	Metro District Health Services	***EPI***	Expanded Program on Immunization
	MOU	Maternity Obstetric Unit	***PMTCT***	Prevention Mother-to-Child Transmission of HIV

Note from interview Mr xxxx*: (written consent form)*
"He is the Information Manager in the clinic. He does all the stats on paper, and he reports only to the Metro District Services (Woodstock). Some confusion about the reports from STI and EPI - used to be City but now Province? MDHS reports to Provincial central Department of Health (where it goes into Sinjani?). Only the reception has a computer. He does the headcount calculation on PC, but submits on paper (see form) – deadline 7th of the month. IM knows little about eKapaII, iDart or other electronic systems. Claims that V. A. is the Clinic manager (she is Sub-District manager). MOU submits reports to CoCT (MOU register, PMTCT, ANC, HIV counselling and testing register. "

Figure 5: Note to self after clinic visit

Phase 3: Work practices in clinical care, coordination, sensemaking

The second visit in the field was done in November 2009, aiming at closing some gaps in the information from the first visit. In the cases where the informants were interviewed more than once, preliminary analysis and reflections from the previous visit were presented to the informants. The drawing of actors involved in health care services (figure 4, p.71) was for example presented to the interviewees, who then could comment or add to the total picture.

As the process of interviewing and analysis proceeded, my interest in the human aspect increased. I became curious about how people's expectations, while awaiting the electronic system to be implemented, influenced their evaluation of the system(s), once the systems were installed. In the interviews I asked about peoples' experiences, views, visions, and expectations related to the electronic system(s) that were, or were about to be, implemented.

The results and following reflections led to more search for theory, and I found sense-making theory (Weick, 2009) promising. The sensemaking perspective (Weick 1995) *"[..] focuses on how people in organizations construe the situations in which they find themselves […]"* (Bansler and Havn, 2004).

Following the ICT and design aspect, I sensed the expectations that prevailed in some facilities, related to getting the systems in place and awaiting huge improvements; what I judged to be rather unrealistic. And/or there were disappointments related to the electronic systems already been implemented, but not meeting the expectations. Thus, I was reflecting on the idea of using sensemaking perspective prospectively, i.e. how to take advantage of what I found to be a mismatch between expectations coming from higher levels visions and promises, and the reality in health work practices.

Still not fully dedicated to my role as an intermediary in this process, I did communicate some of the information I collected to the participants. This was indeed an interesting issue to discuss with the informants, but subsequently turned out to be difficult to apply for analysis and support for results and arguments. I realised that I needed to be more specific about this, both my own awareness in terms of how I wanted to use it, and also as to how to inform the people involved, and I did not follow up this trail.

Phase 4: Coordination – identifying key topics

Thus, in the third visit and interviews, I left sensemaking theory, and the GT philosophy was in the end what guided the analysis and my own sensemaking of the material. Results from the analysis led to new questions and interests, and also new theoretical focus. I realized that there were (at least) two key traces that were interesting: 1) the health work practice focus, i.e. to follow the patient trajectory related to information needs and coordination, and 2) the design aspect: the system(s), modules, and interfaces in what I saw as a hybrid system. The idea of seamless integration, combined with the many actors involved in a chronic patient, like the HIV/AIDS patient, seamed challenging. Focus on the HIS and how it was implemented in the field, had shown a less ICT integrated reality than the impression I had from literature, and two issues emerged: first, the role of manual systems and how ICT systems and paper based tools (the collection of artefacts) worked in coordinating patient information, later leading to the idea of, and attempt to, theorizing 'hybrid systems'. I decided to focus on what I found standing out in my investigation: the fact that capturing patient data, forming the longitudinal patient record, was comprised of a number of tools and technologies, paper and electronic in particular. This collection and process might be seen as an information infrastructure, or I wanted to consider the collection of artefacts comprising the patient record as *one* hybrid system.

Phase 5-6: Coordination - hybrid components

The analysis from the visits led to focusing on the combination of paper tools and electronic systems in the next two phases, with a particular interest in the interface between paper and electronic systems. How was the data transferred from paper to electronic systems? At what level were data transmitted? Who captured the data into the computer systems? How were data retrieved and who had access? How was clinical patient data available for clinical personnel? How, or was the electronic systems implemented useful for patient management in particular, but also facility and program management and surveillance?

At the last field visit, I followed the hybrid system idea and approach, focusing on the combination of the technologies. I asked users about their opinions on information needs and functionality in their day-to-day work practices. The use of ethnographic data collection methods, and the longitudinal study, made it possible to observe how the collection and use

of data employed both electronic and paper-based tools, such as the barcode stickers on paper tools.

I searched for models to sort and order the technologies, modules and interfaces involved, and found Ulrich's (1995) model of "Mapping functional elements to physical components" useful, where 'the functional elements' in this case would be work practices. Combined with Parnas (1972), "On the criteria to be used in decomposing system into modules"; listing paper and electronic components, and the interfaces between them, as described in Ch 2.5.1,

The hybrid components would increase complexity, but also flexibility and feasibility, enabling flexible configurations at different levels, and related to context (WHO table 8, p.56)
In Norway, after the last field study, I did analysis of field-notes in more depth, including transcription of recorded interviews. Some of the informants were followed up over a longer time period by email correspondence.

	Time period/Place	Focus - purpose	Methods
Pre-studies	[Accepted for PhD Jan 2008] Trivandrum, Kerala Feb/March 2008, 5 weeks	Pre-study of HIS in Kerala, apply for permission to do research (not granted – b/c of HIV/AIDS)	Following HISP workers, meeting with Health- and HIS Managers/ clinic visits in Kerala, and in Western Cape
	Cape Town, Western Cape. July 2008, 2 weeks	Pre-study of health services and HIS field in The Western Cape Province, Primary Health Care	
Phase I	Oct 2008 – May 2009; NSD accept Jan 2009; Ethical clearance UWC-March 2009; Permission WCDoH; Permission City Health June	Getting permission, and access to doing research	Register in NSD[28]; Ethical clearance application SA/WC; Proposal WCDoH; Proposal CityHealth.
Phase II	May-June 2009, 1 month Cape Town/Cape Winelands Districts	Obtain basic knowledge about the health service practices and patient record systems; Grounded Theory approach; Relate findings to aims/objectives	Setting the stage: getting appointments, interviews, observations, notes, analysis, pre-concepts
Phase III	November 2009, 1 month Cape Town/Cape Winelands	Filling in gaps from phase II; Sense-making theory approach	Interviews, feedback to interviewees; observation; analysis
Phase IV	April – May 2010, 1 month Cape Town /Cape Winelands	Follow up interviewees – focus on hybrid system/ coordination related to longitudinal patient records	Interviews/feedback, observation, document analysis
Phase V	November 2010, 1 month Cape Town/Cape Winelands	Follow up the hybrid systems approach – users' opinions on information needs and functionality	-- " --
Phase VI	2011 -2019	Analysis of data, looking for gaps in the data collection, follow-up Writing thesis	E-mail with some of the participants for clarification and asking for additional data (hermeneutic circle)

Table 12: Research process and field study

[28] Norwegian Social Science Data Services

Type of unit	Participants/ professions	informants	Interviews	Data sources other than interview
Health directorate, IT-management, Program management	IT director ARV program manager ARV doctor/researcher Business analyst	4	8	Observation meeting (City health) E-mail, user manuals, RMR tick-sheet, PREHMIS forms, barcode 'poster'
Sub-District Management	Sub-District/ARV clinic manager Information officer	2	6	E-mail, plans and forms, statistics, registers
PHC clinics (+TB)	Clinic manager, nurse (TB), nurse (HIV counselor)	3	4	Patient cards (clinic, TB), photos, TB register forms
CHC´s with Sub-Units. (MOU, pharmacy, reception, TB section)	Clinic managers, Information manager, Nurses , Data capturers, Pharmacists	18	27	Patient cards (Clinic, CHC, TB), paper forms, various reports: RMR, TB reg, ANC…
ARV- clinics (One HIV/TB combined)	Clinic managers ARV doctors Nurses Pharmacists Data capturers	11	21	ARV patient held cards, clinic forms, statistics, ARV report, printouts from eKapa and PHCIS ….
Total		38	66	

Table 13: Data collection - total

3.7. Role of the researcher - ethics

In interpretive research the role of the researcher is important in that the *"researcher's prior assumptions, beliefs, values and interest always intervene to shape their investigations"* (Orlikowski and Baroudi, 1991). A consequence of this view is that no value free data can be obtained, and the researcher also becomes a part of the research environment. It is therefore important to be conscious about the role of the researcher in collecting and analysing data (ibid).

To follow the chosen approach for data collection in my case would require a certain degree of involvement, and the need to build a relation of trust to the persons involved in the study. It was thus particularly important to be aware of my role and how this relation would affect my interpretations. Crang an Cook (2008), discuss the issue of researcher's involvement with the people included in the study, and how doing ethnography differ from a more detached scientific approach (ibid p. 7). They emphasize the need for the researchers to conceptualize themselves, as well as the people they study.

To meet this requirement, as an introduction in the interviews, I gave a short background of my position and professional background, and the purpose of the study. In my view, my sex, age and professional background may have had an impact, in terms of being a woman in her 60'ies, working for many years as a professional social worker. I assume this goes, both for me, concerned about people on the 'ground', and for the respondents, mostly female facility managers. With my background in social work, they anticipated that I had certain knowledge about working on the 'ground floor'. When doing fieldwork for my Masters (in Cape Town), this was commented on by the participants a couple of times: *"Oh, you are a social worker, then you might understand what we are up to here"*.

The fact that I was less concerned with identifying failures and obstacles in the information systems and organisation, but more looking at how the people involved in patient care coped

with the current information system(s), may also have affected the way questions were performed, and the responses.

In South Africa, with their history of Apartheid, research being conducted by white Europeans might also have an impact on the attitudes of the participants, but not necessarily. I met with white, coloured and black people, and I did not sense that the colour of skin made a difference. It is however difficult to imagine how you are seen by people from a difficult country and culture.

3.8 Generalizability, validity and reliability

How to generalize from a single case study related to interpretive research, has been questioned and disputed. A number of researchers claim that, the generalizability concept as applied in positivistic research, is not applicable in the interpretive tradition (Walsham, 1995; Silverman, 2001; Lee and Baskerville, 2003; Flyvbjerg, 2006), and they present different ways of generalizing from the collected data.

Walsham (1995), suggests four types of generalization from interpretive case studies: 1) the development of concepts, 2) the generation of theory, 3) the drawing of specific implications, and 4) the contribution of rich insight. In discussing "The Mann Gulch Disaster", Weick (1993), argue for possible generalization from one case, claiming that: *"if we can understand this collapse, we may be able to forestall similar disasters in other organizations."*

Lee and Baskerville (2003), have developed a framework of four types of generalizing as alternatives to the statistical perspective in positivistic research, with two 'building blocks', i.e. 1) making a distinction between empirical statements and theoretical statements, and 2) between what the researcher is generalizing *from,* and what he is generalizing *to.* The combination generalizing from empirical statements/from empirical statements (data) to description (EE), involves *'generalizing data to a measurement, observation, or other description',* which may equal the *'thick description'* as introduced by Geertz (1973), as well as '*the contribution of rich insights'* and *' the drawing of specific implications'* by Walsham (1995).

In the choice of case and selection of sample for a case study, Silverman (2001), introduces 'purposive sampling' as a means to 'illustrate some feature or process in which we are interested', much in line with Flyvbjerg (2006), who argues that, "*the strategic choice of case may greatly add to the generalizability of a case study"* (ibid, p.226*).*

As described in section 3.6, I started out with a 'purposive sampling' of sites and selected themes related to the field of interest; then let the findings from phase to phase guide the further process of data collection. I would argue that, through the focus on patient records in a particular setting, the sampling chosen, and the rich data material collected from the field presented, this case study presents a 'thick description'. The case contributes to rich insights that also might be applicable in other settings, as well as leading to the drawing of specific implications.

Validity and reliability relate to whether the findings from the case study represent 'the truth', i.e. how the case description conveys the contribution from the informants through interview etc., and how these case data have been analyzed.

As one source of improving the validity of data, Miles and Huberman (1994), suggest feeding findings back to key informants during data collection; a strategy that I have followed through the field study. Yin (1984), states that the reader of the case study should be able to follow the derivation of any evidence from initial research questions to the conclusions of the study. This chain of evidence will improve the reliability of the data. In this way, researchers can better contribute to the knowledge building process.

I would argue that, through the case description and analysis, and the methodology in this chapter, I have met these requirements. There will always be different possible interpretations of the data presented, and also what Miles and Huberman (1994), call biases based on 'researcher effects'. In section 3.1, I have discussed the question of the researcher's subjective interpretation in interpretive studies, and accounted for how my 'story' came about.

Chapter 4 The research context

In interpretive research, and with a hermeneutic perspective, it is important to understand the object of study in its context (historical, organizational, living conditions and health challenges). In this chapter, I present the wider context of the case and problem domain of my study. The chapter outlines the visions, goals and plans for health care, health programs, and health information systems developed by international actors, and national authorities in South Africa, and how they are expressed in strategic documents and guidelines, as a background to understand how they have influenced local levels implementation in practice.

In the first section, I will give a brief description of the historical, political and economic background of South Africa, and section 4.2 gives an account of the health profile, challenges, and policies related to health and health care, and the health care service organization. Section 5.3 elaborates on the fight against the HIV/AIDS pandemic in South Africa, and finally, sections 4.4 and 4.5 give an overview of the health information systems in the country, and the monitoring of ART.

4.1 South Africa – historical, political and economic context

Figure 6: Map of South Africa in the Sub-Saharan context

Like many other countries on the African continent, The Republic of South Africa has a history of colonization, ruled by both the British and the Dutch people. In 1902 the South African Union (SAU) was formed and in 1910 the Union became part of the British Commonwealth (BC). In 1961 the SAU left the BC and became The Republic of South Africa. From 1948 to 1994 the National Party ran a system of racial discrimination that came to be known as *apartheid*, an Afrikaans term for the state of being apart; a political system that was strongly criticized from the international communities.

After many years of internal and international resistance and fight against the apartheid regime, the first free and democratic elections were held in 1994. The African National Congress (ANC) won the elections and the new South African Government started to reconstruct their society in order to provide the people with equal rights and opportunities. A 'Reconstruction and Development Programme' (RDP) was developed with the assistance of a wide range of non-governmental organisations (NGO's) and research organizations with the aim to develop:

> *"[…] an integrated, coherent socio-economic policy framework. It seeks to mobilise all our people and our country's resources toward the final eradication of the results of apartheid and the building of a democratic, non-racial and non-sexist future. It represents a vision for the fundamental transformation of South Africa"* (National Department of Health, SA 1997).

The country had in 2011 a population of 51,7 million people, with a mix of races and groups. The Black African group count for 79,6 %, White 8,9 %, Coloured 9 % and Indian/Asian 2,5 %[29]. The white population was reduced to 8,9% from 11% in 1996 due to what is called the 'brain drain', i.e. educated white people leaving the country for better payment and working conditions to Great Britain, USA and Australia. This decrease in the white population is a problem that also affects health care where there is a shortage of doctors and nurses.

South Africa – country profile	2011	2013	2016
Population	51,77 mill[30]	52,77 mill	54,97 mill
Area (sq. km)	1,22 mill		1,22 mill
Life expectancy at birth (years) (m/f)	52,8	56/62	
Infant mortality rate (per 1,000 children)[31]	46,70		
Under 5 mortality rate (per 1,000 children)	57	45	
Human development index rank in the world	121	118	
Gross national income per capita (US$)	9,469	12,240	

Table 14: Country profile South Africa

4.1.1 South Africa – a developing country?

In the Introduction chapter 1.4 (b), I have discussed the developing country concept, and the various metrics for classification related to income and human development, where South

[29] Statistics South Africa, Census 2011

[30] Statistics South Africa, Census 2011

[31] Estimates Developed by the UN Inter-agency Group for Child Mortality Estimation (UNICEF, WHO, World Bank, UN DESA, UNPD)

Africa has a relatively high score compared to other Sub-Saharan countries. Lynge Nielsen (2011, p.3), claims however that:

> *"When it comes to classifying countries according to their level of development, there is no criterion (either grounded in theory or based on an objective benchmark) that is generally accepted",* and according to the United Nations Statistics Division, "*There is no established convention for the designation of 'developed' and 'developing' countries or areas in the United Nations system"*[32].

South Africa may in many respects not be considered a 'typical developing country', with the second largest economy in Africa behind Nigeria, and the country classified as an Upper Middle-income[33] country in the World Bank system. Infrastructure in South Africa is relatively well developed, Internet access as well, if not in all parts of the country, and not always well functioning. Doctors and nurses are well educated, which has in fact led to the mentioned 'brain drain' to other countries. Computer literacy may vary from high competence to little or no skills, what might also be the case in so-called developed countries.

Within the 'Upper Middle-income country' sub-category, and within the country's boundaries, there are however huge variations as to the level of development and living conditions. There are still extreme gaps in income, education and living conditions between the white and black population, despite the visionary goals and efforts from the new Government.

What is different from western countries, and what is shared with other countries under the 'developing country' umbrella, is the high burden of the disease in the case of the HIV/AIDS pandemic, also combined with the high incidence of TB, and the challenges that follow in terms of meeting the increasing needs for medical treatment (ART and MDR TB[34]), care and life-long follow-up of people with a chronic disease. This also implies major requirements for management of services and program monitoring.

4.2 Health policy, health profile, and health care system

South Africa has since the end of the apartheid regime in 1994, gone through a major restructuring of the health sector. A part of the RDP[35] in South Africa was transformation of the health system, from quality health care for the few, to a decentralized health system based on primary health care. In 1994, "A National Health Plan for South Africa" was prepared by ANC with the support of WHO and UNICEF, and in 1997 the Department of Health released a "White Paper for the Transformation of the Health System in South Africa" with the following aims for restructuring the health sector:

a) To unify the fragmented health services at all levels into a comprehensive and integrated National Health System (NHS);
b) To reduce disparities and inequities in health service delivery and increase access to improved and integrated services, based on primary health care principles;
c) To give priority to maternal, child and women's health (MCWH);

[32] http://unstats.un.org/unsd/methods/m49/m49regin.htm
[33] http://data.worldbank.org/about/country-classifications
[34] Antiretroviral therapy and Multidrug-resistant tuberculosis
[35] Reconstruction and Development Program

d) To mobilize all partners, including the private sector, NGOs and communities in support of an integrated NHS. (NDoH 1997).

As recommended by the World Health Organization, South Africa builds their public health services on a district model, with the overall objective:

> *"To improve the health status of South Africans through the prevention of illnesses and the promotion of healthy lifestyles and to consistently improve the health care delivery system by focusing on access, equity, efficiency, quality and sustainability" (NDoH, 2013).*

The country is divided into 9 Provinces, and the Provincial Departments of Health provide the health care services in cooperation with the Private Sector (Mars and Seebregts, 2008). Primary health care (PHC) clinics are supposed to provide a "PHC core package of health services", which is *"An integrated package of essential primary health care services available to the entire population*" (NDoH, 2000). In presenting norms and standards for the PHC package, the National Department of Health declares that:

> *"The national task is to define **what** services are required to best meet the health needs of the nation. It is for provinces and local government to decide, in the light of local circumstances, **how** these services are to be provided. Because of these different roles this national document is about **what** services at **what** standard are required" (ibid, bold in original).*

PHC clinics in South Africa are primarily nurse-driven, with doctors visiting occasionally, while community health centres (CHC) require doctors on site, as they are referral centres (Daviaud and Chopra, 2008).

A major challenge today is the shortage of health personnel in the public health sector, including doctors, nurses and pharmacists. In a study on human resources requirements for PHC in six of the poorest districts across four of the nine provinces in South Africa, Daviaud and Chopra (2008) found that there is a huge shortage of staff, especially doctors, and especially in rural areas, exacerbated by inequitable deployment between districts and between sub-districts. Policy responses by the authorities have not been sufficient to close the gap between the required numbers of doctors and nurses, and the available human resources.

In a discussion document commissioned by the Henry J. Kaiser Family Foundation, related to progress and challenges in efforts to improve the health of South Africans since 1994, a summary of 'Accomplishments' and 'Shortcomings' is given. Main accomplishments are for example

- 'free PHC'
- 'the essential drugs programme'
- 'clinic expansion and improvement', and
- 'improved immunisation programme'.

Among the shortcomings are:

- 'Insufficient prevention and control of epidemics',
- 'including 'limited efforts to curtail HIV/AIDS'.

The document sees insufficient health professionals in public sector as a result of

'Skewed allocation of recourses between public and private sector', and among 'Weaknesses in health systems management', points to 'insufficient delegation of authority' and 'operational inefficiencies'. It is also emphasized that *"Accomplishments of the past decade are largely overshadowed by the burden of AIDS on mortality and the health system"* (Harrison, 2009, p.2).

According to recent strategy documents from the National Department of Health (NDoH 2013, p.11), the country faces a 'quadruple burden of diseases' made out of:

- HIV and TB prevalence;
- Maternal mortality ratio, (infant and child mortality rate that are higher than the global average);
- High prevalence of non-communicable diseases (such as cardiovascular disease and metabolic disorders like asthma and diabetes);
- Unacceptable high rate of violence and injuries prevalence.

The biggest health challenge in South Africa today is the HIV/AIDS pandemic. About 6,3 million people were estimated to be living with HIV in South Africa in 2013, with 19,1% of the adult population (15-49 years) affected. There are geographic variations with some provinces more severely affected than others. The Province of Kwazulu-Natal had a prevalence of 40%, while in the Province of Western Cape the overall HIV prevalence was the lowest in the country, at 15.7%, although, two of the metropolitan areas registered prevalence rates of 33% and 29% respectively, reflected by background socio-economic conditions (NDoH 2007).

The main health challenges related to the HIV/AIDS epidemic are:

- The large number of people living with HIV;
- The rapid development: in terms of increased spread of the virus and number of people infected, and increased number of people eligible for ART due to change in the health policy as to when to start on ART, and medical regimes;
- Need for knowledge, clinics, medicines, and infrastructure in galloping speed;
- Global involvement in terms of visions, guidelines, support and need for control, which entails reporting requirements, both from the international health authorities, and the donor agencies.

The increase in TB incidence is another major challenge. According to the Global Tuberculosis Control Report from WHO[36] (2007), southern Africa is the only region in the world where TB incidence is still rising. About 1% of the population of about 52 million in South Africa develop active TB disease each year, which is worldwide the third highest incidence of any country after India and China, and the incidence has increased by 400% over the past 15 years[37]. This is much due to the HIV/AIDS epidemic, and it is estimated that two of three TB patients have HIV.

[36] www.who.int/tb/publications/global_report/en

[37] http://www.tbfacts.org/tb-statistics-south-africa.html

South Africa – health statistics	2013
Total expenditure on health per capita ($, 2012)	982
Total expenditure on health as % of GDP (2012)	8,8
Life expectancy at birth m/f (years)	52/62
Probability of dying under five (per 1000 live births)	45
Probability of dying between 15 and 60 years m/f (per 1000 population)	463/350
AIDS related deaths	200.000
HIV prevalence (aged 15-49)	19,9
TB incidence	1%
HIV/TB co-infections	66%

Table 15: Health statistics South Africa 2013[38]

4.3 Health information systems

The 'Reconstruction and Development Programme' of 1994 was aiming at a reconstruction of the health sector with a focus on a decentralized, district-based PHC. This also required a change in the existing vertical health information systems. The National Health Information System of South Africa (NHISSA) Committee was established in 1995 to coordinate the planning and development of the health information system across all provinces. A district health information software system (DHIS) was developed, to support decision-making in health management at all levels (Braa and Hedberg, 2002). The DHIS software is facility based and allows health services to capture routine anonymized data. The system was adopted as a national standard in 2001 and implemented at district and provincial level.

For health care services at PHC clinics, paper tools (tally sheets) are often used for counting patients visits, and type of service rendered. Routine monthly reports (RMR), based on the national standard data elements, are done paper based, and submitted to the Sub-District and further to District. At Provincial level the DHIS captures the aggregated data to be sent from the Provinces to National level.

Vertical health programs run in parallel (TB, HIV/AIDS, PMTCT[39], EPI[40]), and registers are kept at the clinics, with quarterly reporting to higher levels. Registers are also to a large extent done paper-based in the clinics. Some clinics may have offline electronic registers, but not having the infrastructure to submit electronically, and the reports will then be submitted either by fax, or other standard storage devices, such as a memory stick. A few larger clinics with sufficient resources and infrastructure will have online electronic systems. There are strategic plans for implementing a three-tier solution for monitoring ARV and TB (NDoH, 2012).

For patient management, information about the individual is needed, and individual patient records at clinic level are mainly done paper-based. A few larger clinics may have an

[38] who.int/countries/zaf/en/index.html and UNAIDS.org/en/regionscountries/countries/southafrica
[39] Preventive Mother to Child Transmission
[40] Expanded Program on Immunization

electronic patient record (EPR) system implemented, and depending on resources and capacity, capturing either just the patient's demographic data, type of visit, and next appointment, or in advanced cases, also some clinical data, but the EPR will not cover all the details included in the paper record (folder).

The Provincial Departments of Health are responsible for individual health information systems and telemedicine in their provinces. Provinces are however free to choose their own health information systems and solutions, as long as they report on the agreed upon data elements/indicators in a format that can be exported to the DHIS (Mars and Seebregts 2008). Overall, there is a wide range of health information systems in the country with little standardization. The 9 Provinces use five different major systems. Interoperability of systems, defined as:

> *"[…] the sharing of usable data based on the needs at the various levels, for the purpose of making decisions and various other purposes in terms of service delivery",*

has been identified as a major issue to be addressed by the NHIS/SA (StatsSA, 2009). Section 4.3.1 will present plans and achievements of the eHealth strategy in the country.

4.3.1 eHealth in South Africa

At the fifty-eighth session of the World Health Assembly (WHA) in May 2005, Resolution WHA 58.28 on eHealth was adopted. The resolution urges member states:

> *"To develop the infrastructure for ICTs for health as deemed appropriate to promote equitable, affordable, and universal access to their benefits, and to continue to work with information telecommunication agencies and other partners to strive to reduce costs to make eHealth successful"* (NDoH-SA, 2012, p. 11).

Although WHO has noted the potential impact that ICT can have on health care delivery, and urges the member states to consider drawing up long-term strategic plans for developing and implementing eHealth services (WHO, 2005), they recognize that the local level of health care in many developing countries does not have the resources and infrastructure required for implementing electronic solutions. For information handling they recommend to eventually combining paper and computer systems, and in any case to have solid paper-based backup systems (WHO, 2006).

The delivery of eHealth services in public sector facilities in South Africa is the responsibility of the Provincial Departments of Health, while the responsibility for eHealth policy and strategy development resides with the National Department of Health (NDoH, 2012, p.10). Stakeholders within eHealth and IS development, and Health Departments both at National and Provincial levels in South Africa have visions and urge for the development and implementation of electronic systems and EPR's to improve health systems performance.

A strategic framework for the implementation of an electronic health record system (eHR.za 2008) has been developed, and the national eHealth policy aims to:

> *"[…]strengthen the development of a comprehensive and integrated health information system; facilitate the development of health information standards; implement security measures to safeguard the privacy of patient information*

inherent in EPR; ensure that all health care facilities have access to adequate ICT infrastructure; […]" (Mars and Seebregts, 2008, p. 24).

The NDoH has implemented a number of electronic health information systems, such as the District Health Information System (DHIS), and the National Electronic TB register, ETR.net. The ETR.net software is being used in all 9 Provinces at various levels. The South African national goal for PHC is to digitize and integrate the existing PHC information systems, and in line with the recommendation from WHO, the National Department of Health (NDoH) has formulated an eHealth strategy for South Africa. The document "eHealth Strategy South Africa", was in 2012, launched by the NDoH, providing "*[…] the roadmap for achieving a well-functioning national health information system with the patient located at the centre"* (NDoH, 2012, p.5).

The framework defines an EHR as "a longitudinal collection of personal health information of a single individual, entered or accepted by health care providers, and stored electronically".

4.4 Fighting HIV/AIDS in South Africa

The first deaths from AIDS in South Africa occurred in 1985 under the apartheid regime, but the early efforts to meet the disease were minimal[41]. Also, after 1994, the new governments have a history of denial and reluctance related to the pandemic and to initiating more ambitious HIV/AIDS programs (Schneider and Stein, 2001; Parkhurst and Lush, 2004).

The South African National AIDS Council (SANAC) was established in 2000 as a national body to oversee and advise government on HIV and AIDS in South Africa. SANAC is a voluntary association of institutions established by the national cabinet of the South African Government to build consensus across government, civil society and all other stakeholders to drive an enhanced country response to the scourges of HIV, TB and STIs[42]. However, during the years 1999-2008, the Health Minister of South Africa recommended treating AIDS with vegetables as an alternative to antiretroviral medicines, and the number of HIV infected people and HIV related deaths escalated. December 1998, the grassroots movement Treatment Action Campaign (TAC) was launched and began pushing the government for access to treatment.

In 2001, the United Nations General Assembly (UNGASS) held a special session on the HIV/AIDS pandemic, and issued the "Declaration of Commitment on HIV/AIDS." The Joint United Nations Programme on HIV and AIDS (UNAIDS), is the main advocate for coordinating global action on the epidemic. In April 2004, the "Three Ones"[43] agreement on HIV/AIDS was launched by UNAIDS, and the agreement was adopted by developing countries, donors, and UN agencies, promoting universal coordination in the fight against AIDS. The agreement states three key principles as guiding principles in coordinating the nations' responses to HIV/AIDS. The principles are:

[41] www.sahistory.org.za/
[42] http://sanac.org.za
[43] Joint United Nations Programme on HIV/AIDS (UNAIDS). "Three Ones" key principles: coordination of National Responses to HIV/AIDS: guiding principles for national authorities and their partners. Geneva, UNAIDS, 2004

- One agreed HIV/AIDS action framework that provides the basis for coordinating the work of all partners;
- One national AIDS coordinating authority, with a broad-based multi-sector mandate;
- One agreed country-level monitoring and evaluation system.

Three Ones Principles	South African National Implication
One HIV/AIDS action framework that provides the basis for coordinating the work of all partners	Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa (NDoH 2003); The HIV & AIDS and STI Strategic Plan for South Africa (NSP 2007-2011); National Strategic Plan on HIV, STI's and TB 2012-2016
One National AIDS Coordinating Authority with a broad base multi-sector mandate	The South African National AIDS Council (SANAC - established 2000)
One country-level monitoring and evaluation system	Monitoring and Evaluation Framework for the Comprehensive HIV and AIDS Care, Management and Treatment Plan for South Africa (2004)

Figure 7: South African implications of "The Three Ones" agreement

In accordance with "The Three Ones" principles, the South African Cabinet in November 2003 approved the 'Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa' (NDoH, 2003), to strengthen the management of HIV, AIDS and STI's in the country. The South African cabinet approved a plan for universal ARV treatment. However, two years later, the number of people actually receiving ARV treatment remained far below the objectives outlined in the plan[44]. The Operational Plan included the development of a Monitoring and Evaluation (M&E) framework for the program. In 2007, a new 5-year National Strategic Plan was launched, which called for a multi-sectorial response to the pandemic. In the South African "Global AIDS Response Progress Report 2012", the country's political commitment to fighting the disease is emphasized, and major achievements mentioned are:

- Reduced levels of Mother to Child Transmission (MTCT)
- Increase in the number of people tested for HIV
- Increased coverage of ART
- Enhanced political leadership around Roll-out of the Male Medical Circumcision programme
- Strengthening of provider-initiated counselling and testing.

There are however still key challenges mentioned, such as:

- Prevention efforts to lower new infection through combination treatment
- MTCT has not (yet) been reduced to zero
- Multi-sectoral coordination remains a challenge, and
- Lack of effective implementation in some rural areas.

South Africa, being ranked three in the world in terms of countries worst affected by TB, with a high incidence of TB/HIV co-infection, led to the National HIV/STI and TB programs being coordinated in order to fight the dual epidemics in the society. Building on these

[44] http://www.sahistory.org.za/topic/history-official-government-hivaids-policy-south-africa

previous documents, the HIV & AIDS and STI Strategic Plan for South Africa 2007-2011 was developed to:

"(a) Prevent the spread of HIV, STI and TB infections, and (b) to mitigate the impact of the dual HIV and AIDS and TB epidemics on society […]."

This was followed up by a new National Strategic Plan on HIV, STI's **and** TB for 2012-2016 (NDoH, 2011), guided and coordinated by SANAC. The Plan provides goals and strategies for the response to the diseases, with ambitious and comprehensive long-term visions, such as,

"[…] zero HIV and TB infections", and *"zero preventable deaths associated with HIV and TB",* with the following goals of *"reducing new HIV infections by at least 50% using combination prevention approaches",* and *"reducing the number of new TB infections and deaths from TB by 50%". (NSP 2012-2106, p.12).*

One important initiative in fighting the disease is urging people to take the HIV test and know your status as early as possible. On World AIDS day, December 1st 2009, the President announced that, the following directives to address the HIV epidemic in South Africa would be launched on the 1st April 2010:

1. A massive campaign to mobilize all South Africans to get tested for HIV and to ensure that every South African knows their HIV status.
2. Increased access to treatment for children under one year of age that test positive for HIV. This will contribute significantly towards the quality of life for infected children and reduction of infant mortality.

3. Patients presenting with both TB and HIV infection will be initiated on ART if their CD4 count is 350 or less shifting from the old guidelines of initiating treatment when CD4 count is less than 200. TB and HIV will be treated under one roof. 1% of the population has TB and co-infection with TB and HIV is 73%. The policy change will support programmes to reduce deaths arising from undetected TB infection among those living with HIV.

4. All pregnant HIV positive women with a CD4 count of 350 or with symptoms regardless of CD4 count will have access to treatment; a shift from eligibility for treatment when CD4 count is less than 200.

5. All other HIV positive, pregnant women with higher CD4 counts will be put on treatment at fourteen weeks of pregnancy to prevent mother to child transmission of HIV.

6. All the health institutions in the country should be able to provide HIV counselling, testing and treatment.

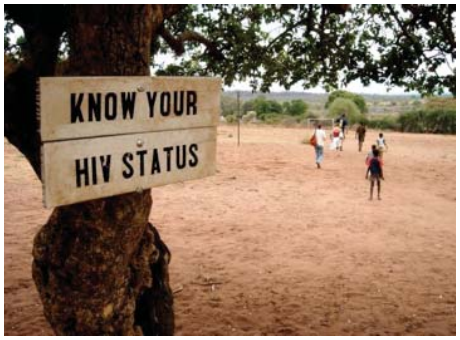


Figure 8: "Know your HIV status" Photo: J.Rawlinson (www.avert.com)

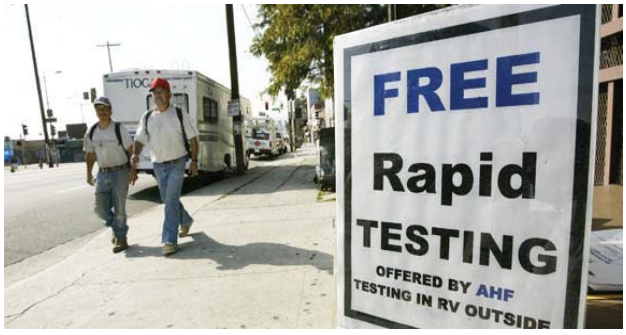


Figure 9: FREE rapid testing (http://act.mtv.com)

In March 2010, the Minister of Health in South Africa, Dr Aaron Motsoaledi, held a speech on the occasion of announcing a national HIV Counselling and Testing (HCT[45]) campaign[46], where he referred to the President's announcement in December, and confirmed the prevention and HIV testing promotion strategy, and the new treatment protocols.

To meet the needs within HIV/AIDS care and treatment, national requirement for establishing ARV clinics were developed, and until 2010 there was an evaluation process for a facility to be accredited as an ARV clinic. The HIV/AIDS pandemic required medical competency from doctors, and from the start the newly established ARV clinics were doctor-driven and nurse assisted.

The fact that the status of the disease has changed from being a deathly disease, to becoming a chronic and treatable disease, also had implications for the organization of the health care services in the country. The decision to consider HIV a chronic disease implied that care and treatment should be taken care of within the PHC system/clinics, and not in special ARV clinics, which had been the case until the new regulations. The National Department of Health launched in March 2013 new 'Guidelines for ARV Treatment', to be implemented from 1st April 2013. Standard national eligibility criteria for starting lifelong ART regimens were extended from a CD4 count of <200 cells/mm^3 (or with severe HIV disease irrespective of CD4), in the 2010 ARV treatment guidelines, to < 350 cells/mm^3 (or with severe HIV disease, WHO clinical stages 3 or 4, irrespective of CD4) in the new guidelines 2013. This change again put great pressure on the PHC clinics to meet the need for HIV testing and follow-up of HIV+ people; lacking the human resources to actually follow up people after the first HIV test (Clinical staging of HIV/AIDS, WHO 2005).

The "Global AIDS Response Progress Report 2012" pointed also to the challenge of realizing the ambitious goals, and mentioned reviews that have pointed to the fact that: *"simply having policies in place does not constitute an effective programme – implementation is the key issue"* (SA Global AIDS Progress Report 2012, p. 38).

As a consequence of the general shortage of doctors, also in HIV/AIDS treatment, and as the knowledge regarding this particular treatment has increased among the health personnel, the strategy is now to strengthen the skills among nurses, so that the HIV/AIDS care and treatment can be nurse-driven and doctor assisted, as opposed to previous requirements.

> *"Faced with a chronic shortage of doctors, South Africa moved to nurse-initiated antiretroviral treatment (NiMart) in April 2010. Now, government plans to roll out nurse-initiated MDR-TB treatment, and to make it and NiMart available at all primary healthcare, antenatal, TB and mobile outreach clinics by 2016, according to the National Strategic Plan on HIV, STIs [sexually transmitted infections] and TB."*[47]

4.5 Monitoring ART

The 2001 Declaration of Commitment adopted by the General Assembly Special Session on HIV/AIDS (UNGASS), included a call to monitor national responses to the HIV epidemic. Focus was in the beginning on aggregated data for control and management, and Country

[45] previously known as Voluntary Counselling and Testing (VCT)

[46] http://www.info.gov.za/speeches/2010/10032611051001.htm

[47] http://www.irinnews.org/report/95681/south-africa-first-nurses-trained-to-initiate-mdr-tb-treatment

Progress Reports were submitted to UNAIDS every second year since 2004 (Alfven et al, 2014).

The last decade, the importance of follow-up of a patient in HIV/AIDS care and treatment has been strongly emphasized. In 2006, WHO published "Patient monitoring guidelines for HIV care and antiretroviral therapy (ART), "*[...] to aid in the development of an effective national HIV care and antiretroviral therapy (ART) patient monitoring system"* (WHO 2006, p.8).

Patient monitoring serves both clinical management of patients and generates data used for program monitoring and management. The preferred means of monitoring progress for chronic diseases is through cohort monitoring, and according to the *"Patient monitoring guidelines for HIV care and antiretroviral therapy (ART)*" (WHO, 2006), one objective was to introducing the practice of a simplified cohort analysis for HIV patients on ART (WHO, 2006, p. 8). 'Cohort' defined:

> *"Cohort monitoring involves registering all the patients diagnosed with a certain condition within a particular catchment area over a period of time and reporting regularly on standard clinical outcomes" (Maher 2012).*

Standard clinical outcomes in a rapid cohort model may be:

a) Duration on ART
b) Total adults starting ART
c) Deaths since starting ART
d) Lost to follow-up since start
e) Transfer out since start, and
f) Remaining in care = (total – losses to follow-up – deaths – transfers out)

(Boulle et al, 2008)

Essential minimum standard HIV care and ART patient monitoring data – four categories (WHO 2006, p.9):

I. Demographic information
II. HIV care and family status
III. ART summary
IV. Patient encounter information

4.5.1 TIER.net

The document "eHealth Strategy South Africa 2012-2016", shows a "Five-year Macro plan for the Health Sector", with visions and problems related to eHealth in the country, also presenting a strategy and guidelines for developing and implementing ART monitoring:

"The national Tiered Strategy for ART Monitoring:

> *In December 2010, the National Health Council (NHC) technical task team approved the Tiered ART Monitoring Strategy comprising of a paper-based register (the ART register), non-networked electronic register (TIER.net), and a networked disease specific EMR system (SMARTER39) for HIV/ART patient monitoring in line with the WHO's 3-Tiered ART M&E strategy. The strategy provides the tools to standardize ART monitoring nationally with a system that best suits the various needs of facilities, sub-districts, districts and provinces and the resources available to manage the systems.*

All three tiers of the 3-Tiered ART Monitoring System are mutually exclusive and generate the same core set of data reported into the DHIS as the centralized aggregated database for all health information. As guidelines, the paper-based register is suited for facilities with no electricity or no computer and with less than 500 patients. The electronic register (TIER.net) is suited for facilities with regular electricity, a computer, no network infrastructure and with 500-2,000 patients. The EMR (SMARTER) is suited for facilities with network infrastructure and over 2,000 patients. TIER.net and SMARTER offer increased functionality where ICT infrastructure and capacity exist to manage the system." (NDoH-SA 2012, p. 20)".

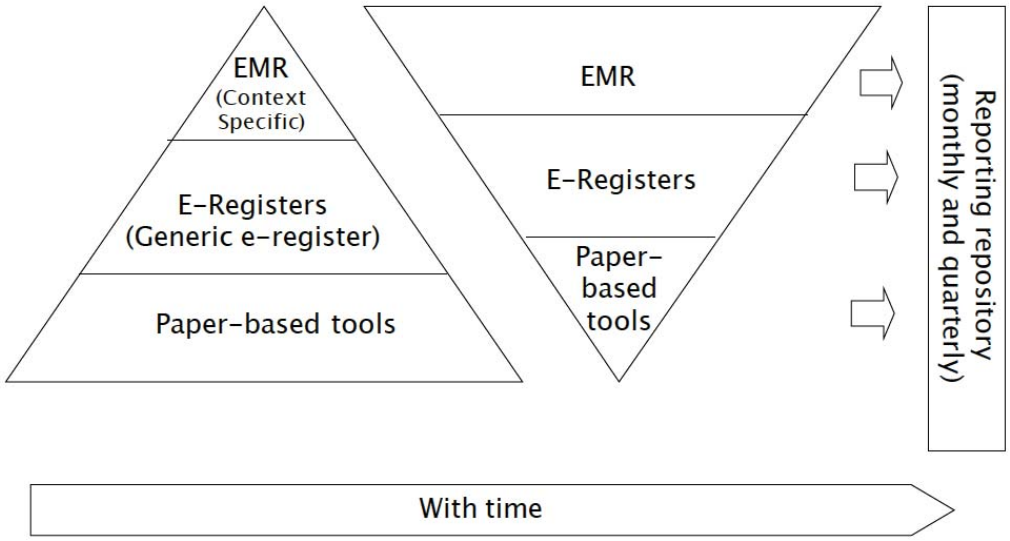


Figure 10: Plan for implementation process of the 3-Tiered ART monitoring system (Osler & Boulle, 2014)

The next chapter will give a more detailed presentation of the case, the locations, services and health work practices, and also the vision and plan for Tier.NET in the context of The Province of the Western Cape.

Chapter 5 The Case

In the previous chapter, I have described the wider context for my research site. The global and national visions, the goals and plans related to health care provision and health monitoring in fighting the major health challenges, that have provided the preconditions for implementing these at the provincial and district levels. This chapter will first give a more detailed description of the setting for my case (sec 5.1): the demographic situation, health profile, organization of health services in the Province of the Western Cape, and the health information systems in the Province with an emphasis on the HIV/AIDS pandemic. Sec 5.2 presents the sites selected for the fieldwork study.

5.1 The Province of the Western Cape

Figure 11: Location of Western Cape Province in South Africa

The Western Cape Province is situated at the south-western tip of the African continent and extends over 129,386 km^2. Cape Town is the largest city and capital of the Province. Of the approximately 6,6 million people[48] (2018 estimate), living in the province, 66% live in the Cape Town metropolitan area. The townships in Cape Town were created as living areas for non-whites under the apartheid system, and they are still home to a large percentage of Cape Town's population. The Western Cape human development index (2017) is the highest in South Africa (0,764) compared to the South African average (0,699), and to the neighbouring Province of the Eastern Cape (0,649), being one of the lowest in the country. Western Cape has had a net positive migration of 192.401 people between 2011 to 2016, being one of the most industrialized provinces in the country. Only the Province of Gauteng had higher migration; in both cases the reason is people moving in search for job opportunities[49]. Although the Province has high scores on life conditions, there are huge inequalities when it comes to income and unemployment, housing and health status. Some of the townships in the Metropole have the highest prevalence of HIV/AIDS and TB in the country, and the highest unemployment rate.

5.1.1 Health policy and health profile

The Department of Health, Western Cape (WCDoH) is responsible for providing health services to the people in the Province in cooperation with the Private sector. The aim is to deliver a comprehensive package of health services, which includes preventive, promotive, emergency and curative services, rehabilitation, and chronic care (WCDoH AnnualReport, 2009-2010). The vision for health care in the Province as expressed in policy documents is: *"Equal access to quality health care" (*WCDoH, 2009*),* and *"Quality health for all"* with the mission:

> "*To provide equitable access to quality health services in partnership with the relevant stakeholders within a balanced and well managed health system*" (WCDoH, 2012).

[48] https://www.statssa.gov.za

The Department of Health declared in 2003 the policy document "Healthcare 2010" as the long-term strategic plan and framework for health care in the Province, building on the national and restructuring plans from 1994 (Health Western Cape 2003). The document describes the areas of HIV/AIDS, TB and trauma, together with 'lifestyle diseases' (such as cardiovascular disease and diabetes mellitus) to form the major burden of diseases in the Province.

There was an emphasis on the need for restructuration of the services to reduce inequities, and to be able to provide basic access to quality services for the whole population, with two main objectives:

> *1) The need substantially to improve the quality of care of the health service, and*
>
> *2) The need to bring expenditure to within affordable and sustainable limits* (Healthcare 2010, p.13).

Inter-related plans for 'Service Delivery', 'Infrastructure', 'Human Resource', and 'Financial Implementation' were developed, and targets set for the plans. Implementation of the plan is described to be *"an incremental, step-wise process"*, and the implementation "*is dependent on the enthusiastic support of all levels of management" (ibid p.39).*

The Department builds their policies on global and national goals. 'Annual Performance Plans' (APP) and 'Annual Reports' (AR) are developed for each financial year. The APP 2009-2010, states that:

> *"The policies, priorities and strategic goals of the Department are guided by the Millennium Development Goals and the priorities of the National Department of Health at a national level, the Provincial Growth and Development Strategy at a provincial level and Healthcare 2010 on a departmental level"* (WCDoH 2009, p.21).

The 2006-2007 AR describes HIV and TB together to be the most significant cause of premature death, and to account for approximately 22% of the burden of disease in the Province (WCDoH, 2007[50]). The 2009-2010 APP describes the difficult situation for the Province in terms of need for health services and the shortage of resources, and according to the report, the key challenge is the implementation of the Comprehensive Service Plan (CSP) approved for implementation in 2007.

> *"The need for health services continues to outstrip the available resources for health care in the Western Cape and will do so in the foreseeable future" (APP2009-2010, p. 4).*

In 2011, the document "Healthcare 2020" was launched, starting with some reflections on what worked, and 'lessons learned' in previous plans (WCDoH, 2011, p.3).

> *"Despite the fact that the provincial health outcomes are good, they are still significantly behind what is required by the MDG targets. Achieving these targets has now become one of the key drivers of the strategy for 2020"* (ibid, p.9).

The document also emphasizes the constant lack of resources to meet the goals and targets:

[50] http://www.westerncape.gov.za/dept/health/documents/annual_reports/2006

"There will always be a tension between limited resources and health needs with the latter being almost without limits. This requires that the department constantly stretch and optimize the value of the health rand[51]. It is important to ensure that the priorities are identified and that scarce resources are allocated to the most cost-effective interventions. Productivity and operational efficiency must be addressed" (Healthcare 2020, p. 10).

In 2009 the HIV prevalence in the Province was 16,9%, although one sub-district in Cape Town had since 2004, had an HIV prevalence estimate consistently higher than the national prevalence of 29,4% (Healthcare 2020, p. 47; APP 2011-12, p. 17).

> "*The failure to observe a decline in prevalence in high HIV burden in the Province may be partly due to the declining mortality as a result of access to antiretroviral therapy (ART)" (ibid).*

In order to achieve the intended national outcome for health there will be a focus on the following areas:

1) Increase life expectancy
2) Decrease maternal and child mortality
3) Combat HIV and AIDS and decreasing the burden of disease from tuberculosis
4) Strengthen health system effectiveness.

Western Cape Province	2006	2009/2010	2011/2012	2016/2017	S. Africa 2012
Life expectancy at birth m/f	63/68	61,9/65		64,2/69	50,4/54,1
Infant mortality	26	22		7	48
Under 5 mortality		25[52]	23,8	22,1	
HIV prevalence	15,1	16,9/18,5			12,2[53]
TB incidence (per 100,000)	1,038	909			690
People on ARV treatment		54,703	115,087	230,931[54]	2 mill

Table 16: Health statistics Western Cape Province

5.1.2 Health care services - The Province of the Western Cape and City of Cape Town

The management of Provincial health service delivery are divided into five rural district municipalities, administered by the Provincial Government (Cape Winelands, Eden, Overberg, West Coast and Central Karoo), and one urban district, (The City of Cape Town). The health services in the City of Cape Town are provided by two health administrations: The City of Cape Town Health Directorate (City Health) and the Provincial Department of Health (WCDoH). The City Health districts are further divided into Sub-Districts, while the Provincial Government in the Metropole has combined two and two Sub-Districts into a Sub-Structure management (figure 12). The restructuring of the Metro District was based on factors such as population density, maximum distance to facility and more, with the overall goal to secure equitable access for all to health care facilities (CSP 2007, p.15).

[51] SA currency

[52] WCDoH Annual Performance Plan 2009/10

[53] South African National HIV Survey, 2012

[54] WCGHealth Annual Report 2016/2017

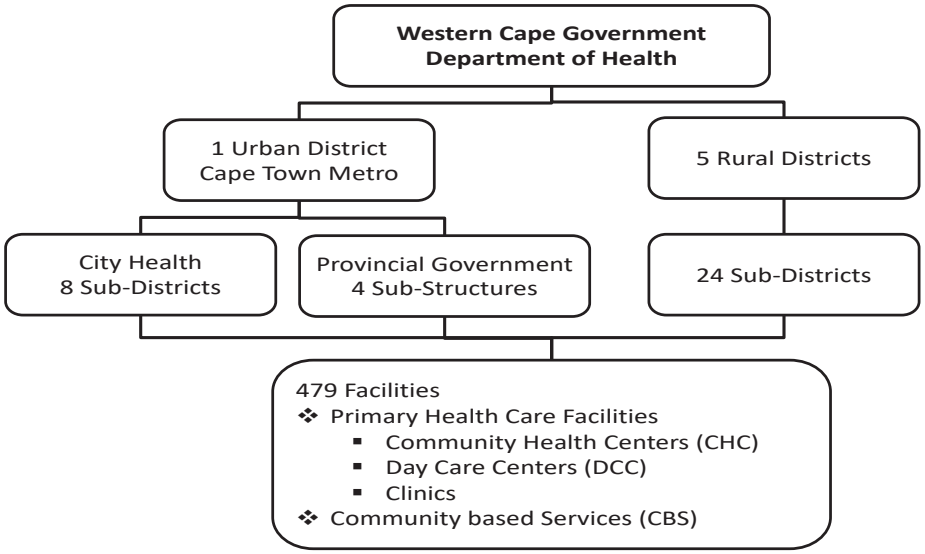


Figure 12: Western Cape Government Department of Health - management structure

The joint vision for the City Health and WCDoH is *"Together we can deliver better health care for Cape Town"* (CoCT 2007, p 93), and City Health's vision for HIV/AIDS and TB is:

> "(..) *to work together with the provincial health department to mainstream a multi-sectorial response that mobilises all City sectors in a developmental intervention to fight HIV/AIDS and TB, thereby reducing the number of new infections (especially among the youth). We also aim to reduce the impact of HIV/AIDS on individuals, families and communities and specifically on the Council workforce and reach an 85% cure rate for new smear positive TB cases over the next 5 years".*

The strategy for health service delivery is to focus on primary health care (PHC) services, community-based care (CBS) and preventive care, supported by secondary and specialized tertiary services. All sub-districts in the Province are supposed to offer a full package of PHC services. The package of care to be provided at primary health care facilities will be in line with the national policy (APP 2009/10, p. 225). HIV testing and counselling are included in the package and rendered in all PHC units. Every clinic has a referral path to a Community Health Centre, which in turn has a referral path to a district hospital. Primary healthcare services were mainly delivered at the community health centres (CHC's), clinics and mobile units (Foster, 2006), and the CHC's and clinics were primarily nurse-driven, supported by medical officers and pharmacists (WCDoH, 2010).

Until 2003, the Provincial Authorities were responsible for curative care in the Province, while the City Health, and the Local Authorities in the rural regions were responsible for preventive care, provided in PHC clinics. Since 2005 the Provincial authorities have taken full responsibility for personal primary health care (PPHC) in the rural districts, with a stepwise plan for transforming the structures. The plan for the transfer process was to be implemented in three phases. The Department provided the funding for the PPHC services from April 2006. This was followed by full managerial responsibility, from March 2006, and

thereafter, the transfer of staff and assets used by local government to deliver PPHC services by July 2007 (APP 2009/10, p.14).

Where the transfer and integration of patients and patient folders was carried out, it put a heavy burden on the PHC clinics. One clinic in my study had before the re-organization a catchments area of 5,000, increasing to 26,000 after the change, a challenge that was acknowledged by the Department in the APP 2009/10:

> *"A challenge is that the physical infrastructure transferred from local government requires significant upgrading to meet the required standard and that no additional funding has been allocated for the maintenance and upgrading of these facilities" (ibid, p.14).* The APP 2009/10 comments also that, *"The personal primary health care facilities currently operated by the City of Cape Town in the Metro will continue to be operated by the City pending the resolution of the funding and transfer of the services to the Provincial Government"* (ibid, p.299).

The implementation of the Comprehensive Service Plan (CSP) continued to be a key challenge for the Health Department, and despite efforts to merge the services, the APP 2013/14 still mentions that *"[…] the fragmentation of delivery of PHC services in the Cape Town Metro District between local and provincial government*" remains a challenge (WCDoH 2013).

5.1.3 HIV/AIDS care and treatment

The Provincial Department's fight against the HIV/AIDS epidemic is guided by the Millennium Development Goals (MDG), where the MDG # 6 is: "Combat HIV and AIDS, malaria and other diseases, and the target set, to: *"Have halted, by 2015, and begun to reverse the spread of HIV and AIDS, malaria and other diseases".* Among the indicators to measure progress are: "HIV prevalence among 15-24 years old pregnant women"; "number of children orphaned by HIV and AIDS", and "prevalence and death rates associated with TB" (APP 2009-10, p. 21).

Despite the reluctant national efforts in the early 2000's, an initiative to providing ARV was taken in the Cape Town township of Khayelitsha already in 2001 – a pilot project run jointly by the Provincial Government and the organization "Médecins Sans Frontières". Data on patients starting ART were captured into facility-based registers, and quarterly cohort reports were aggregated, using a paper-based monitoring system (Boulle et al, 2008).

> *"South Africa's first public sector project offering ART was established at community health centres in the Cape Town township of Khayelitsha, where clinics began treatment in May 2001. By June 2003, over 5000 patients had enrolled and over 600 children and adults had started treatment. The costs of drugs, viral load tests and the wages of half the clinical staff have been met by Médecins Sans Frontières; the remaining costs have been covered by the provincial government[55]".*

As described in chapter 4, the provision of ART was in the beginning of the pandemic provided by accredited ARV clinics. In the province, the patients were either seen in the ARV clinic, or, in the rural areas, the ARV clinics would provide remote services to the smaller villages or farms.

[55] www.who.int/3by5/treatmentworks/en (accessed 28.01.2008)

At the end of the 2006/07 financial year, 50 sites in the Province were providing anti-retroviral (ARV) treatment[56]; by the end of March 2009 there were 54,703 patients on ARV treatment at 66 accredited ARV sites, and 20,751 additional patients were started on antiretroviral therapy in 2008/09 (AnnReport 2008/9, p. 14). By 2009/10 the number of accredited ARV sites had increased to 81 sites (table 17). In addition to the organizational change, the change in the requirements for being eligible to receiving antiretroviral treatment allowed thousands of new people into the ART program. The antiretroviral treatment program continued to expand rapidly, from 54,703 patients in March 2009, to 115,087 patients on antiretroviral treatment in 2011/12, and as death due to HIV showed a decreasing trend, more people would remain in the ARV program.

Year	ARVclinics	Clients HIV tested	Patients on ART
2007/2008	50	266,682	26,111
2008/2009	66	353,959 + 96.411 in PMTCT program	54,703
2009/2010	81	397,707	75,000
2011/12	177		115,087
Dec 2012[57]		1 065,386	132,000
2017/18		1.373,615[58]	

Table 17: Number of clients, HIV tested and on ART - public health sector (WCDoH 2013).

The new national policies to integrate ARV treatment in PHC was included in the Provincial policies, but was only partly implemented in the provincial health services towards the end of my data collection period (end Nov 2010). The Provincial decision was to stepwise implementing the change in the rural regions, while the consequences in the Cape Town clinics were too extensive to be implemented without huge re-organizing of both buildings and care provision, and was put on hold. The 'chronic patients' section' in a large clinic might already have an overload of patients, not being able to receive hundreds or even thousands of new patients without more resources in terms of more space, personnel and infrastructure.

5.1.4 Health information systems (eHealth)

To meet the challenges in health care service delivery, the Provincial Government of Western Cape Health Department emphasized the importance of health information, and the Department has developed their own e-health strategy. In 2005, there were 77 different electronic systems in use for monitoring and reporting purposes (including hospitals, pharmacy, accounting and billing), of which 11 was said to be *"playing a major role in current processes"* (WCDoH 2005, p. 45). DHIS is the national Access based standard

[56] http://www.westerncape.gov.za/dept/health/documents/annual_reports/2006

[57] WCDoH Annual Performance Plan 2013/2014

[58] Western Cape Government Health, Ann Report 2017-2018

system, while The Province of the Western Cape has developed a web-based parallel, named Sinjani. DHIS and Sinjani are both systems that capture monthly aggregated data from health facilities, either from paper forms or electronically from facilities with Internet access. The Province exports aggregated data from Sinjani to the DHIS on national level. Reporting systems relevant for the clinics were DHIS, Sinjani, Electronic TB reg, and Electronic Epidemiology information system. As some of the ARV clinics also were co-located within a hospital, they would share some of the functionality with the hospital information system (HIS) Delta 9 or later the new Clinicom HIS, and in some sites, the pharmacy system J.A.C.

The following sections present the electronic information systems most relevant for PHC patient care, and the system for monitoring ART in the province. These include:

- Clinicom (Hospital IS)
- PHCIS (Primary Health Care Information System)
- PREHMIS (Patient Record and Health Management Information System)
- ETR.net (electronic TB register)
- J.A.C./iDart (pharmacy systems).

[Ref: Table 18, p.105: Electronic HIS in the Province of the Western Cape]

Clinicom Hospital Information system

The Clinicom Hospital Information System (Clinicom) is the central authority for the allocation of patient numbers, issued by the Provincial Patient Master Index (PPMI) via web services. PPMI is part of the Clinicom. The application is designed to provide a single electronic patient record across the Province.[59] It stores demographic patient information, was first piloted in the three large academic hospitals in the Western Cape, and will in turn be rolled out to the remaining hospitals. Clinicom replaces the 'Delta 9' hospital system, and builds on a different logic, which provided some problems in the transition period.

> *"With Delta 9 you could work backwards, and enter later if the system was too slow or they were too busy, or you could make a dummy. With 'Clinicom' you cannot do that" (interview Hospital Information Manager, 2010).*

PHCIS (Western Cape Department of Health)

The scaling up of ARV rollout motivated the development of a system to support and monitor clinic and patient management, and the Primary Health Care Information System (PHCIS) was developed. The PHCIS is a modular system being developed to interface to Clinicom and the PPMI, and is used at Community Health Centres and Clinics for the centralized registering of patients and record keeping (Foster 2007).

PHCIS allocates each patient with a unique ID number through PPMI via Clinicom, which can be used universally throughout health facilities[60]. The Clinicom Database is the only unit to generate the unique patient ID number, and should Clinicom be down and PHCIS is running, the PHCIS Database will generate temporary numbers for admission of new patients (PHCIS manual, p.12). The system reports on duplicated records and has the ability to merge duplicates (Foster, 2007). The modules making up the full PHCIS were:

[59] www.intersystems.co.za/sa
[60] www.capegateway.gov.za

- PHCIS Basic - the administration system
- [CRADLE - the Obstetric and Gynaecological records system, register antenatal visits and deliveries and births [later integrated in PHCIS Basic]
- PHASE - the interim appointment system implemented until such time as it is fully integrated
- eKapa - an HIV/AIDS and TB monitoring and evaluation information system, also developed to form the basis for any chronic disease information system (implemented in only a few clinics - ref. sec 5.1.5 for details).

All these sub-systems comprise the same basic modules, make use of reusable code, and can share a common database (PGWC 2008). A plan for stepwise implementing the PHCIS started with providing network infrastructure and hardware needed to implement the system, to selected CHC's in the Province[61]. The rollout of the PHCIS to CHCs began in April 2006, and by June 2009, PHCIS was implemented in 42 facilities. There were however inequities in the Province related to infrastructure and computerization in the health care services, and the plan for the full PHCIS was to be managed in various stages and to be implemented step-wise.

CRADLE

CRADLE was the Obstetric and Gynaecological records system that was the forerunner of PHCIS. Like the other PHCIS modules, the unique Clinicom patient ID number comes from Clinicom, and it registers antenatal visits, deliveries and births. Shortly after the end of my fieldwork, Cradle was integrated into the basic PHCIS (e-mail with informant).

***eKapa[62]* - Monitoring ART (and TB)**

Since 2000, the Provincial Government of Western Cape has fought against TB/HIV in Cape Town (ref pilot project in Khayelitsha). The Health Department of the Province, City of CT, and the University of Cape Town (UCT) in cooperation, developed a system for routine monitoring of the interventions in the HIV/AIDS program (eKapa module of PHCIS), which was implemented in some of the HIV/ART clinics (WCDoH 2004).

The system was introduced in 2004, and the guidelines were at that time intended for a system entirely paper-based, although some sites had computer systems that covered some aspects. The system considered three levels of information:

- Clinical record-keeping for individual patient monitoring (visit summary and patient-retained cards)
- Facility record-keeping for aggregate reporting and facility management (registers)
- Individualised cohort monitoring at a central level based on electronic medical records.

[61] https://www.westerncape.gov.za/news/primary-health-care-information-system-community-health-centres

[62] Evaluation of the Khayelitsha AIDS Program - eKapa

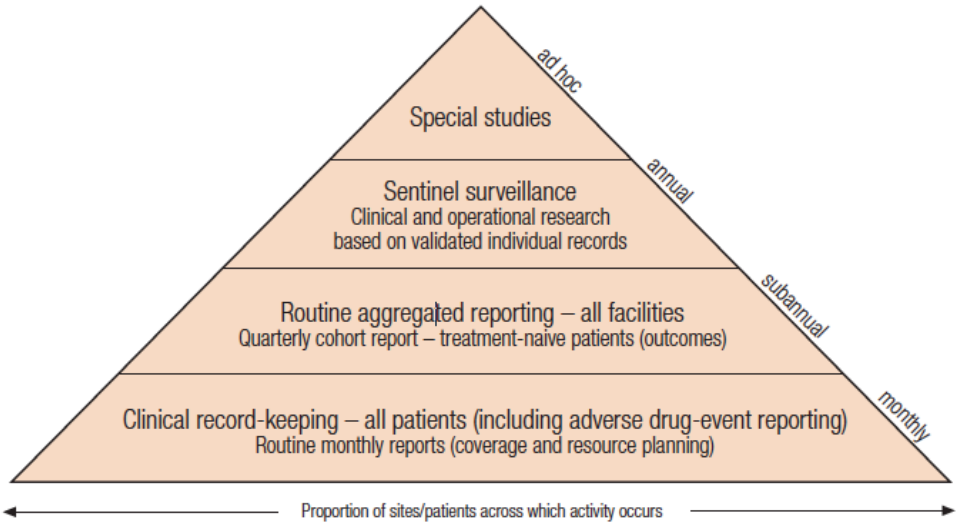


Figure 13: A tiered routine monitoring system for ART in Western Cape Province ART programme (Boulle et al, 2008)

The Health Department suggested a standard for a patient folder in the clinics, and outlined a system for keeping clinical information for individual patient management based on three components: 1) a folded A3 card containing demographic, baseline and occasional information, 2) visit summaries stapled into the folder, and 3) a patient-retained record (card) equivalent to the TB patient-retained card. The ART register captures date of starting on ART, patient name, age and gender, folder and ID numbers, viral load, CD4 count and WHO staging, starting regimen, monthly information, outcome (i.e. transferred out/lost to follow-up/date of death), and closing of the cohort. The monthly report captures the total numbers on ART (number of patients remaining on ART), and new patients starting ART for the first time at the facility. The quarterly report provides cohort information regarding clinical outcomes (WCDoH 2004).

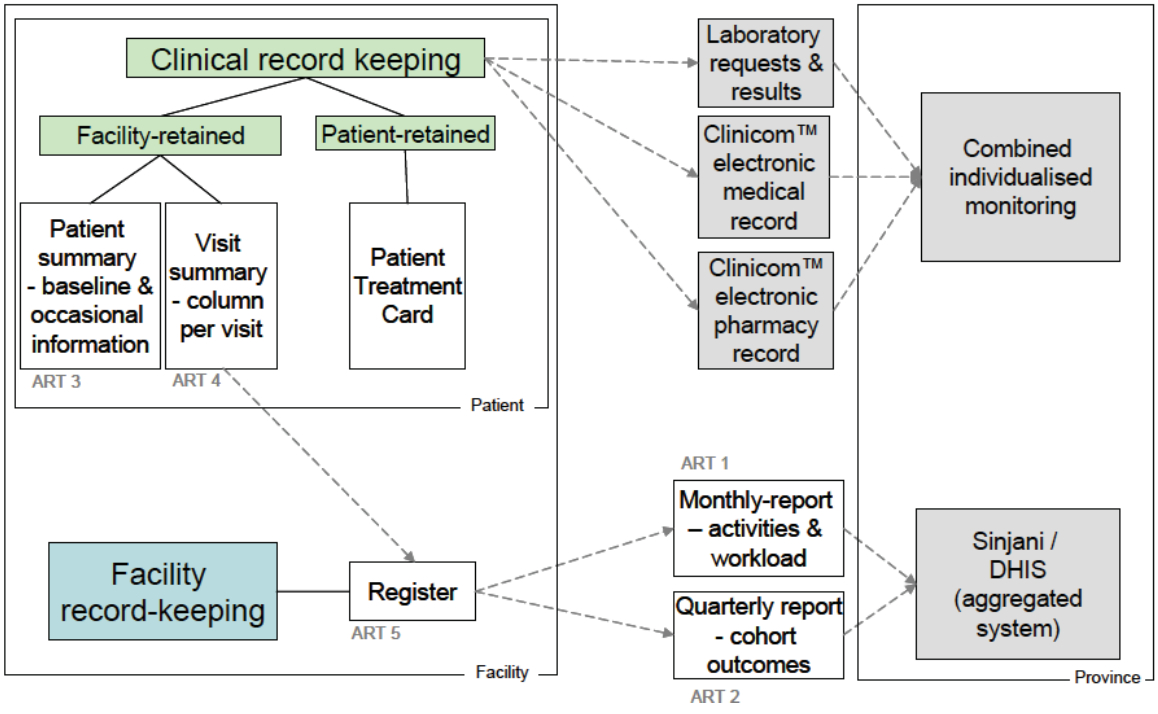


Figure 14: Routine monitoring ART (WCDoH 2004, p.1)

TIER.net in The Province of the Western Cape

The high burden of HIV/AIDS in particular, and the monitoring of large cohorts of patients in ART with paper-based systems only, motivated further the development of an electronic register based on a 3-tier approach strategy. The TIER.Net software (Three Interlinked Electronic Registers-TIER), chosen as a national strategy for ARV monitoring (ref Ch 4.5, p. 88), was developed and piloted in the Western Cape Province.

The system was formally known as the HIV Electronic Register or e-Register, and the TIER.net strategy was aiming at integrating three priority health programmes: HIV, TB and Maternal and Child health (MCH). It was however acknowledged that, the sites struggling with monitoring the increasing number of HIV/AIDS patients, did not have the resources and capacity to implement a full EPR system. TIER.net would thus include a paper-based system (tier 1), an electronic version of the paper register (tier 2), and full electronic medical record software, eKapa (tier 3) (Osler and Boulle, 2010). The system has been built to be able to export to and import from eKapa, and would capture minimum data elements and resulting indicators required to monitor the HIV and ART services. The 3-tiered approach would allow the departments to choose a tier based on context and resources at the time of implementation, and as more resources became available, the facilities would transition to the next tier. All three tiers are interoperable, and can produce the same reports. The tier strategy was considered a flexible solution as one health region could be running one or a combination of the tiers (Osler and Boulle, 2010).

eKapa TIER.Net operated offline, only requiring a computer and was developed to serve in the interim, until clinics are connected (UCT, Sept 2012). It is acknowledged, that:

> "*Transition from paper directly to EMR systems is often not immediately feasible, and implementing a bridging solution can be a pragmatic alternative"* and *"The choice of tier is based on context and resources at the time of implementation; (....)"* (Osler et al, 2014, p.2).

PREHMIS (City Health)

In the Metro district, City Health had developed their own electronic HIS, the Patient Record and Health Management Information System (PREHMIS), running on an Open Source Desktop. The system had been developed based on the earlier 'Patient Folder Application (PFA)', a standalone system that was installed on a local PC in the PHC clinics run by City Health. The previous PFA included the various health registers, and could compile reports to all the programs (TB, Immunization, VCT etc). PREHMIS was installed in all City Health clinics. The system captured patient details and visits, but no clinical data, which were entered manually into registers. Only data items for the routine monthly report (RMR) were captured. Negotiations were going on (2010) to get the full functionality of the PFA entered also in the PREHMIS. The system had the option to access the National Health Laboratory Service (NHLS) for lab results. Otherwise, when you accessed NHLS online, you could only see the results and print, but not export/import the data electronically.

The fact that City and Province shared the Clinicom patient ID made it possible for all clinics online to look up a patient, and the patient's visits at what clinic. Neither PREHMIS, nor PHCIS without the eKapa, entered clinical data, so sharing of clinical data was not an option. End 2010, City Health submitted monthly reports parallel to the DHIS at District level and

to Sinjani, but aimed at leaving DHIS soon and continuing with Sinjani (Information manager). The two administrations cooperated on a solution in the barcode-system to be able to coordinate and merge data elements for reporting.

Pharmacy systems – JAC and iDart

Keeping track of medicines was important, both related to drugs dispensed to a particular patient, and to monitor stock in the clinic/pharmacy.

In 2008 the PGWC signed a contract to rollout the ***JAC*** Medicines Management system across the Province. The system was in use in the three major academic hospitals in Cape Town and there was a plan to a sub-sequent rolling-out of the system to the main public sector hospitals and community health clinics[63]. JAC is linked to the Clinicom system.

iDART (Intelligent Dispensing of Antiretroviral Treatment) is a pharmacy dispensing tool (only), to help manage and monitor ARV stock control and patient therapy dispensing. The iDART is linked to eKapa to get patient PMI info and to feedback dispensing information and pill counts. It was an option within eKapa and was implemented in 4 Cape Town clinics.

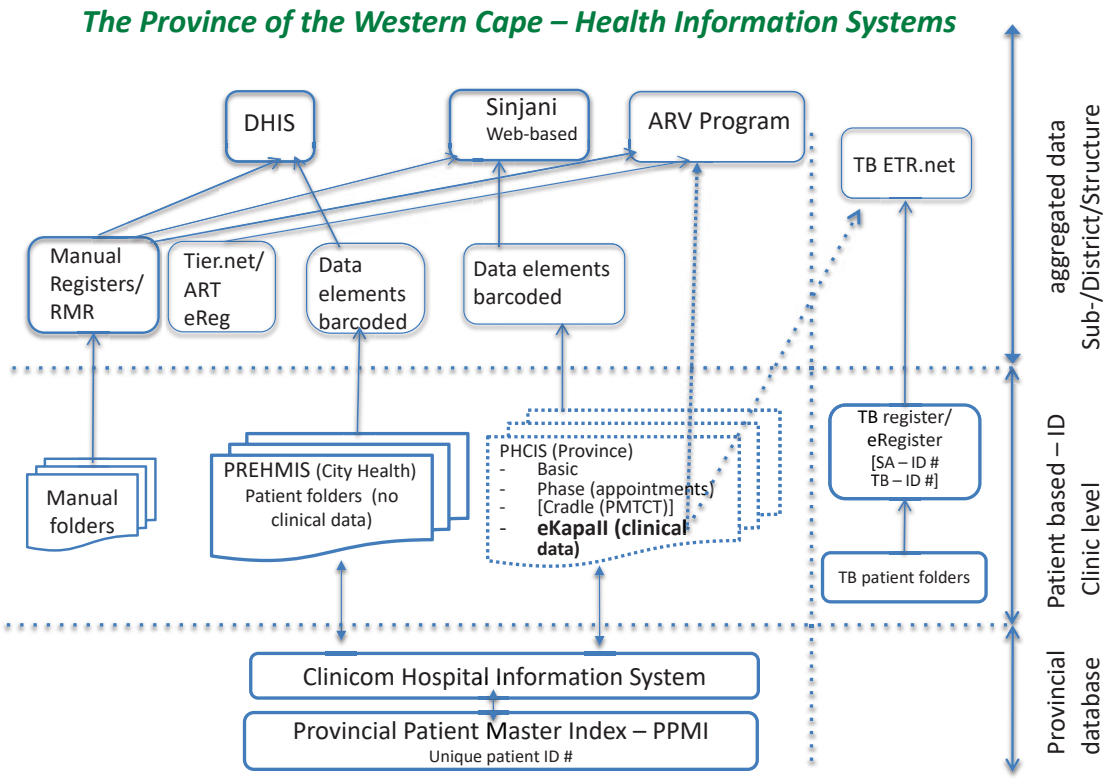


Figure 15: The Province of the Western Cape – Health Information Systems

5.1.5 Patient records

There are three possible technical solutions when creating a patient related health information system. I.e. a system based on:

[63] www.jac-pharmacy.co.uk

- Paper forms and folders only;
- Integrated electronic patient records; or
- Combining electronic patient records and paper tools, i.e. a hybrid information system.

The situation at most PHC clinics in the province (2010) was that patient folders and reporting to a large extent was done using a combination of paper tools and electronic systems support. Patient data were collected in the clinics using standard paper forms contained in a patient paper record (folder/envelope), and stored locally in the clinics.

There were still smaller clinics in remote areas, and mobile clinics, that were entirely paper-based in their data collection, but most clinics had at least one computer (in the reception). Doctors and nurses would make their notes on the paper forms, and data clerks would after a patient's visit enter encounter demographic data, date of visit, and eventually new appointment on the patient retained card, and/or into the electronic systems. The long-time goal in the Western Cape Province was to connect all facilities in the provincial digital network, thus being able to build up a patient master index of all people visiting a health facility in the Province, and to be able to integrate information about one patient across health services.

Electronic patient records in PHCIS and PREHMIS

PHCIS Basic caters for

- entry and maintenance of demographic information;
- a single patient record number retrieved from the Clinicom, if available, national ID, passport # or other ID # will be entered;
- print patient labels using barcodes;
- captures patient assessments;
- offers limited medical records tracking;
- caters for tracking of patients visits and outcomes (coded with ICD10's);
- supplies standard reports for management and administration;

The system did however not utilize all its functionality. E.g. the coding of ICD10 would need medical knowledge, that most data clerks did not have, and supervision or help from doctors would be needed.

When a new patient is registered, personal information will be entered in the electronic system, and a unique ID will be issued. Paper labels with barcodes are printed, and a patient retained card issued, with a barcode label on it. The remaining printed barcode labels are kept in the paper folder, and later used for prescriptions, referrals etc. Handheld scanners are used in the reception at repeated visits for identifying the patient in the system and for capturing new data.

As the implementation of PHCIS through the Province had to deal with different contexts and levels of infrastructure, there would be different ways of actually being able to use the electronic system, and to add or look up a patient with the ID number. Despite sound developed strategy and performance plans, the WCDoH acknowledges the fact that:

> *"[...] even in this relatively well-resourced Province [...], the infrastructure, connectivity, support and human resource challenges were such that it was not*

possible to transition all mature sites straight from the paper-based registers to the EMR system."

A Business Analyst presented the following 'list' of potential problems and alternatives involved in using the system:

"1) There is no power:
It is possible to have a printout of the facility list to use as a lookup for the folders, but not possible to add new patients and allocate a patient ID. Notes will have to be taken manually and entered later when power is restored.

2) There is power to computer but no network connectivity:
A PDF file of the patients may be used as a lookup for the folder number, and an offline headcount scanning has been implemented. This allows the clerks to scan the folder numbers to register that a patient attended on a specific day. There is also the RMR scanning available (offline), which will also scan the folder number, but in addition will scan a medical staff member, and a service rendered (as part of a list of RMR Elements for reporting). As soon as network connectivity is restored, the data in the queue is uploaded to the central server.

3) There is network connectivity, but for whatever reason there is no connection to the PPMI (Clinicom Web Services):

In this case the clerks can continue to select patients, update details, scan headcounts, enter appointments etc., but the adding of new patients is affected insofar as no Clinicom number can be allocated at that time. What happens is that the patient is added to the PHCIS database with a Temporary Number which allows the patient to be processed in the usual manner with lab specimens, dispensed drugs etc., but the record is at this time (possibly) not on the Clinicom server. At the next attendance of the patient, the temporary number is 'merged' with a permanent number allocated by Clinicom (assuming the network is now up) and the temporary number is maintained as historical info against the patient, and a new number is issued (Informant in e-mail, 2010). This did also lead to duplicates, which then needed to be identified and then merged. These scenarios did happen, and led to extra work and even need for hiring extra personnel sometimes, to cope with the backlog."

Figure 16: Duplicate and Temporary paper folders to later be merged in PHCIS

Osler et al (2014) also mentioned why the transition from paper to electronic systems was often not immediately feasible:

> *"Despite paper register systems coming under increasing strain, the evolution from paper directly to an EMR solution is not viable in many contexts. Most EMR systems require wide area networks, facility-level infrastructure including computers and local networks, and structured helpdesk support. Well-designed and context-appropriate systems might still fail due to their dependency on infrastructure and support."*

The authors further recommend, what they denote 'middle tier', or 'bridging solutions' pointing to the three-tier solution (ref TIER.net, p.100).

ART - eKapa

The eKapa software was initially built for HIV/TB, but has later (2012) been adapted for general PHC (UCT/CIDER 2012). The first eKapa software, the HIV/ARV/TB module in the overall PHCIS, was used in combination with paper registers as a two-tier system. Like all the modules, it is linked up with Clinicom, to get one unique ID number for the patients. Demographic data, like name, address, date of birth, i.e. identification data, contact details, date of visit, tests taken and this kind of statistical data are registered. The system is not integrated with HIV Counselling and Testing program, and the TB system. One clinic in the study combined HIV/ART and TB treatment, but although eKapa captured TB data, and the paper folder was shared between all stations in the health facility, these data were still captured in two different information systems, the eKapa and the manual TB register.

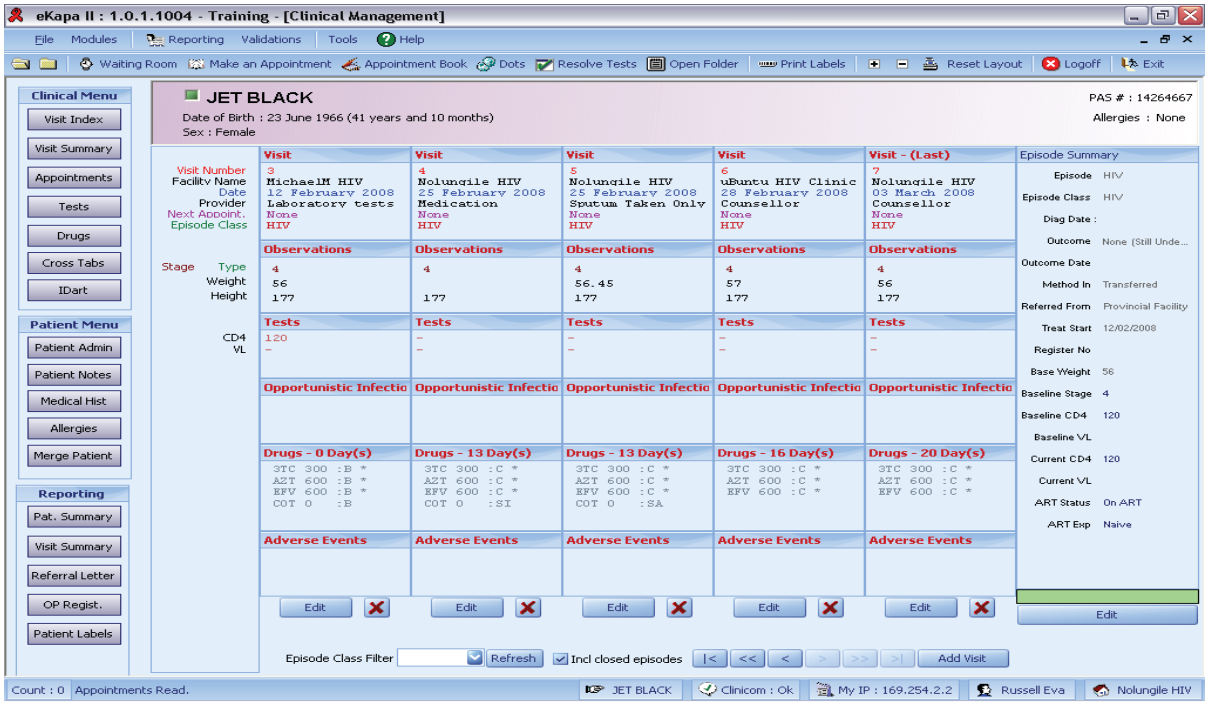


Figure 17: Screen from eKapa – test example

eKapa was implemented in 7 CHCs in Cape Town (as of 2009), and the plan was to roll out the system to all ARV clinics with more than 2000 HIV patients. Due to lack of resources, and bandwidth constraints, it would be a stepwise process to reach out to all relevant facilities. Clinics with patients over 700 and less than 2000 patients would make use of an electronic register, and clinics with less than 700 patients would make use of paper registers and the provincial stationary (Osler and Boulle, 2010). The system links to the iDART dispensing system (a pharmacy dispensing module of eKapa).

Like in PHCIS, also in **PREHMIS,** the patient's ID comes from Clinicom/PPMI, is bar-coded and labels are printed and used on the patient folder, the patient retained card, for blood and urine tests etc. The data elements from the national minimum dataset are also bar-coded, and the practitioners in the clinic have their own barcode assigned. In the patient's paper folder, an RMR tick sheet for PREHMIS is enclosed, to be filled in manually after visits. When the paper folder returns from the clinicians to the reception, the data clerk scans the patient, the practitioner and the visit's barcoded items with a hand scanner, and then enters into the electronic system(s).

Neither PREHMIS nor eKapa captured all the information contained in a paper folder. The clinical notes done by nurse and doctor, assessment done by home visits, written consent forms, x-ray results, and more, would not be registered electronically. Thus, to get a comprehensive picture of the patients' medical and social situation, both the patient paper folder and the EPR would be needed.

A complete patient record would comprise:

- A paper envelope with a folded patient record (with visit summary, and an extensive number of paper documents, such as: referrals, prescriptions, assessments, agreements and more);
- A patient retained card;
- An electronic patient record with a patient ID (tracking); demographic data; and in eKapa also some clinical information;
- Barcode-stickers printed to be used on paper documents –> linking to patient ID in EPR.

TB - TBReg and ETR.Net

HIV and tuberculosis (TB) are so closely connected that their relationship is often described as a co-epidemic[64] One reason for not combining the TB and ARV patient retained cards into one, was that TB is a curable disease, while HIV/AIDS was a chronic disease. The TB national standard comprised the TB patient held card, and patient folder – both blue coloured, to easily being recognized. They were kept separate under treatment, and later filed within the overall patient folder, for the nurse/doctor to see the person was a returning TB patient.

TBReg is a paper based, facility TB register that uses carbonized register sheets. It was rolled out in Western Cape in 2002 (Mars and Seebregts 2008). All clinics in my study used this system, while one PHC clinic also had the electronic TB system ETR.Net implemented in one computer (only). There was however no online connection between the clinic computer

[64] https://www.ifrc.org

and the TB coordinator at Sub-District level, so the TB coordinator would come and physically export the data onto an USB pen, and then later enter the data centrally at his office. The TB section in the clinic did still fill in the manual register; only they did not have to submit the register paper sheets to Sub-District.

ETR.Net is a national system designed to capture patient-based TB data only (including HIV surveillance among TB patients). The system is not integrated or share information with other patient-based systems in the District/Province such as for example the eKapa/PHCIS. As of 2010, the clinics submitted the paper register sheets to the Sub-District information manager, who entered the data into the ETR.Net, and then exported the data to the District Information Manager.

Electronic system	Functions
Clinicom Hospital information system [HIS]	Central authority for the Provincial Patient Master Index; allocates unique patient ID numbers
PHCIS basic	Patient records with demographic data, appointment module, folder tracking. Caters for clinical notes - ICD10 coding of diagnosis -but not in use. Prints labels with bar-coded information about the patient, ID etc.
Cradle (PHCIS module)	Obstetric and gynaecological record system used in MOUs. Registers antenatal visits, deliveries and births – now integrated in Basic
eKapa (HIV/TB module in PHCIS)	Captures demographic data, id-data, contact data, date of visit, clinical data… (also used for research)
eRegisters (ARV and TB)	Electronic version of the paper registers
iDart (intelligent Dispensing of antiretroviral treatment)	Dispensing information related to patients' medication; Monitors ARV stock
PREHMIS	Captures demographic data, but no clinical data. Data elements from the national minimum data set (NMDS) are barcoded, (figs 45-46) as also the clinicians and the patient. Compiles Routine Monthly Report (RMR)
ETR.net	National TB system. Captures patient-based TB data only (incl. HIV surveillance among TB patients)
National Health Laboratory System - NHLS	Most laboratories use the NHLS – clinics can receive results online, by phone or on paper
DHIS (District level)	City Health submits aggregated data according to NMDS[65]. Compiles reports to programs and Provincial Information Office
Sinjani (District Level – web-based)	Same function as DHIS – only interfaces with the PHCIS modules

Table 18: Electronic HIS in the Province of the Western Cape

[65] National Minimum Data Set

5.2 The case study locations

As described in the Methodology chapter, the clinics and units selected for the fieldwork have been chosen with the aim to cover multiple contexts and health care practices, in following a patient with HIV/AIDS from the first HIV test, to being accepted for treatment in the ARV program. The aim was to understand the need for information at these types of services, and the informational artefacts used for capturing, storing and sharing this information. As ARV and TB are closely related, and treatment coordinated, TB treatment would also to some extent need to be included in the account. In the following sections I will give a more detailed description of the services, information systems and artefacts in use at the different clinics included in the study.

5.2.1 The sites (Districts, Sub-Districts and clinics) – and services

In ordering the health services into hierarchical administrative levels, ranging from PHC at the lower level, to programme and district management and higher, the variety of PHC clinics may often be presented as *one* type or level of health care service providers. In a data collection and 'information flow sense', they have the same guidelines and requirements, but in their work practices, the clinics may in fact be very different in a number of ways. Factors that have an impact on service delivery and data collection may relate to population size in the catchments area, geography (urban or rural), infrastructure, and types of services provided, assigned to the clinic.

With different number of people in their catchments area, a clinic might serve from 5000 up to 400.000 people. The clinics were also situated in very different geographical and infrastructural environments; people living in the outskirts of big cities in densely populated townships, or in dispersed small villages close to farms in the urban areas. In the latter there was for example no public transport, or any transport available, like the minivan-buses in the more densely populated areas. You would thus need your own car to visit a clinic, which the majority of poor families did not have. There were also still areas with no Internet connection, and/or very unstable power supply, making computerization difficult, if not impossible.

In my case and field-data collection there were many different types of clinics receiving persons with HIV and/or AIDS for HIV testing or for care or treatment. The initial HIV tests were taken at all health service facilities (PHC, CHC, ARV and hospital). These facilities had very different information system configurations depending on the factors mention above. Some of the smaller clinics in a rural area were without Internet connection, and completely paper based when it comes to patient records etc., or they had a local, offline electronic system, to keep a database of patients visiting the clinic. A small PHC clinic in the rural district, worked at the beginning of my study mostly paper based, but in the course of my fieldwork, a basic version of PHCIS was implemented, and patients for ART were now being received in the clinic. A big ARV clinic in a township in Cape Town on the other hand, had from the start of the field study already the advanced HIV/AIDS patient based module of PHCIS (eKapa) implemented, but due to the complexity and the scope of the re-organization from ARV clinics to PHC in this geographic area, the ARV clinic and the current organization of the chronic health services remained.

Four of the totals of seven facilities included in the study were located in Cape Town, with three of these clinics sited in the townships of Cape Town. The clinics in the townships were all accredited ARV clinics, and were sub-units within a larger Community Health Centre (CHC). The ARV clinics in the study were very different in size (headcount) and structures. One clinic had for example 5000 patients in the ARV program, and they provided combined TB/HIV/AIDS services, while the other two had from 570 to 2900 patients on ARV treatment, and with separate TB sections. The fourth clinic in Cape Town was located in a different suburb, close to an industrial zone. The clinic was a so-called 'combined' clinic, meaning that the City Health clinic and the provincial CHC were co-located with shared reception and staff, but there were two clinic mangers. They provided different services, and submitted separate routine reports. The managers emphasized that they wanted the people coming into the clinic to experience the site as *one* clinic, and they tried to make the patient's path at a visit as smooth as possible. City Health had the administrative authority; thus, they used the PREHMIS system for electronic patient folders, but the RMR and other reports were done manually and submitted to their respective health administrations. There was also a pharmacy in the premises, which was used by both units.

The three clinics in the rural region were located in the Westcoast/Winelands District, and in two different sub-districts. One small PHC clinic did not provide ARV treatment, but did HIV testing, and they did TB treatment. The clinic had an HIV counsellor, and did the HIV test and the following CD4 testing (i.e. sent sample to laboratory). If the CD4 count was < 250 (limit at the time of the study), they referred the patient to the ARV clinic.

The ARV clinic in this city was located in the Hospital, but had a separate entrance to the clinic (figure 20). There was also a separate TB section and a pharmacy in the Hospital premises. There were two PHC clinics to serve the population in this town, while the smaller villages in the surroundings had small local clinics with limited personnel. The ARV clinic was the only ARV clinic in the area, and did also serve the surrounding villages. Because of long distances and difficulties for the people to go to the ARV clinic in town, the ARV doctor would do outreach to those clinics.

Even more distant were some of the farms, and mobile clinics, managed and staffed by the hospital, went out to the farms, with nurses, patient folders, and medication. In total 12 clinics were served, and 5 mobile clinics went out to the farms. There would be a visit once a month, seeing new patients, and bringing medication, prepared by the pharmacy, to patients already enrolled in the ARV program. The fact that the ARV doctor was visiting on a fixed day every month meant that it was difficult to keep confidentiality around the ART patients. The alternative was however that, patients would have to come into the City. With no public transport and no cars, this had previously led to that the ARV patients died.

These remote clinics did not have computers, thus the patients there would not be registered in Clinicom, even if they were seen by the ARV doctors. One ARV doctor said he wanted to register these patients at the ARV clinic, to be able to print barcode stickers to put on blood samples they sent to the lab and more. Data management did however not allow this, because it would give the wrong headcount for the "mother" clinic.

End 2010, when I did my last field visit, the ARV clinic was no longer active, as the new strategy to treat ARV within the PHC clinics was implemented in this city. The HIV/AIDS patients were distributed to the PHC clinics and the patients' folders (paper) transferred to the clinics respectively. The ARV doctors from the hospital provided training of the nurses, and they were also available for support when needed. This outreach system was supposed to take away the HIV/AIDS stigma, among other things. As HIV would be treated as any other chronic disease, the information would also stay in the PHC clinics.

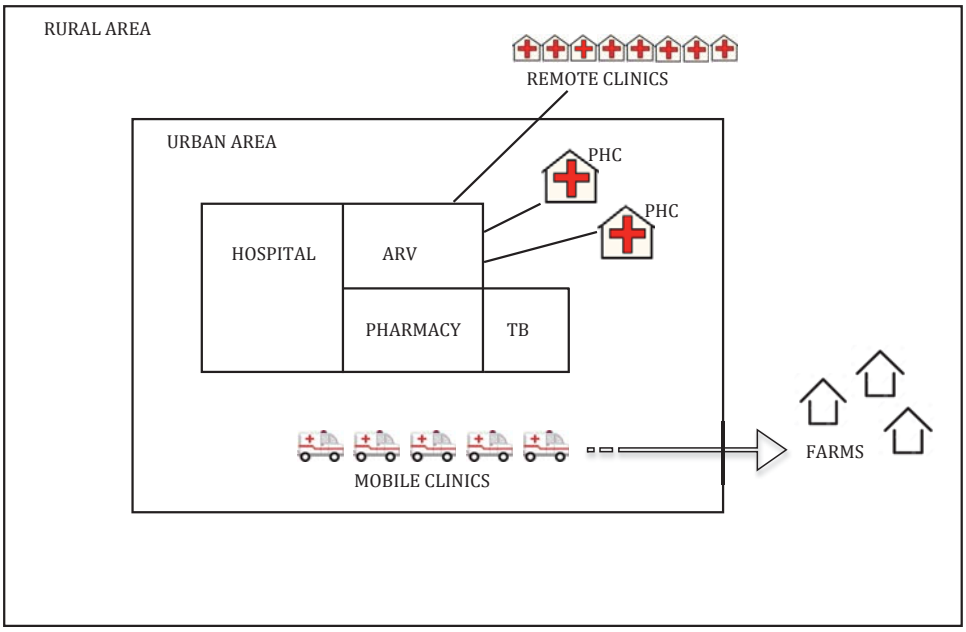


Figure 18: ARV clinic, serving PHC clinics in one city, and remote villages and farms

This would however add workload for the PHC nurses, so, according to the ARV doctor, there would be need for additional data clerk to do the day-to-day capturing. The clinics had counsellors for pre-counselling, but not adherence counselling, so one adherence counsellor would travel around to the outreach clinics. People living on the farms would go to the nearest clinic. An ARV doctor was now supposed to go to the clinics a day a week, or every second week.

The last clinic in the study was located in a neighbouring city. This was a relatively large CHC with a large catchments area. The clinic also had a TB section and a pharmacy. At my first visits here, ARV patients were received at the neighbouring hospital, but the clinic did TB, ANC[66] and VCT[67], and all patients were offered to take the HIV test. If the patient agreed to take the test, and the test was positive, a CD4 count would be taken. If the CD4 count was <250, he would be referred to the hospital. If the patient were on TB treatment, he would go to the hospital for ARV, and the clinic for TB. If in ANC, and CD4 count was >250, ARV would not be given, but the clinic would give vitamins, and what was required

[66] Antenatal care

[67] Voluntary counselling and testing

for the first 28 weeks of pregnancy. After birth, the babies would stay in the PMTCT[68] program.

The future plan was that the hospital should cover TB, ARV and PMTCT, to better coordinate treatment, and also make it easier for the patient. The hospital in this city would also serve the clinics in the surrounding area. As in most of the clinics, they wanted more resources to be able to give better services. Here, one doctor claimed that NGO's prioritized the big cities, and did not show interest in rural areas.

Figure 19: Small village with clinic served by the ARV clinic in Hospital

Figure 20: Entrance to ARV clinic and Pharmacy within the Hospital premises

[68] Preventive mother-to-child transmission

Chapter 6 Findings and analysis

In this chapter, the case data collected will be analyzed related to the research aim, with the focus on information needs, data collection and coordination of data, using the conceptual framework suggested. There are different administrative levels in PHC, all using first level patient data; personal and clinical information at lower level, or in aggregated format for higher levels managing their responsibilities; all with different information needs and challenges. The analysis will identify the tools for data collection and the information flow, with the focus on coordination. What are the coordinating artefacts, and how do they function to meet the information needs? The analysis has two main focus, i.e. 1) the health work practices, and their information needs, and 2) the health information systems, designed to meet these needs. **Section 6.1,** will have the health work practices, the patient trajectory, information needs and coordination, in focus**.** I will describe the information needs in HIV/AIDS care and treatment, the data collection process, and the coordination of it in more detail: how information is captured, stored and shared.

This section looks at coordination of information related to one patient across time and space, i.e. a) keeping a record of the patient *in* a clinic over time, b) sharing information *across* health service providers involved in the care and treatment of a person living with HIV/AIDS (including referrals, laboratory test results, TB tests, inpatient stay in hospitals, X-ray, prescriptions and pharmacy). Finally, I will also include c) reporting of aggregated patient data, as these data are motivating many of the data elements that are registered in the clinics. Although not directly involved in patient care and treatment, but planning for it, they are building on individual patient data. Clinic management, District management, and Programme monitoring will be treated as one 'level' in the analysis. These three administrative levels have different information needs and responsibilities, and challenges, but are closely connected in the data collection and data flow.

Sections 6.2 – 6.4, have an information system focus. Information system design and research is focused on technology, and mostly on electronic systems in particular. In this case study, 'technology' involves both paper and electronic tools, **the hybrid**. This hybrid health information system will be analysed with a focus on the collection of artefacts involved in the process, the modules involved in the composition of the system as a whole, and the interfaces, i.e. how they coordinate data, and thus meet the information needs. I have also looked at the redundancy of data registering, in terms of duplication and overlap.

To describe the artefacts and technologies in use, I will use the ordering concepts of 'collection of artefacts' and 'coordinative artefacts' from CSCW. In IS terminology these 'collections of artefacts', would correspond to the components in the (hybrid) information system, and the 'coordinative artefacts', may refer to standards and/or interface in IS terms.

The components and interfaces in a hybrid system are designed and configured using different logics at the different levels in the health care and health information hierarchy, depending on a number of determining factors. In **Sec 6.3,** the artefacts in the different contexts, and their affordances will be discussed; i.e. what are their properties, and how, or if they are suited to meet the information needs in the particular contexts.

Reducing redundancy in paper based HIS is one argument for introducing electronic systems. A core aspect when introducing the concept of 'hybrid information systems', is the possibility for increased redundancy across multiple component system. **Sec 6.4** discusses the affordances of a hybrid system related to the question whether information is captured more than necessary in the components involved, and the role that redundancy may play under certain conditions. Finally, sec 6.5 gives a brief summary.

6.1 Information needs in HIV/AIDS care and treatment

There might not be an 'objective truth' on what are the information needs at the different levels in HIV/AIDS care and treatment. Stakeholders (politicians, doctors, nurses, IT enthusiasts, and more) will present different needs according to work practices, preferences and visions. Chronic care will for example have other requirements than acute conditions, and for higher level management, the manager in a combined clinic explained that, they had to submit two different RMR's, because the City Health wanted more information about their health workers and their workload than the Western Cape Department of Health (WCDoH).

Although the different PHC clinics and ARV clinics provided different types of services, and thus had different information needs related to type of facility and the services they provided, there were a number of shared information needs. All clinics at PHC level in the Western Cape were supposed to provide a core package of services (Healthcare2010/ WCDoH 2007), including the HIV test. As mentioned previously, the HIV/AIDS treatment was initially provided in dedicated ARV clinics. The reason being that ARV was new to the health sector, and specific medical knowledge was required. ARV doctors did diagnosis and initiation of treatment, with nurses assisting. In one of the PHC clinics, that previously only did the HIV test, and then referred to the ARV clinic if the test was positive, the practice had changed during my study. This Sub-District had implemented the new requirement from the Health Department related to ARV treatment, and all clinics were now considered ART clinics, or "*every clinic now has an ARV site, […]"* (Clinic manager). As this structure of ARV treatment services changed during my study, the information needs and information systems in the sites changed consequently.

In the following sub-sections, the information needs related to one patient will be presented in terms of: 1) patient identification, 2) follow-up/medical adherence, 3) clinical information and history, and 4) information needs for clinic and program management.

In addition to different type of clinics, and contexts, there were also different professional groups, and their view on the key information needed in HIV/AIDS care and treatment differed, across the professions as well as within a professional group. A basic and shared information need was, however, the need for patient identification, which is a prerequisite for following a patient over time, for keeping a longitudinal patient record, and sharing information across stations in a clinic, or across health service providers.

6.1.1 Patient identification

Regardless type of facility, and level of technology, registration and identification starts in the **reception**. For the receptionist, identification of the person is the first and most important task. At the first visit in a clinic, the person will need to bring some kind of ID document to

prove his identity. This could be a national ID booklet, a referral letter from another facility, a pension card, a payment slip, or a passport. A proof of address and a phone number is also required (ref Poster, figure 21). The importance of identification was recognized, and had high priority in the Province. The building of the Provincial Patient Master Index database (PPMI) with unique patient ID, hosted by the Clinicom Hospital Information System (Clinicom), was an important step, enabling identification of a person in a facility, as well as across the health service providers.

Identification of a person was however not a straightforward task in the clinics. There might be obstacles in identification both in paper and electronic systems, due to reasons such as: people did not always bring the required documentation for identification, or they did not have one. Some people did not have an South African ID, e.g. NGO workers from overseas did not have a national ID, which the systems tried to overcome in different ways. Other problems pertaining to identification related for example to wrong date of birth given, or a confusion in names, i.e. people mixed family name and first name, or misspelled names, or a person would use several names, and state different names in different clinics. Infants were for example in Clinicom registered with their first name beginning with 'baby' or 'twin' followed by the mother's first name. In some clinics they mentioned that people often did not bring their cards, and could only be identified by name. If they did not find the folder, but were sure that the patient had been to the clinic before, they would issue a new card, with a pink A4 sheet on top, to show that they did not find the patient folder. The doctors then knew that they needed to be extra careful when examining the patient, because there might be information missing, important for treatment.

The electronic systems covered some of these variations in the search procedures, for example by the option to switch family name and first name. The user manual for search in the PHCIS was very detailed in suggesting different ways of searching, and some clinics also had staff looking for duplicates to prevent too many double records. There were three types of search in PHCIS:

1) alpha search (name),
2) number search (date of birth, patient ID #, national ID or other, for example a temporary number or a passport ID), and finally,
3) there was an option to search in 'recent lists', which allowed search in the last 10 searches, in case this patient's record was currently searched.

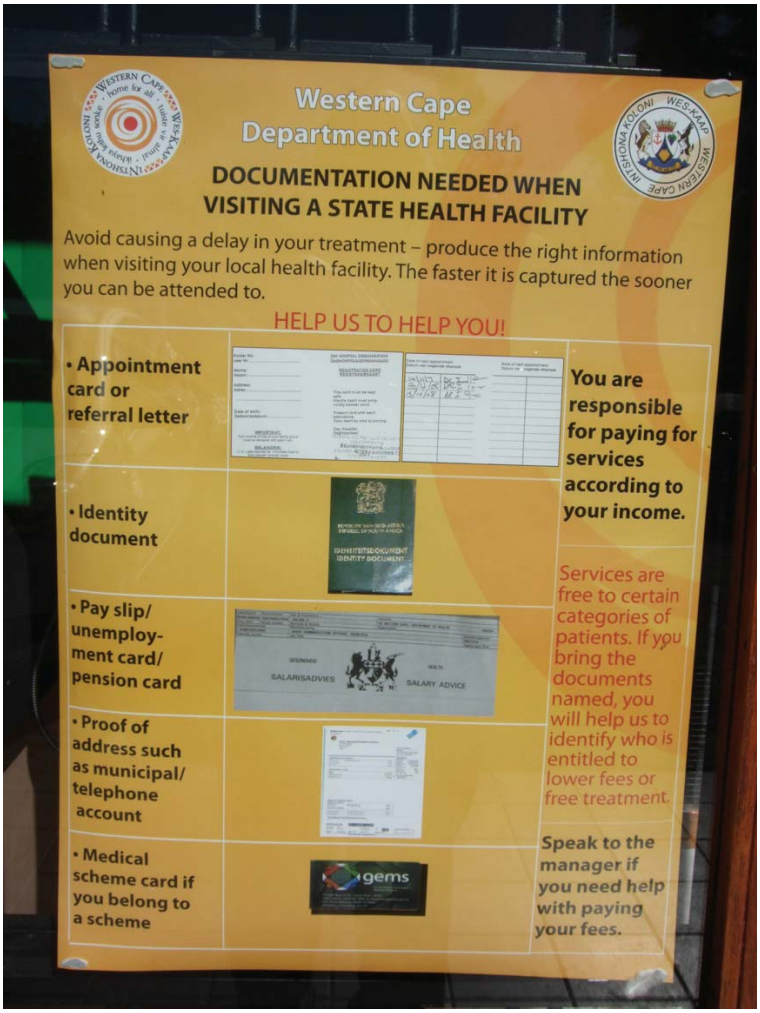


Figure 21: Western Cape Department of Health - documentation required

The eKapa UserGuide also added the following functionality:

> *"When working with eKapa, you will always search 2 databases: eKapa Database and Clinicom Database. There are very important reasons for this:*
>
> *a) The Clinicom database is very large with millions of patient's records already on the system. There is a good chance that your new patient's details are already entered here and may be selected for use in eKapa;*
>
> *b) Each time you search for a patient that often visits your clinic, it will save you a lot of time and frustration if the data is stored in the eKapa database;*
>
> *c) Information stored on the eKapa database may be updated on the Clinicom database. This ensures that a patient will have a single unique identifier across all facilities in the Western Cape"* (interview Business analyst, 2010).

If not identified in the databases, a new unique ID would be issued through Clinicom, and barcode labels printed. If available, national ID, passport # or other ID # will be entered additionally, for more secure identification. In Cape Town, where the health services were provided by the two health service structures: City of Cape Town (City Health) and The Western Cape Department of Health (WCDoH), City and Province shared the Clinicom patient ID, which made it possible for all clinics online to look up a patient, and also the previous visit at what clinic. The three first digits in the folder# will tell which clinic has issued the first folder, then in a fixed order the patient ID etc (business analyst, 2010).

> *"When a patient comes to a City clinic (City Health), the registration will be done in the reception. The patient ID comes from Clinicom, and the barcode and stickers is genius. Everybody loves that. The paper folder goes to the nurse/doctor and they will enter the type of visit on the RMR tick sheet for PREHMIS (figure 47, p.148). The practitioner will have his own code, which is entered into the field*" (City Health information manager).

As described in Ch 5.1.4 there are different electronic systems in play, and they had chosen different ways of assigning a personal ID. The ETR.net (TB) and the NHLS[69] had both their unique ways of assigning an ID #: TB used national ID# +local reg. nr., while PHCIS (all modules) and PREHMIS used the Provincial Patient Master Index (PPMI) to allocate a unique patient ID and folder # and later search in the PPMI for the patient. This added complexity to the identification of people.

> *"**NHLS** gather all sorts of folder numbers, all sorts of patient identifiers. One of them they flag as a medical record number, but they don't specify from which system it comes. So, we've got to pick up this medical record number and try and find those patients within our database. The sad thing is, there is about well, there are 3 systems that use the same structure – 4 systems, that use the same structure – with that medical record number, so when we look at the medical record number, what we've got to do, we have to confirm that medical record number with, I think we do it with the date of birth. So, we say, if the medical record number is the same, and the date of birth is the same, then the chances are, this is the same patient" (*Business Analyst, 2010*).*

In case of a new patient in clinic, a new folder would be created (paper *and* electronic), with different formats and structure(s). In a small clinic in the study, without an electronic system implemented, and using a paper-based system, the folder would have the name and other personal data on the front page. A sequential patient clinic number would be assigned and put on; the numbering starting anew every year (for example: 2010/25), and the folders were filed by name. In this clinic, the patient would be identified by personal data, such as name, address, and date of birth, and the folder would be searched for in the paper archives. In the smallest clinic in the study, the TB sister also claimed to know her patients in person, so that this was not a problem. She would personally keep track of the people living in the catchment area.

At the end of my fieldwork period (Nov2010), this clinic had the electronic system PHCIS I implemented, which led to a change in the filing system; now filing by folder number issued by Clinicom, but still keeping the old numbers.

Migration of people was also one reason why following-up of a patient was a problem, and denial of the HIV diagnosis another. The denial often led to what the health personnel labelled 'shopping around'. The following quote is from an interview with a TB/HIV nurse:

> *"I: so, from the Clinicom you get name and [...]*
> *Nurse: […] you get the number, and the names and you put it in the computer and they jump out and you can see, oh that was your address here, or Delft, Cape Town or Port Elisabeth, but you can see where he shopped around, all the time. And especially when the patient comes to you and say, no, I want to be […]. You see, the problem that our patients have? … and I don't know where is the*

[69] National Health Laboratory Service

problem; if it's pre-counselling; if it is nurses; if it is doctors, I don't know. A patient will go to the clinic at XXX, then he is positive; then he doesn't accept it, but post-counselling has been done. And the patient - they wrote the patient accept his condition. Then the patient comes to our clinic. Then he comes and tells you, 'I was never been tested', in the hope that most probably, they're going to test me negative this time".

Some also tried to cheat and manipulate their ID on a card, for example by replacing the photo and change one digit in the ID number, as they did not want to be recognized. According to the health workers, this was mostly due to the HIV diagnosis and stigma. An information officer explains different problems with identification, and how they try to cope with this in their system:

"Not each patient has a unique ID. In a lot of the areas we have refugees, who don't have national ID numbers, and we have got people who have, for whatever reason an illegal ID. We do checking on their ID number. The ID is coded with date of birth, male/female, nationality – used to have race, but race is now dropped – all race is 8, which means other. I have personally experienced that a person came in with a false ID; the person came in, I was working with the rollout, patient came with an ID book. I scanned it, typed in the data, claiming to be a male, but the ID number said female. You could see that the page had been split and another photograph had been put in."

"You also get cases where two people might have the same ID – then one is false, somebody has got the real one. You got this problem as well, so you got to find a way of overcoming it. I know the national drive was to use ID numbers. We use that as a supporting ID – it will be entered into the system. What we do cater for is: there are cases where patients are not searched correctly. They check in Clinicom, but do not find the patient there then, the next thing they do is, they add a new patient, exactly the same patient, but they misspelled something. That happens very much with our surnames. What we do eventually, we have got staff that check this information and look for possible duplicates, and check it out and say, ok, this is a duplicate. If they find a case, they make a phone call and check with the patient: are you this person? And then does 'patient merge'" (information officer, 2010).

The insecurity related to identification was particularly emphasized in one clinic, where the nurses claimed that the Clinicom ID was not safe. They had at least three times people coming with a false ID that belonged to somebody else. People would then have to provide proof that they are who they claim they are. The nurses therefore claimed that one should always have and use three different ID sources to secure their identification: National ID, Clinicom ID, and the clinic folder number.

6.1.2 Follow-up HIV/AIDS - Adherence

"Skinny as a broomstick
With black spots
My sister's children
Coughed and died
My brother coughed and died
I was coughing and dying
The enemy was in our bodies
Making us cough and die
Eating us like worms
But some of us
Still made love
And made each other cough and die

We all died
Coughed and died
We died of TB
That was us
Whispering it at the funerals
Because nobody ever said AIDS"
'Nobody ever said AIDS' by Eddie Vulani Maluleke
(in Rasebotsa et al, 2004)

Once identified and registered in clinics and systems, being able to follow up a patient is of particular importance for ARV treatment, and for the patient's adherence to the therapy. The strict regime for regularly and life-long medication in the ARV program is a question of life or death. The prescribed medication has to be taken four times a day, every day, for the rest of the patient's life, and if not, drug resistance will be developed. This was emphasized in literature, and by health personnel. One of the ARV doctors, said that, if the patients do not adhere, they will be taken out of the program because of resistance. Although, in certain cases, the doctor might be willing to give the person a second chance after a thorough assessment. This important issue was given great focus, both in terms of keeping track of the patient in time, and to identify the reasons for the patient to fall out of the treatment. Before being accepted for the ARV program, there would be a "Pre-ART Adherence Counselling visit" (figure 25, p.120), and the patient would need to sign a "Patient Commitment to Treatment" contract (figure 26, p.121).

To follow up the patient in a clinic, an appointment system was essential. At the end of a visit, depending on the HIV stage and need for follow-up, a new appointment would be made at some interval, and then entered in the patient retained card, whether paper- or electronic system in clinic. If there was an electronic system implemented, the date and time will also be registered in the appointment module.

"Lost-to-follow-up", was defined as *"not seen 180 days since last visit, or 90 days after not turned up to last given appointment"*. Possible reasons for lost-to-follow up were given by nurses and doctors, like: :

> *"It might be because the patient does not accept the diagnosis and rather stay home to get sicker and sicker at home and then getting hospitalized, and then die. They would rather die than accept the diagnosis and get treatment*"(TB nurse).

> *"[...] we have learnt that one of the biggest barriers to adherence of therapy here is alcohol abuse, drug abuse, and non-disclosure, so we want them to disclose before they go on ARV's because then, you start them on ARV, and also we make them sign consent that we can send a sister from hospice to come and do a home visit, and she goes to the home, and she talks to the family, and then she can realise whether there is a disclosure or not*" (ARV doctor).

There were various strategies to following the patients. The appointment module in PHCIS allows for printing lists of next day/week's patients, thus providing information to retrieve the paper folders and prepare for the consultations. This also became a way of controlling patients' adherence to treatment. One clinic would print a list of today's appointments (only chronic patients got appointments), and the paper folders were retrieved from the archives. On the appointments printout they tick when they have found the folder, and if the patient does not show up, they mark that. To further rationalize the patient process in clinic and prepare for nurses and doctors, the folders were stacked according to the hour of the day (figure 24, p.118).

One clinic with eKapa installed, printed out a list of the next week's appointments every Friday, and gave it to the ARV counsellors. If patients did not show up, the counsellors would call the patient twice. If they did not get in contact with the patient, they would visit them at home eventually in cooperation with the TB section, as they did often have the same patients. According to one TB nurse, thus a home visit might be crucial, to find the reason for not meeting to appointment, and eventually to motivate the person for continuing treatment. Some claimed however that, using the phone was not a good way of contacting the HIV/AIDS patients, because of the stigma. There might be more than one person in a family using the mobile phone, and often several people shared one 'shack' in the townships. If the person did not want to disclose his HIV status, a phone call might reveal his status.

A report from the home visit would be filled in by a person from Hospice services (Home care), and the report filed in the patient folder. I asked a nurse if she thought this report carried important information for her care, and the respond was: *'definitely'*! The need for keeping consent forms and reports from home visits was also confirmed by ARV doctors.

Figure 22: Scanning the barcode label

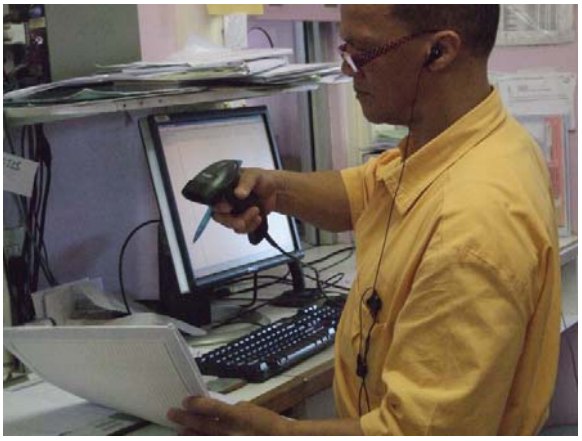


Figure 23: Hand scanner and printed barcode labels

Figure 24: Upper left: list of patients with appointment for the day, then sorted by hour of the day. (Folder will be retrieved and put on top of the hour-sheet)

In a clinic, working mainly paper-based, and with a largely illiterate population, all patient groups (diagnosis) were scheduled for specific days of the week. Each week in the month had its own colour; the first week was for example yellow. For the patient's next visit, a yellow sticker would then be put on the patient's card. In the reception of the clinic, there was a flag with the colour of the week, so that, according to the TB and HIV nurse:

> "[…] *if they are not sure when their next appointment is, they can look into the clinic, see the colour and compare with their card, if this was their week for visiting the clinic. And most people pass by the clinic every day"* (2010*).*

In this clinic, the TB and HIV nurse claimed to know her patients, and she would personally keep track of the people living in the catchment area. If the patients tested HIV positive, and they had TB, TB would first be treated for 6 or 8 months and then referred to ARV treatment. If the patient was HIV+, but the CD4 count was > 250, they would offer the test again 6 months later. This clinic did have one computer in the reception, and would at the end of my field visits have PHCIS implemented. Smaller villages in the rural areas were however completely without computer and network, and had to rely on the patients to follow up their appointments, and local knowledge.

One clinic explained that they did not have the capacity to follow-up HIV+ patients as required, and referred to the new rapid procedure of HIV testing[70]. The new procedure was leading to more patients, and increased the pressure on the health workers, thus they only managed to do the monthly audit. They referred people to the hospital for follow-up, which in fact could also no longer receive more patients. The clinic was supposed to give ARV treatment now, but they would need more space to be able to see more patients, and need more staff. The managers were looking for new ARV sites (clinic manager, 2010).

In addition to the need for patients keeping their appointments, follow-up also required that the patients brought whatever information they held in terms of patient cards, x-rays, or referrals. Nurses and doctors in the clinics had different experiences whether the patients brought their cards and letters or not. Some nurses and doctors claimed patients invariably

[70] National HIV Counselling and Testing Policy Guidelines, Department of Health, SA, 2010

came without an x-ray or patient retained cards, or the cards were treated badly and almost not readable, while others claimed the opposite.

> *"What happens here, lots of patients come here to see me, they get referred from the mobile clinic at the farms, then mobile clinic will give the referral letter with copies of the blood result to the patient to bring here. But the patients come here and say, no, we didn't get a referral letter – so I am sitting here and can't go on, because I have no information"* (ARV doctor).

Related to this issue, nurses referred to people coming in from the Eastern Cape, bringing a personal health 'booklet' in A5 format, as a kind of longitudinal patient record, which they kept as a treasure. The 'booklet' was seen to keeping their 'personal history', and brought with them to the clinics. The booklet was however not seen as entirely positive by all service providers. One pharmacist, that had seen the booklets from the Eastern Cape, said she was not impressed, claiming that booklets were rather messy, not clean, or with chronological, easy to read information. It was not *'easy for the eye'*, and information that they were looking for, such as previous prescriptions, would be put in between everything else.

To ensuring that patients kept their appointments, there were different ways of controlling adherence to the prescribed medication**.** To electronically control adherence to medication was not easy, and this was mostly done manually by nurses and pharmacies. It was followed up in various ways, and there were different views on the best way to follow up adherence:

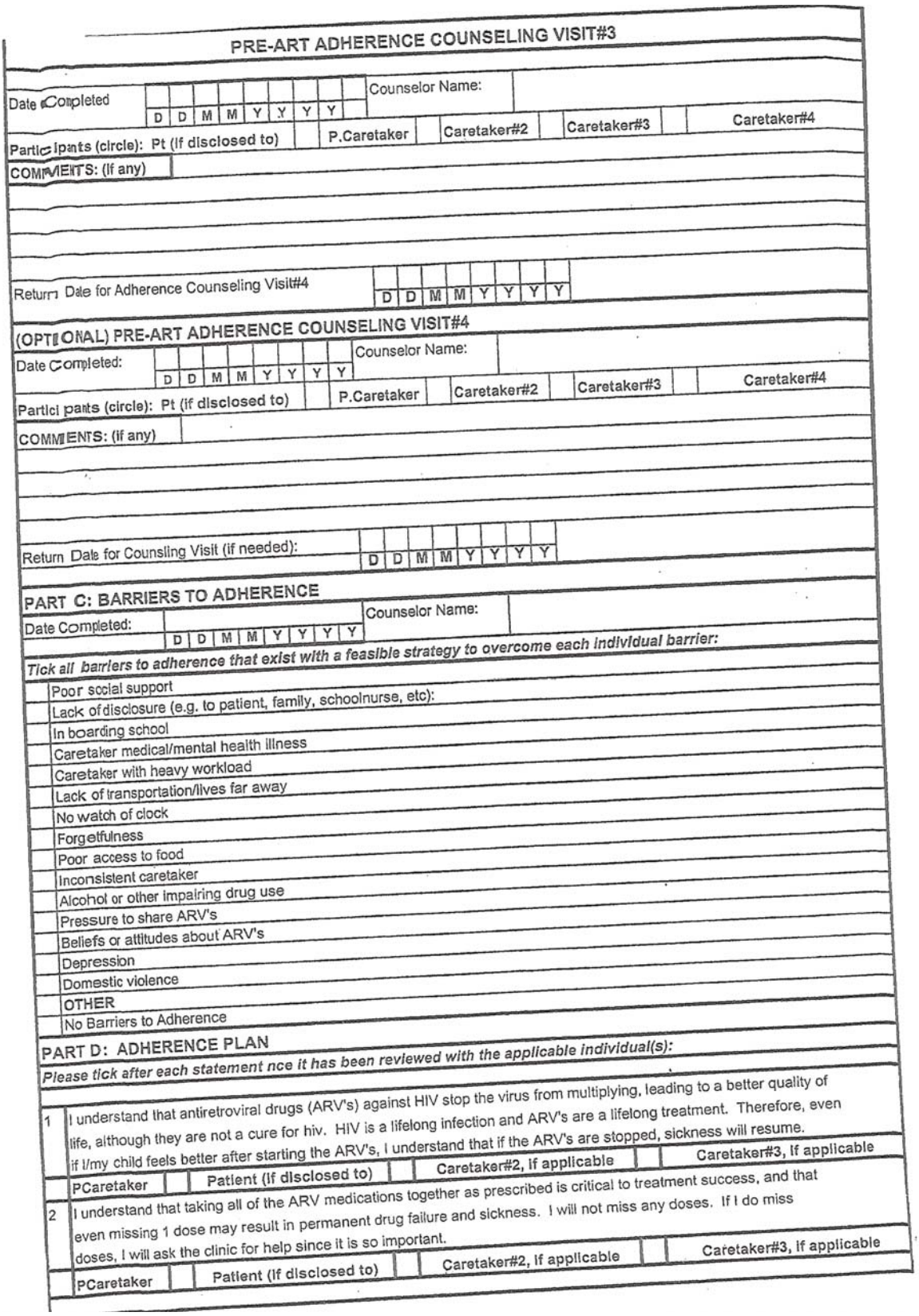
> *"We do not calculate adherence by counting pills. People are clever. They know that they get pills for more than the days they are supposed to take them, and know exactly how many they are supposed to bring back, so the return of pills does not tell us anything. We base our adherence on viral load. If it goes down, people take their pills, or else they get sick again."* (Nurse and ARV clinic manager*).*

One pharmacy had a different strategy:

> "*The counsellor does the counting for each patient and enters on paper form, which is then given to the pharmacy. To prevent the patients from cheating them, the pharmacist gives out different number of tablets each time […]".*

iDart was the only electronic system that did adherence calculation, that is, in the pharmacies, where iDart was implemented. According to the Business Analyst:

> *"The pharmacist dispenses what is in the prescription, and enters the drugs in iDart. iDart draws all the patient information, not the episodic information, just the patient information, and he looks at the script, and he dispenses in iDart the drugs that were entered. When they go to the pharmacist, the pharmacist will then also do the pill count, so he will take how many pills this patient bought, how many pills he has dispensed, and what is in hand, […] that information from iDart is fed back to eKapa" (June 09).*



PRE-ART ADHERENCE COUNSELING VISIT#3

Date Completed: D D M M Y Y Y Y | Counselor Name:

Participants (circle): Pt (If disclosed to) | P.Caretaker | Caretaker#2 | Caretaker#3 | Caretaker#4

COMMENTS: (If any)

Return Date for Adherence Counseling Visit#4: D D M M Y Y Y Y

(OPTIONAL) PRE-ART ADHERENCE COUNSELING VISIT#4

Date Completed: D D M M Y Y Y Y | Counselor Name:

Participants (circle): Pt (If disclosed to) | P.Caretaker | Caretaker#2 | Caretaker#3 | Caretaker#4

COMMENTS: (If any)

Return Date for Counsling Visit (if needed): D D M M Y Y Y Y

PART C: BARRIERS TO ADHERENCE

Date Completed: D D M M Y Y Y Y | Counselor Name:

Tick all barriers to adherence that exist with a feasible strategy to overcome each individual barrier:

- Poor social support
- Lack of disclosure (e.g. to patient, family, schoolnurse, etc):
- In boarding school
- Caretaker medical/mental health illness
- Caretaker with heavy workload
- Lack of transportation/lives far away
- No watch of clock
- Forgetfulness
- Poor access to food
- Inconsistent caretaker
- Alcohol or other impairing drug use
- Pressure to share ARV's
- Beliefs or attitudes about ARV's
- Depression
- Domestic violence
- OTHER
- No Barriers to Adherence

PART D: ADHERENCE PLAN

Please tick after each statement nce it has been reviewed with the applicable individual(s):

1 I understand that antiretroviral drugs (ARV's) against HIV stop the virus from multiplying, leading to a better quality of life, although they are not a cure for hiv. HIV is a lifelong infection and ARV's are a lifelong treatment. Therefore, even if I/my child feels better after starting the ARV's, I understand that if the ARV's are stopped, sickness will resume.

PCaretaker | Patient (If disclosed to) | Caretaker#2, If applicable | Caretaker#3, If applicable

2 I understand that taking all of the ARV medications together as prescribed is critical to treatment success, and that even missing 1 dose may result in permanent drug failure and sickness. I will not miss any doses. If I do miss doses, I will ask the clinic for help since it is so important.

PCaretaker | Patient (If disclosed to) | Caretaker#2, If applicable | Caretaker#3, If applicable

Figure 25: Pre-ART Adherence Counselling Visit form to be filled in by counsellor

PATIENT COMMITMENT TO TREATMENT

(1) I understand that antiretroviral drugs do not cure HIV/AIDS and I remain HIV positive even when taking the drugs.

(2) I need to take all my pills as instructed, everyday for the rest of my life and I should not share my drugs with anyone. If I do not take my pills as instructed, they may stop working on the virus in my body.

(3) It is essential to inform my caregivers about other medicine including traditional medicines, which I may take while on antiretrovirals.

(4) I understand that my medicine may cause undesirable effects to my body especially at the beginning of treatment but this does not always happen . If it does, it is important that I communicate this to my caregiver.

(5) It is important to share my HIV status with the people close to me since I will need a lot of support during my treatment. They should be trained to be a part of my care team to help me benefit from this care.

(6) I know that I am on antiretrovirals , I am still infected with HIV. Through unprotected sex I can pass it on to other people and I can also be re-infected. As a result, I should prevent spreading the virus to other people by using condoms. Whenever possible I will inform my sexual partner that I am HIV infected and on antiretrovirals.

(7) I should try as much as possible to stick to one care centre and keep all my appointments throughout my care.

Name of Sponsor/ Care Taker.....

Relationship to Patient.....

Sponsor Signature.....

....

Health Care Provider Signature Patient Signature

Confidential Patient Document

Figure 26: Patient Commitment to Treatment

6.1.3 Patient clinical information and clinical history

In addition to the need for identification and adherence to ARV treatment, the health workers needed to measure and follow the development in the patient's clinical data over time. According to the ART Guidelines from WHO (2006, p. 16): *"[…] essential minimum standard HIV care and ART patient monitoring data"* should cover four categories:

I. Demographic information
II. HIV care and family status
III. ART summary
IV. Patient encounter information.

In the categories III and IV, some data elements are here listed for more details:

III. ART summary:

- ART history prior to entry
- ART START date/treatment cohort (including details related to cohort)
- First-line regimen (list drugs)
- If SWITCH to or SUBSTITUTE within second-line regimen or higher: dates, reasons, new regimens,
- ART interruptions: dates, reasons
  STOP ART: dates, reasons
  LOST (temporarily): dates
  RESTART: dates
- Transfer In, Transfer Out: date, facility transferred from or to
- DROP: dates
- DEAD: date

IV. Patient encounter information:

- Encounter date, whether scheduled or not, next scheduled follow-up visit date;
- Months on current regimen;
- Current functional status, clinical stage, weight, height (for children);
- TB status, TB treatment start/stop dates;
- Pregnancy status, estimated date of delivery (EDD), family planning method(s),
  prevention of mother-to-child transmission of HIV (PMTCT) referral/provision;
- Possible side-effects (including drug allergies), severity;
- New symptoms/diagnoses/Opportunistic Infections;
- Laboratory test dates and results;
- Prophylaxis: medication, dose dispensed, start/stop dates, reason for discontinuation;
- ART dispensed: regimen code, dose dispensed, (start/stop dates);
- Adherence assessment (pill count, self-report, other) and reasons for both ART and Prophylaxis;
- non-adherence;
- Referral or link to other clinical or supportive care;
- Hospital days since last outpatient visit.

There were different services provided from the various types of clinics, from offering HIV test only, to ARV clinics with full ARV treatment; pharmacies, mother and child sections (MOU), X-ray, laboratories for blood and urine samples, and hospitals. Most clinics used The National Health Laboratory Services (NHLS) for blood and urine tests, and the NHLS form also required detailed information about various conditions and tests (figure 35, p.135). The need for, and tools for identification, follow-up and adherence, also applied across dispersed service providers. Information needs in clinic and across service providers would to some extent be identical. For all actors, at any time to have a complete record, was a challenge.

For a returning patient, data would have been registered in the standard paper folder and forms. Except for the eKapa module, the EPR did not capture patient clinical data. As TB and HIV were closely related, information about TB was very important for the ARV treatment, as well as other Opportunistic Infections. TB sections had, in addition to information about HIV/AIDS, a number of specific information needs related to the TB treatment, as shown in the TB treatment card (figure 40, p.140), and TB clinic/hospital folder (figure 31, p.131).

The pharmacy would need access to the patient register (Clinicom) for demographic information about the person. In addition, they needed to know the health status (CD4, VL and WHO staging), coming from the prescription, and also details about the current medication, such as type and number of pills. According to one pharmacist, they can look up the patient in Clinicom, to see the patient, and where he has been, but not what type of medication was given. They did however need to know the type, the number of items to dispense and number of scripts, including the prescript from the doctor. Pharmacies that calculated adherence also needed to monitor the number of items they dispensed for one person, and administratively they needed to report the total number of items dispensed and number of prescriptions handled. One pharmacist had developed locally a form needed to cover all their information needs (figure 27, p 126).

As mentioned, HIV+ patients often travelled around, and went to different clinics, thus, very often there was no existing ART folder with a complete picture of the patient. In some cases, the patient would bring an ARV card with some key information, or a referral letter. When I asked nurses and doctors what they see as the key information they would need to give quality treatment to the patient, I had different answers:

> ***ARV Doctor I:***
> "*If you can have a diagnosis, the treatment and what was the medication that was given and if he was hospitalized and whatever, so that would help us tremendously, because that information, even if the patient gets hospitalized, […], they come back here and they say, no, they did not give me a discharge letter. But you know they gave them a letter. You also need to have an X-ray, if this was taken somewhere else".*

> ***ARV doctor II***
> *"I would like to put my patient's last CD4, their viral load, and functions tests on, and if this patient get seen somewhere else, they can at least see my information".*

ARV doctor III

- *Personal information*
- *Blood results*
- *Other diseases – infectious (TB ++)*
- *Visits – when, where, weight, (health development that is)*

In an EPR, this doctor would like to add:

- *If possible, x-rays*
- *It should be possible to send referral to other sites, and prescription to pharmacy*

Although the doctor expected an EPR coming in the future, and not as a 'fata morgana', he acknowledged that their caseload probably would be too large, and that, for example entering scanned documents into eKapa might pose a capacity problem in primary health care. Information about other diseases, including mental health was considered important, to get a holistic understanding of the persons health status. One ARV doctor was critical to the single focus on HIV/AIDS in the ARV program. He claimed, the HIV/AIDS guidelines for data collection, only take the focus away from other important information about that person, and prevents people from seeing other things. A complete record that also includes other information would broaden the scope.

> *"In that way other diseases would be seen much earlier, and problems solved (would not get as sick, need to be away from work etc). This is what I have picked up by seeing the patients together with the nurse in the clinic"* (ARV doctor, 2010).

He had previously experience from a different professional practice, and was used to see 'the whole person':

> "*We had an internal patient information system there, but it was local. In the system I could track a patient and get all the information about that person – where he had been, medication, hospitalization etc. We did not have any paper folders at all. Still, I do not think that a computer system can replace the assessment of a clinician. I want to see a patient, and will get for example a clue about mental state that the IS cannot tell me"* (ARV doctor, 2010).

Nurses in PHC clinics also expressed a certain scepticism to the single focus on HIV/AIDS and claimed that TB, diabetes, and other serious illnesses needed as much effort and investments. In PHC clinics, where HIV tests were taken, but not treated, the nurses mentioned what they saw as baseline information:

> *"In addition to the demographic information, it should be some baseline information (where you start): weight, height, urine […], sugar, HB (to know if they are anaemic), the last cervical smear (done every 10 years), eventually last baby born, what method of family planning (using condoms etc), when they were last tested for HIV (they test all patients once a year); for the HIV patients, the CD4 count and the viral load".*
>
> *"I think, diagnosis, because this is a confidential thing, […] you don't know this, which is for the patient very important. New patients coming in, if you get the last diagnosis from previous admission to hospital – because that's mainly our problem: sometimes patients, they have been to hospital, but they don't know*

what happened, why they were there; what operation they had; they can't tell – that would be nice to know".

This clinic had an x-ray section in the clinic. If the patient had been to a private x-ray and brought a CD, they did not have the software to read that CD, which was a problem. X-rays taken in the clinic was stored there.

The Prevention of Mother-to-child Transmission (PMTCT) program was followed up by the MOU[71] sections, and had comprehensive information needs, to follow both the pregnant woman and the unborn child. This was related to pre-counselling, as well as pre-medication and regular HIV tests and follow-up during pregnancy. Thus, specific personal and clinical information needs were related to the services.

One 'complete' electronic patient record to cover for all the information needs was far from becoming a reality, thus it was important to have procedures and backup systems to meet the information needs.

Health service provider	Information needs
PHC clinic	Patient ID, demographic data, if new patient, previous clinic(s); 'baseline' data: (weight, height, sugar, HB, urine), other clinical data, incl. TB, and results HIV test
ARV clinic/hospital	Patient ID, demographic data; referral clinic, basic HIV/ARV (CD4, viral load, WHO staging); other clinical data incl. TB (previous and current), OI's, X-ray
Pharmacy	Patient ID, basic HIV/AIDS info, current medication (type and number of pills), additional diagnosis, to avoid wrong medication
TB section	Patient ID + TB #, previous TB treatment, HIV/AIDS data, and/or OI's
Laboratory	Patient ID and demographic data, detailed HIV/AIDS info, HIV programme status and current treatment, TB and other OI´s.
MOU (PMTCT)	Regular HIV tests, mother and child, to provide medication during pregnancy, and follow-up of child after delivery

Table 19: Service providers and a summary of information needs

[71] Mid-wife Obstetrics Unit

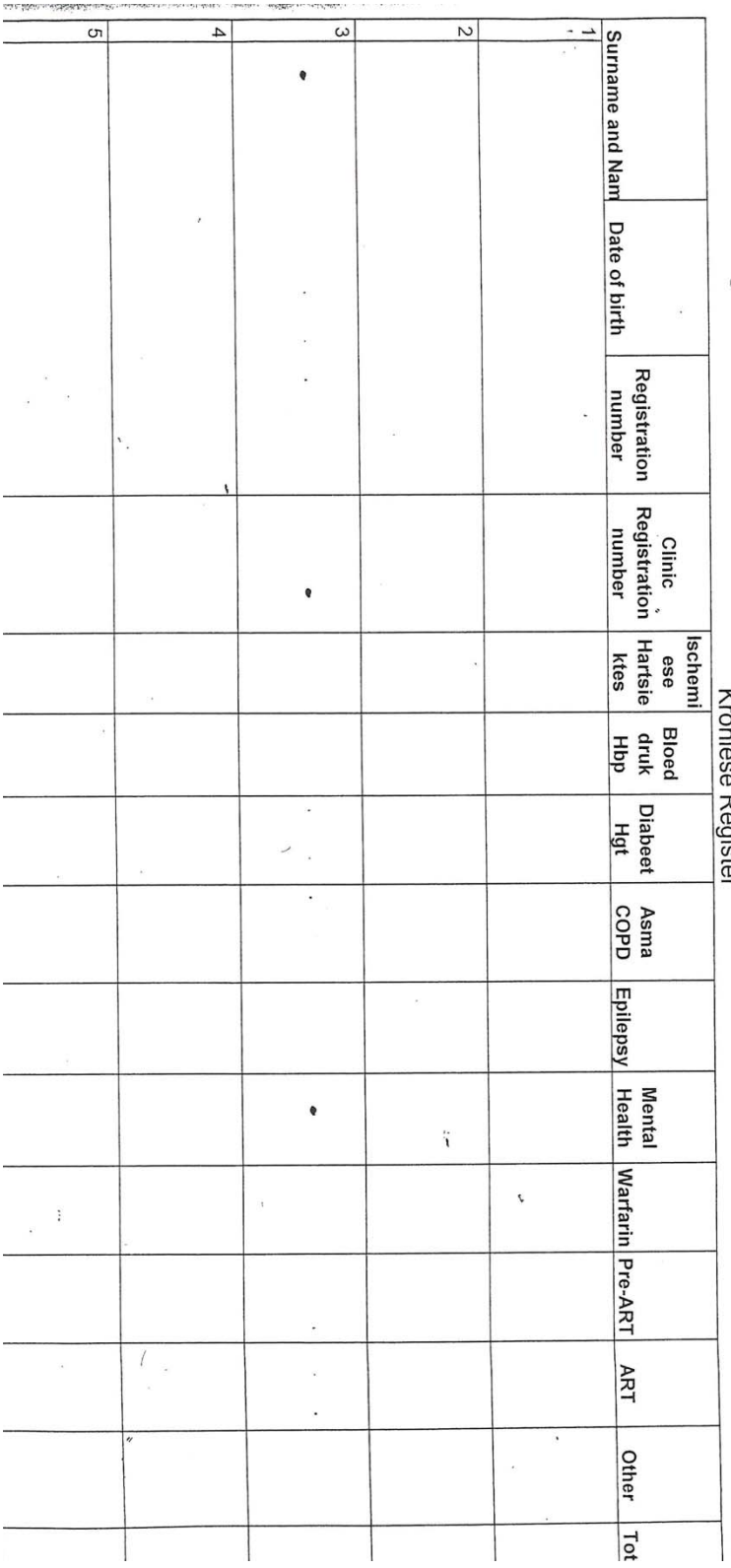


Figure 27: Information needs for Chronic Patients Register – Local developed in Pharmacy

6.1.4 Management

For the Clinic manager, the Clinic and District Information Officer, and the ARV (and TB) program managers, anonymized, disease related, aggregated data (headcount, type of illness and more), were important to manage their responsibilities at their levels, and to plan for future needs, related to medication, personnel, and equipment. The Primary Medical Officer in an ARV clinic described his managerial information needs for planning related to staff and treatment:

- Number of patients
- Patient register (ARV)
- Weekly list of defaulters
- Medicines in stock (from eKapa)
- Staff available.

A number of reports and registers (monthly, quarterly and yearly) had to be reported from the health facilities to health management at (Sub-) District, Programs, National and international agencies. To follow the development and clinical outcomes within HIV/AIDS and ARV treatment, some sentinel sites had been selected to do **cohort analysis** (quarterly). Selected population in the cohort analysis were patients starting ART between 3 and 6 months prior to the analysis, and information regarding treatment and clinical outcomes will be registered and reported (WHO 2006). These reports would either be produced manually, and faxed to the managers respective (figure 48, p.149), or they would be compiled from Clinicom, PREHMIS and PHCIS (and ETR.net).

Summary information needs in HIV/AIDS care and treatment

Sharing information across the different service providers was obviously a challenge. In addition to the 'shopping around' phenomenon, and/or other reasons for people to moving from place to place (drifting harvest workers), local knowledge in a clinic or community was no longer enough, and the most complete patient records, the paper folders, were locally stored and elsewhere not accessible. A fact that motivated the drive towards electronic patient records, and the idea of immediate, and universal access to patient information, regardless location of the service provider.

The need to keep information about one person over a lifetime would of course accumulate enormous amounts of documents. The legal requirement for keeping a record was 6 years after they become dormant (MPS[72], 2012). As the ARV programme expanded, this requirement for storage led to huge amounts of folders to be stored in the bigger clinics. One of the participating clinics had taken the following measures to cope with the challenge: Usually they had kept the folders for 5 years (after dormant), but they had got permission to reduce the time down to 3 years. Still they had to lease accommodation for remote storage. This fact also supported the need for replacing paper records with EHR. The electronic version(s) of a longitudinal record did however only contain a minor part of the patient data needed, and not "*[…] all data and documents generated or received during the care of a patient" (Leiner et al, 2003).* This requirement for complete documentation, confirmed the need for the paper folders and their content, and also the need for combined solutions – the hybrid.

[72] Medical Protection Society

Figure 28: Folder archives in Clinic

6.2 Hybrid health information systems

In Ch 2.6, I discuss the 'hybrid system' concept, referring to the general definition of *"systems having two kinds of components that produce the same or similar results"*[73].

The quote from Clarke (2005) has also been important when analysing the results from the fieldwork and health care work practices:

> *"The term 'hybrid' has been generalized to refer to any recognizable entity that is made up of elements drawn from multiple sources. A hybrid is of particular interest where its elements are derived from heterogeneous sources, or it is composed of elements of a different or seemingly incongruous kind" (*Clarke, 2005*).*

This section will focus on the technologies involved in constituting a patient record, with the focus on the digital and the paper technologies in particular, and their interaction. What are the hybrid modules involved, and how is data collection and coordination achieved, i.e. what are the components (collection of artefacts), and the interfaces (coordinative artefacts)? How is the 'complete patient record' composed within this hybrid system? How do the components coordinate to meeting the information needs as mentioned in sec 6.1? What are the challenges in each of the system components, and how are these challenges met? How does the use of paper and electronic components in combination lead to data being registered more than once, and/or contributes this redundancy to a more robust system, reducing risk of losing important information?

[73] www.thefreedictionary.com

6.2.1 Modularity in hybrid systems - the collection of artefacts

> *"A modular system is composed of units (or modules) that are designed independently but still function as an integrated whole. Compatibility among modules is ensured by "design rules" that govern the architecture, the interfaces, and the standardized tests of the system"* (Baldwin and Clark, 1997).

The patient record may be described as *one* system in the sense that it incorporates all the information as described in sec 6.1, but the record is comprised of many components based on different technologies. In this section, I will present the hybrid components making up the longitudinal patient record.

A typical hybrid patient record in a developing country context, with access to computers, would be a combination of paper and electronic modules, comprising a collection of artefacts, such as:

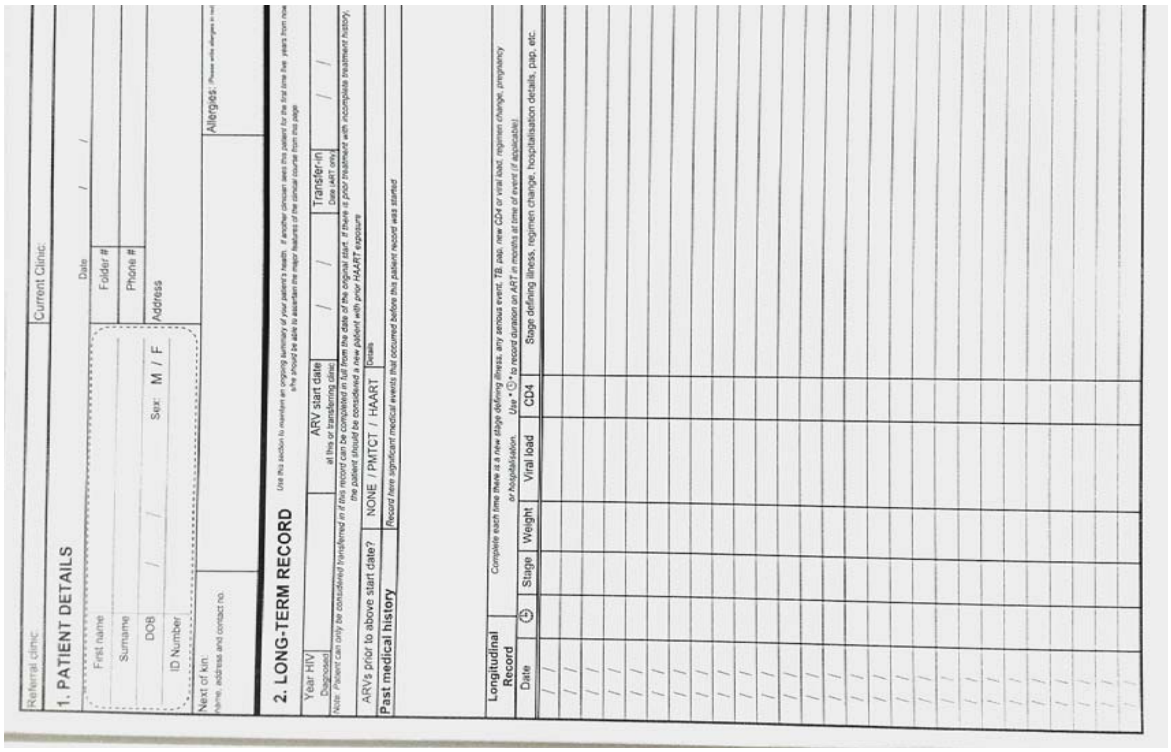
- Encounter form (paper format)
- Patient held card (paper), with personal ID information, appointment dates, and in some cases, medical information, such as viral load and CD4 count for ARV treatment, or sputum bacteriology results for TB. This card is issued at the first visit in a clinic, and the patient is supposed to bring this at the next visits, either in the same clinic or if he travels to another health facility.
- Paper folder or envelope containing the follow-up form, consent forms, lab results and more. For an HIV/AIDS patient with a TB history, a TB folder may be enclosed within the envelope.
- A long-term follow up form (paper) with the patient's trajectory over time, visits, disease specific information, and clinician's notes/evaluation
- Electronic health record - basic (local only or central database if online) with a patient folder containing demographic data, coded encounter data;
  In advanced cases also:
- Clinical data registry, and
- Electronic appointment module
- Order entry module
- Manual or electronic registers (TB/ARV)

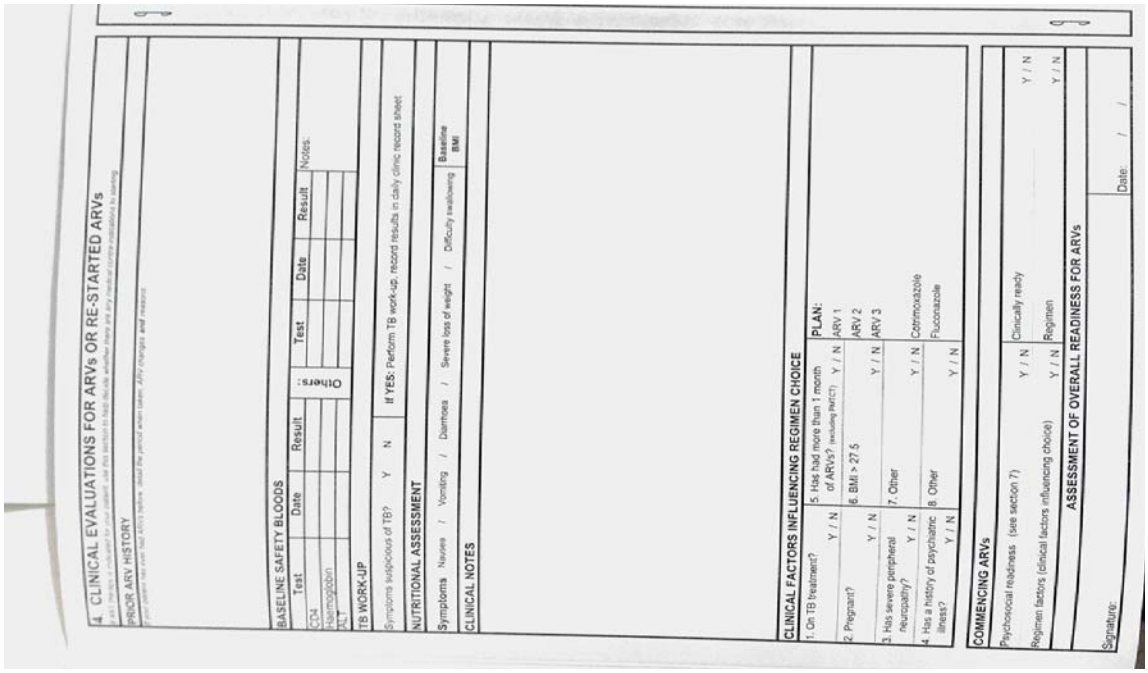
The most important tools for capturing and storing information were the paper cards and forms, such as: the patient folder, the patient retained card, the referral letters, the prescripts, reports and test results. In the following, the paper artefacts will be described in more detail in terms of type of patient information captured, and the process of capturing, storing and sharing information. The electronic patient records, and patient data captured for the patient health record in the Province, were described in more detail in sec 6.1.

a) The patient folder

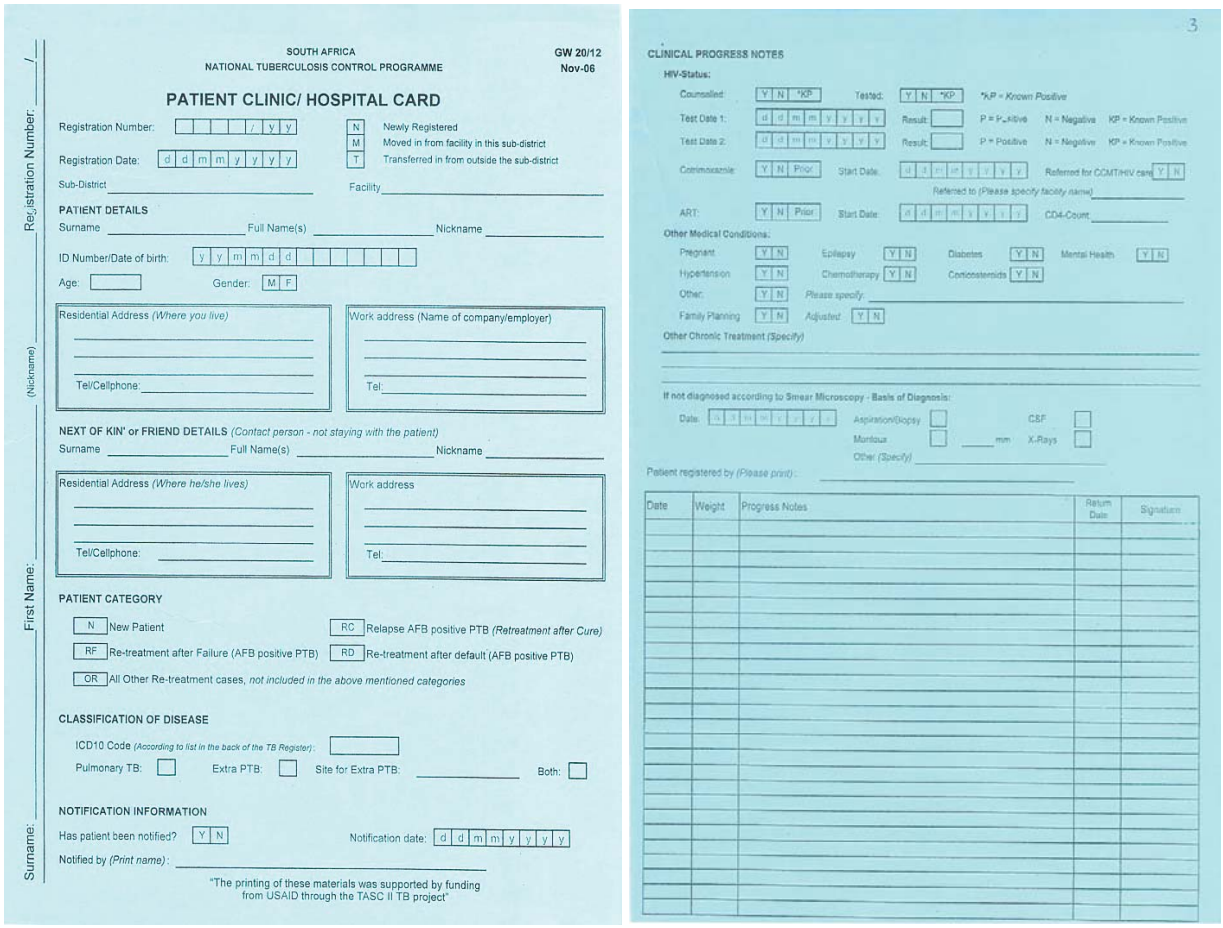
The patient paper folder was standardized through the Province (figures 29-30), as was a follow-up form where information is entered chronologically. At the first visit of a new patient, the clinic opened a patient record. A paper folder/envelope was filled in with demographic and clinical data. The folder got a clinic/folder number, issued locally in the PHC and entered manually. In clinics without computer and the PHCIS or PREHMIS installed, patients were identified, and the folders archived, either by name or by folder number. One of the clinics in the study, without EPR, kept folders also if people left their

catchment area, so that they could be retrieved if the person returned later. The folder or envelope contained in addition to the cover and the long-term follow-up form, and a number of paper forms and notes, as listed in figure 32, p.131. At the end of my fieldwork (late 2010), all clinics in this Sub-District were now authorized to do HIV/AIDS care and treatment. There was no longer a separate ARV clinic in the hospital. The clinics had PHCIS installed; the paper folders were distributed from the ARV clinics to the PHC clinics, and they were now sorted under the ID-number.





Figures 29-30: HIV folder in Clinic, p. 1-3



SOUTH AFRICA
NATIONAL TUBERCULOSIS CONTROL PROGRAMME

GW 20/12
Nov-06

PATIENT CLINIC/ HOSPITAL CARD

Registration Number: / y y

Registration Date: d d m m y y y y

N Newly Registered
M Moved in from facility in this sub-district
T Transferred in from outside the sub-district

Sub-District _____ Facility _____

PATIENT DETAILS

Surname _____ Full Name(s) _____ Nickname _____

ID Number/Date of birth: y y m m d d

Age: Gender: M F

Residential Address (Where you live)

Tel/Cellphone: _____

Work address (Name of company/employer)

Tel: _____

NEXT OF KIN' or FRIEND DETAILS (Contact person - not staying with the patient)

Surname _____ Full Name(s) _____ Nickname _____

Residential Address (Where he/she lives)

Tel/Cellphone: _____

Work address

Tel: _____

PATIENT CATEGORY

N New Patient
RC Relapse AFB positive PTB (Retreatment after Cure)
RF Re-treatment after Failure (AFB positive PTB)
RD Re-treatment after default (AFB positive PTB)
OR All Other Re-treatment cases, not included in the above mentioned categories

CLASSIFICATION OF DISEASE

ICD10 Code (According to list in the back of the TB Register):

Pulmonary TB: Extra PTB: Site for Extra PTB: _____ Both:

NOTIFICATION INFORMATION

Has patient been notified? Y N Notification date: d d m m y y y y

Notified by (Print name): _____

"The printing of these materials was supported by funding from USAID through the TASC II TB project"

Registration Number: _____/_____

(Nickname) _____

First Name: _____

Surname: _____

3

CLINICAL PROGRESS NOTES

HIV-Status:

Counselled: Y N *KP Tested: Y N *KP *KP = Known Positive

Test Date 1: d d m m y y y y Result: P = Positive N = Negative KP = Known Positive

Test Date 2: d d m m y y y y Result: P = Positive N = Negative KP = Known Positive

Cotrimoxazole: Y N Prior Start Date: d d m m y y y y Referred for CCMT/HIV care Y N

Referred to (Please specify facility name) _____

ART: Y N Prior Start Date: d d m m y y y y CD4-Count _____

Other Medical Conditions:

Pregnant Y N Epilepsy Y N Diabetes Y N Mental Health Y N

Hypertension Y N Chemotherapy Y N Corticosteroids Y N

Other: Y N Please specify: _____

Family Planning Y N Adjusted Y N

Other Chronic Treatment (Specify)

If not diagnosed according to Smear Microscopy - Basis of Diagnosis:

Date: d d m m y y y y Aspiration/Biopsy CSF

Mantoux mm X-Rays

Other (Specify) _____

Patient registered by (Please print): _____

Date	Weight	Progress Notes	Return Date	Signature

Figure 31: South Africa National TB clinic/hospital card, p. 1 and 3

Figure 32, gives a list of **paper documents** in the paper folder related to an ARV patient:

Paper documents kept in patient folder related to an ARV patient
• Patient Commitment to Treatment, (figure 26, p121)
• Pre-ART Adherence Counselling Visit form (confidential) filled in by the counsellor, with signed consent for testing by the patient/client (figure 25, p 120)
• The form after the test, filled in with result, and client's reaction to the result
• ARV – Laboratory service order – with results at return (figure 35, p.135)
• Post-test counselling form
• Medical/nursing assessment form, adult and child – if recommended for ART
• Home visit report (to be completed by patient's medical attendant in conjunction with patient and/or family)
• Interview ARV doctor before eligible to ARV treatment – patient (with buddy) – signed by patient
• Medical prescription to Pharmacy (figure 33, p.133)
• Clinical referral letter for ARV/transfer out form (figure 34, p.134)
• Eventually the blue TB clinical/hospital card if previous TB treatment in clinic (figure 31)

Figure 32: Documents in a patient paper folder

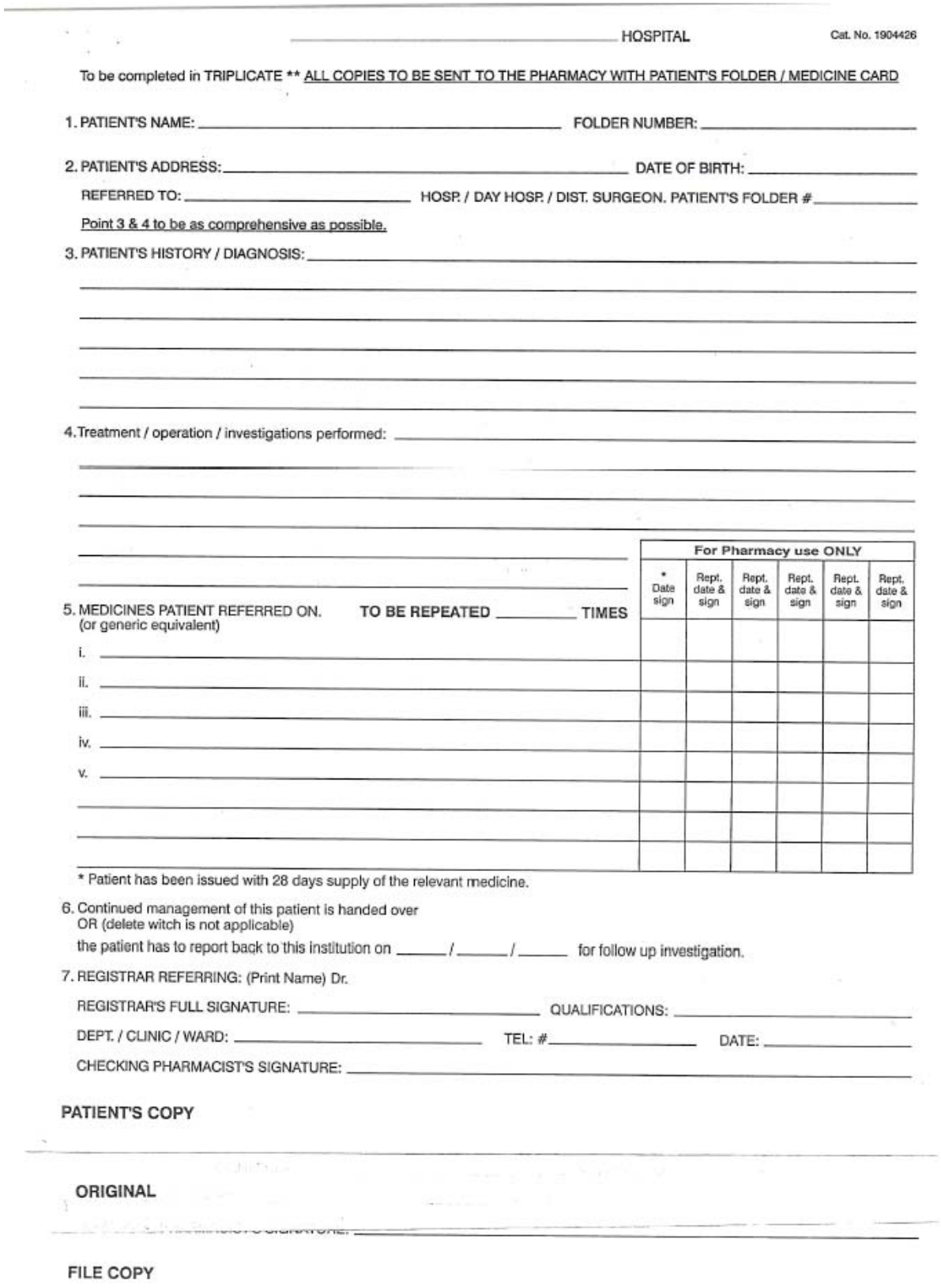
The process for an HIV/AIDS patient from pre-test, taken 'everywhere', to receiving ARV medication consists of numerous steps, all documented and paper forms issued, which later were kept in the paper folder. When the HIV test was taken in a PHC clinic, some of the results would be registered there. If the person were referred to an ARV clinic, the follow-up and results would later be captured and kept in the ARV clinic.

The clinics providing TB services, used the national standard TB cards (figure 40, p.140), folders (figure 31, p.131), and TB register. In the case of TB, there was a separate blue TB-folder. In addition to details and follow-up of the TB tests and treatment, a section for HIV/ ARV tests and follow-up was included. This folder was kept in the separate TB section in the clinic as long as the patient was under treatment. The TB treatment might be for 6, 8 or 12 months. When the treatment was ended, the blue folder remained inside the general patient folder, and if the patient came back to clinic for whatever reason, the personnel would know that he has had TB treatment. A TB nurse assistant described the procedure when a TB patient arrives at the clinic:

> *"The patient gets a paper folder – in the reception they will get a Clinicom barcode number, with a sticker on the TB folder. All information is entered into the paper folder – from there it goes into the Register, and from there into the ETR.net. They use the same numbering as previously, i.e. new from one upwards every year. In the PHCIS in the reception they will enter patient data (from Clinicom), that the patient is on TB (or has been), date of visit and type of visit, like 'entering visit' etc, but no treatment or medication data. So if another clinic on Clinicom looks up the patient they will not get all the information they might need. They will have to call us to get that. "*

The paper folder/envelope containing the patient's history, was kept in all the facilities involved in the study, and came closest to the definition of a complete patient record at the time of my study, although not always containing all clinical data, as described by health personnel, and only immediate accessible locally. **Referrals** to ARV clinic or hospital or **prescription** for medicine were issued using standard paper forms, and copies kept in the folder in the clinic. If a person had been to a hospital or pharmacy before coming to the clinic, a unique ID number (PMI) had been issued (from Clinicom HIS), and a barcode label printed and pasted to their patient held card. The PHC clinic then also entered this information to the paper folder as additional information.

Initial information from the referring clinic was in the referral form, and transferred into the ARV paper folder and ARV card. Information from x-rays and test results from laboratories were delivered in paper forms/reports, entered manually in the patient folder follow-up sheet, and a copy of the report kept in the patient folder. To some extent test results were also entered in the patient cards. Electronic imaging systems for x-ray were not an option in the clinics, and once the doctors had seen the images, they were sent back to the hospital or other x-ray unit, where it had been taken. In a clinic providing HIV follow-up and ART, additional procedures and documents were added. These documents are important when saved in the paper folder, to get the complete history of the patient, and at the same time they work as coordinative artefacts between systems (figures 33/34).



_____ HOSPITAL Cat. No. 1904426

To be completed in TRIPLICATE ** ALL COPIES TO BE SENT TO THE PHARMACY WITH PATIENT'S FOLDER / MEDICINE CARD

1. PATIENT'S NAME: _____ FOLDER NUMBER: _____

2. PATIENT'S ADDRESS: _____ DATE OF BIRTH: _____

REFERRED TO: _____ HOSP. / DAY HOSP. / DIST. SURGEON. PATIENT'S FOLDER # _____

Point 3 & 4 to be as comprehensive as possible.

3. PATIENT'S HISTORY / DIAGNOSIS: _____

4. Treatment / operation / investigations performed: _____

5. MEDICINES PATIENT REFERRED ON. TO BE REPEATED _____ TIMES
(or generic equivalent)

	For Pharmacy use ONLY					
	* Date sign	Rept. date & sign	Rept. date & sign	Rept. date & sign	Rept. date & sign	Rept. date & sign
i.						
ii.						
iii.						
iv.						
v.						

* Patient has been issued with 28 days supply of the relevant medicine.

6. Continued management of this patient is handed over
OR (delete witch is not applicable)
the patient has to report back to this institution on ____/____/____ for follow up investigation.

7. REGISTRAR REFERRING: (Print Name) Dr.

REGISTRAR'S FULL SIGNATURE: _____ QUALIFICATIONS: _____

DEPT. / CLINIC / WARD: _____ TEL: # _____ DATE: _____

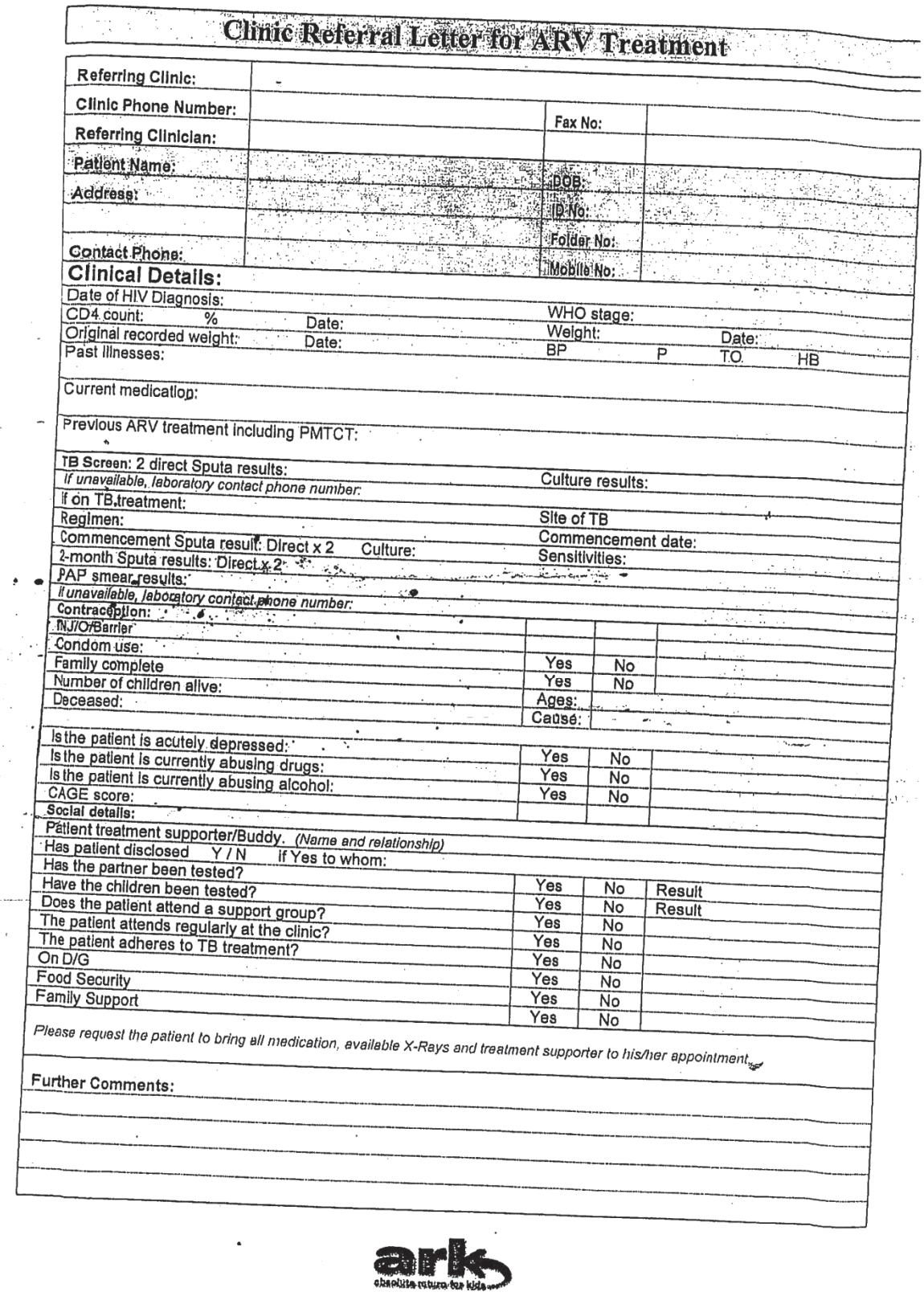
CHECKING PHARMACIST'S SIGNATURE: _____

PATIENT'S COPY

ORIGINAL

FILE COPY

Figure 33: Prescription for medicine (comes with original, file copy and patient's copy)



Clinic Referral Letter for ARV Treatment

Referring Clinic:			
Clinic Phone Number:		Fax No:	
Referring Clinician:			
Patient Name:		DOB:	
Address:		ID No:	
		Folder No:	
Contact Phone:		Mobile No:	

Clinical Details:

Date of HIV Diagnosis:
CD4 count: % Date: WHO stage:
Original recorded weight: Date: Weight: Date:
Past illnesses: BP P TO HB
Current medication:
Previous ARV treatment including PMTCT:
TB Screen: 2 direct Sputa results: Culture results:
If unavailable, laboratory contact phone number:
If on TB treatment: Site of TB
Regimen: Commencement date:
Commencement Sputa result: Direct x 2 Culture: Sensitivities:
2-month Sputa results: Direct x 2
PAP smear results:
If unavailable, laboratory contact phone number:

Contraception:			
INJ/O/Barrier			
Condom use:	Yes	No	
Family complete	Yes	No	
Number of children alive:	Ages:		
Deceased:	Cause:		
Is the patient is acutely depressed:	Yes	No	
Is the patient is currently abusing drugs:	Yes	No	
Is the patient is currently abusing alcohol:	Yes	No	
CAGE score:			
Social details:			

Patient treatment supporter/Buddy. *(Name and relationship)*
Has patient disclosed Y / N if Yes to whom:

Has the partner been tested?	Yes	No	Result
Have the children been tested?	Yes	No	Result
Does the patient attend a support group?	Yes	No	
The patient attends regularly at the clinic?	Yes	No	
The patient adheres to TB treatment?	Yes	No	
On D/G	Yes	No	
Food Security	Yes	No	
Family Support	Yes	No	

Please request the patient to bring all medication, available X-Rays and treatment supporter to his/her appointment.

Further Comments:

Figure 34: Clinic Referral letter for ARV treatment

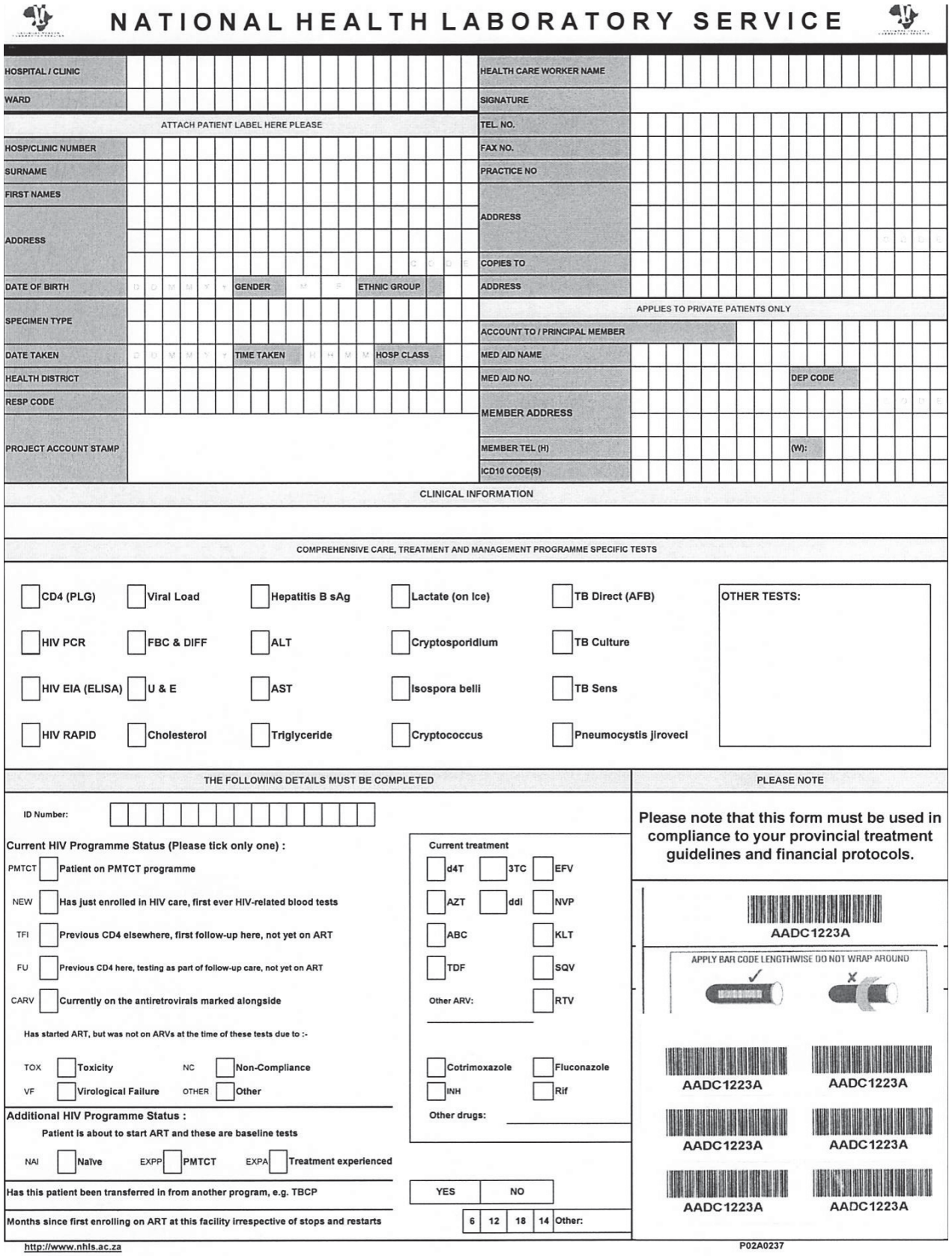


Figure 35: National Health Laboratory Services form for test ordering and results

Process	Data collection tool	Storage	
		Paper	Electronic
Individual pre-test counselling	Paper form	folder in PHC clinic	
Written consent for HIV test	Paper form	folder in PHC clinic	
HIV screening test and result	Referral to NHLS (with barcode label); result by Fax, phone, or online NHLS for printing.	Printed result in paper folder, and captured in long-term form.	Registered in NHLS
HIV positive confirmed	Result from NHLS – see previous	---“ ---	
Post-test counselling. Aim: Patients accept to get to know their HIV status	Paper form – signed by patient	Paper form in paper folder in clinic	
Test for CD4 count	Paper referral to NHLS	Printed result in paper folder - in long-term form	Registered in NHLS
If CD4 count < 200/250/350 →viral load test →referred to ARV clinic	Paper referral to ARV clinic, ARV clinic paper folder + copy referral to NHLS	Test result registered in paper folder/long-term form ARV clinic	Patient registered, and record created in eKapa, if an option, result recorded
WHO Stage (I-IV) assessed by clinician	Paper form	Result registered in ARV paper folder	Result recorded in eKapa, if an option
If eligible for ARV → home visit by Hospice, “Buddy” enrolled	Written evaluation and consent form, signed by buddy and patient	In paper folder in ARV clinic	
If TB → X-ray [complete TB treatment before starting ART]	Paper referral to X-ray, result filled in manually in ARV folder	X-ray kept in X-Ray station/hospital. Returned referral in ARVpaper folder	
Accepted into ARV program → contract signed and medication prescribed	Contract on paper form, signed; medication prescription on paper	Signed contract and prescript copy in paper folder	Pharmacy with electronic system, formal or informal capture medication in system and eventually link to eKapa
Monthly visit to clinic to collect drugs, or later every 2nd month; Or drugs distributed to remote clinics	Prescript registered in pharmacy	Drug dispensed reg in ARV folder, and in Pharmacy system	iDart or locally developed pharmacy e-system
Adherence counselling	Paper form, signed by counsellor	In paper folder in ARV clinic	Visit registered in eKapa

Table 20: HIV/AIDS process from testing to acceptance in ARV program

At repeating visits in the clinic, based on the identification of the person, and where there is no computer, the patient folder (paper) will be retrieved from the archive (figures 29/30, p.132). In case of an EHR in the clinic, the patient will first be looked up in the database, and then the paper folder will be retrieved from the shelves, to get the comprehensive

medical and historical data. The importance of the patient paper folder in clinic was emphasized by an ARV doctor, working in a clinic serving 5000 HIV patients. He described how the procedure related to data collection worked for him:

> *"I do not have a computer on my desk, but use the paper folder. It contains all the information I need. From the visit, I enter new information like test results, comments, medication in the folder. The folder then goes to pharmacy, and from there, to reception where they capture the data. That is, doctors notes are not captured, only date of visit, and other 'facts'* (interview ARV doctor 2009*).*

a) The patient retained card

The patient retained card was another important information carrier. At the first visit in clinic, a patient card was issued by the receptionist (also if using a computer system), for the patient to keep and to bring at the following visits. For identification, all cards are filled in with patient name and an ID #. Clinics online will also print, and stick a barcoded label with the following information: name, postal address, barcoded unique ID, sex, telephone number, if available, and a clinic folder number (figure 36, p.138).

There were different patient cards for ARV, TB, the PHC clinics and Day Hospitals. While ARV and TB cards were national standards, the clinic cards varied across the Districts and Sub-Districts (figures 36 - 41).

The ARV card contained the following information:

- demographic data;
- previous treatment sites and folder numbers if transferred;
- previous ART before start date;
- treatment start date, and details related to the treatment, such as:
- CD4 count;
- virus load;
- regimen changes or other interventions;
- TB treatment;
- prophylaxis changes;
- other significant clinical events.

Information on the PHC and Day Hospital cards varied from demographic data and next appointment only, to additional information, such as medication and type of service. Although, it was mentioned in one clinic that, entering for example CD4 count in the clinic card would reveal HIV status, and they were not sure if this was recommended. One patient might at times have three cards in parallel (PHC basic, TB, ARV), eventually stapled together. I asked an ARV doctor if it would be an option to merge the ARV and TB cards into one card, but she did not think this would be appropriate, as ARV is a chronic disease, and TB curable. On a closer look at the TB card, she suggested that the card should at least hold information about the patient being HIV tested or not, and eventually the CD4 count.

Table 21, p.140, gives a brief summary of the paper artefacts and the key patient information contained:

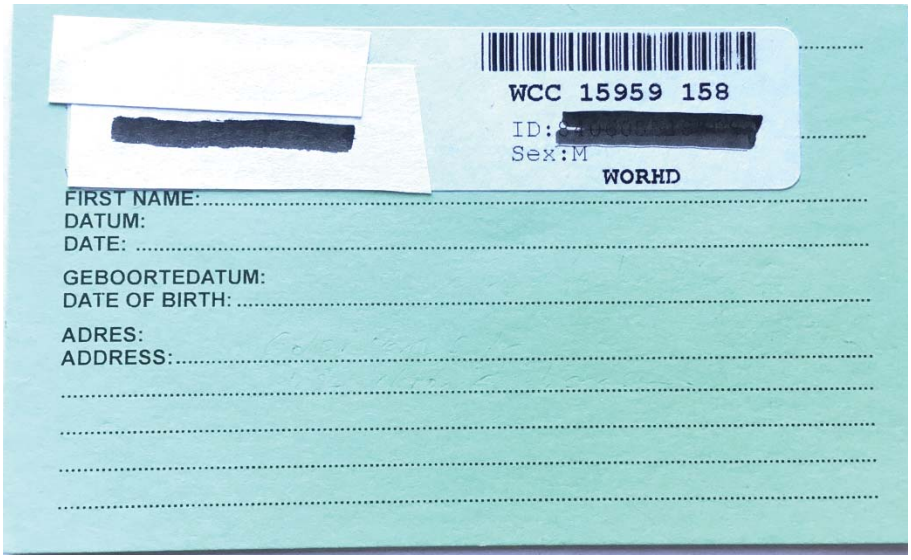
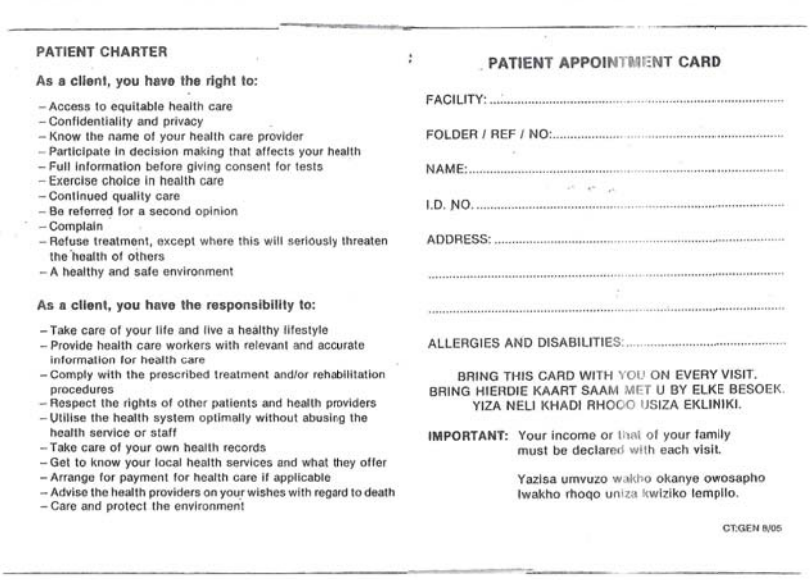


Figure 36: Patient card - Day Hospital (using colour codes for different chronic diseases)



PATIENT CHARTER

As a client, you have the right to:

- Access to equitable health care
- Confidentiality and privacy
- Know the name of your health care provider
- Participate in decision making that affects your health
- Full information before giving consent for tests
- Exercise choice in health care
- Continued quality care
- Be referred for a second opinion
- Complain
- Refuse treatment, except where this will seriously threaten the health of others
- A healthy and safe environment

As a client, you have the responsibility to:

- Take care of your life and live a healthy lifestyle
- Provide health care workers with relevant and accurate information for health care
- Comply with the prescribed treatment and/or rehabilitation procedures
- Respect the rights of other patients and health providers
- Utilise the health system optimally without abusing the health service or staff
- Take care of your own health records
- Get to know your local health services and what they offer
- Arrange for payment for health care if applicable
- Advise the health providers on your wishes with regard to death
- Care and protect the environment

PATIENT APPOINTMENT CARD

FACILITY: .....

FOLDER / REF / NO: .....

NAME: .....

I.D. NO. .....

ADDRESS: .....

.....

.....

ALLERGIES AND DISABILITIES: .....

BRING THIS CARD WITH YOU ON EVERY VISIT.
BRING HIERDIE KAART SAAM MET U BY ELKE BESOEK.
YIZA NELI KHADI RHOCO USIZA EKLINIKI.

IMPORTANT: Your income or that of your family must be declared with each visit.

Yazisa umvuzo wakho okanye owosapho lwakho rhoqo uniza kwiziko lempilo.

CT:GEN 8/05

NEXT APPT.	DATE	TIME	INVESTIGATIONS	SYMBOL	TREATMENT GIVEN	FACILITY	SIGNATURE

Figure 37: Patient card - PHC (front/back)

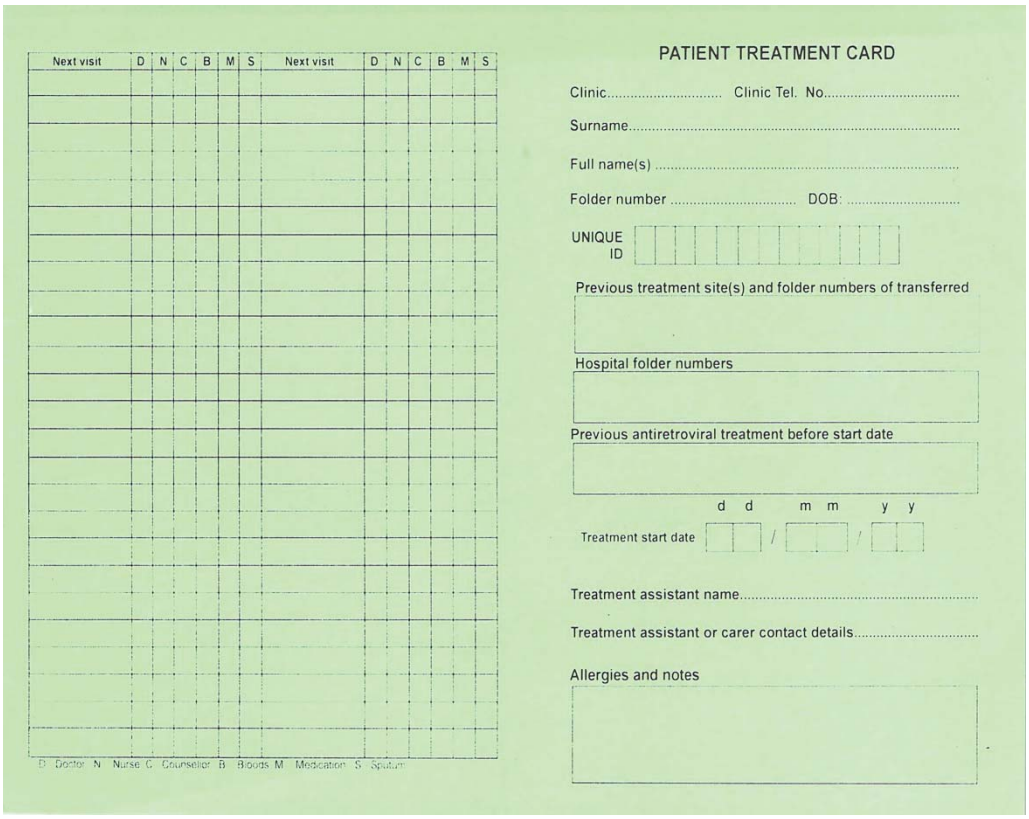


Figure 38: ARV treatment patient retained card, front and back – National and Provincial standard

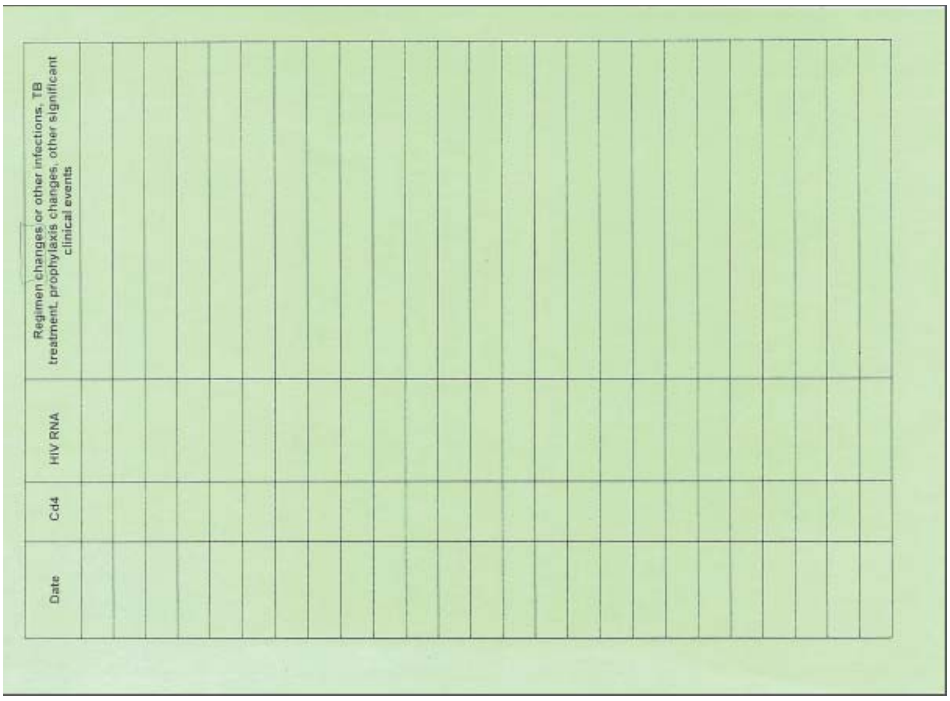


Figure 39: ARV treatment patient retained card (inside) – National and Provincial standard

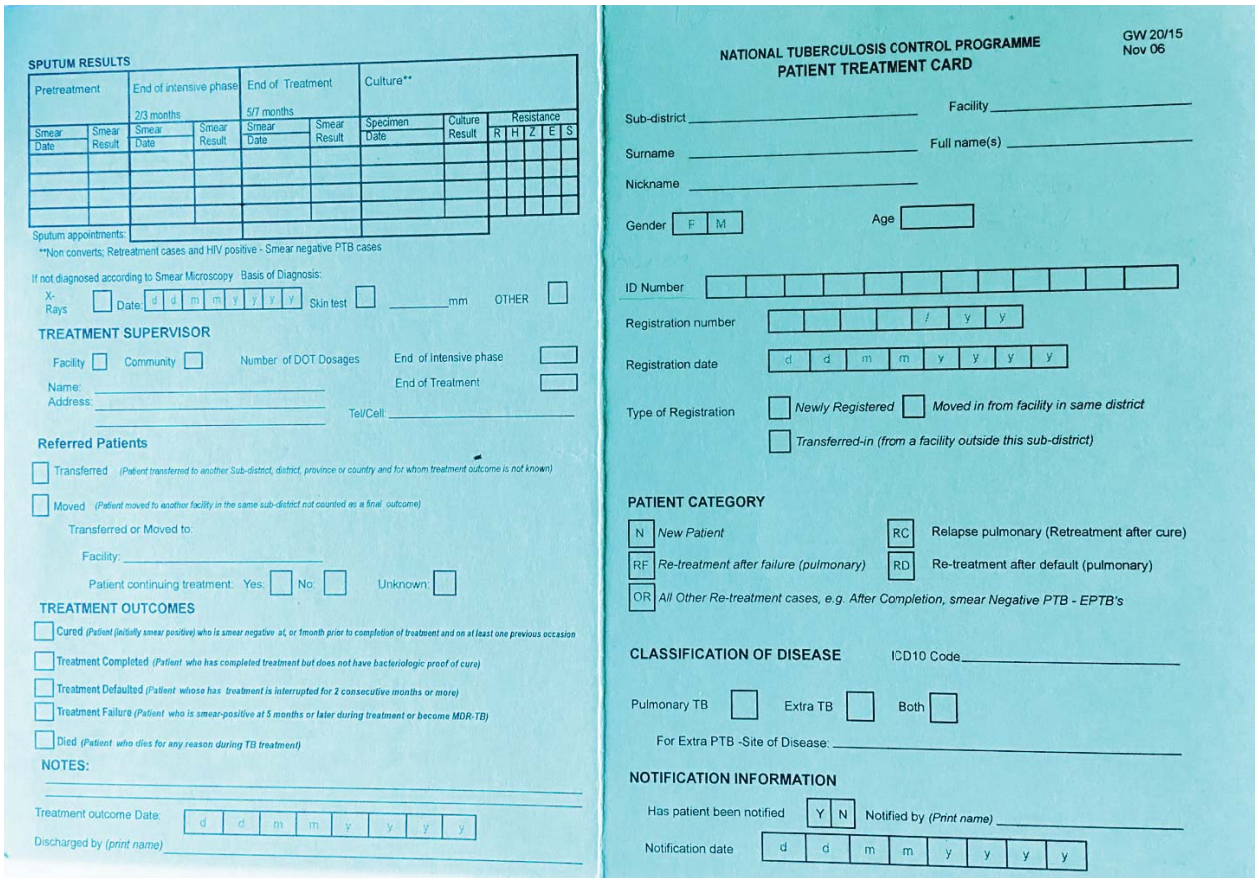


Figure 40: TB patient treatment card – National standard

Information	Artefacts				
	Paper				
	ARV card	TB card	PHC card	Paper folder in clinic	TB folder
ID + folder #	x	x	x	x	ID#/TB-reg#
Previous treatment sites	x			referral clinic	referral clinic
Demographics	x	x	x	x	x
Appointments	x	x	x	x	
CD4/HIV viral load	x		*optional (may reveal HIVstatus)	x	x
Clinical notes				x	x
Medication				x	x
ART history	x			x	x
TB sputum	x	x		x	x
TB treatment and history	x	x			
OI[74]	x			x	x

Table 21: Patient information in paper artefacts

[74] Opportunistic infections

b) *Electronic patient records*

An electronic patient record would under ideal circumstances comprise the same amount of data as contained in the paper folder. According to the definition, following-up chronic diseases like HIV/AIDS, the record will need to accumulate data during a patient trajectory over a lifetime:

> *"The electronic health record (EHR) is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data, and radiology reports."*[75]

As described in Ch 5.1.4 and 5.1.5, the requirements in the definition above was in this case currently not met by the patient records in PHCIS or PREHMIS, or eKapa. The EPR's recorded mainly demographic data and date of visits for follow-up, and even if eKapa included clinical data, the information from numerous paper forms and reports (e.g. assessments from home visits, signed consent forms etc.) as mentioned earlier, were not added.

From the folder number in PHCIS and PREHMIS you could see the clinic that opened the folder for that patient, so that you might call this clinic for additional information. As the ARV doctors did not have computers, and the EPR on their desks, this was often needed, and time consuming, and the health worker did not always succeed in getting contact with the clinic in question, or obtain the information needed. The doctors and nurses emphasized the importance of having the paper forms available in the folders, for checking notes taken during treatment, and to have signed forms for acceptance and home visits, and being able to follow the patient's health status over time.

The medication dispensing system, iDart, was a pharmacy module that communicated with eKapa to get patient information. It had limited functionality, and had been implemented in only one of the clinics involved in the study (in total 4 Cape Town clinics 2010). According to the business analyst:

> *"iDart is stored to this pc's local desk, and will speak* to *eKapa to get patient information. The patient will come from his doctor's visit with a paper folder to the pharmacist. The pharmacist is then online, that is one of the bad things, the pharmacist is online, but the doctor isn't! So, we can't use that (the paper script) as an electronic script, [...] so the paper folder is taken. Because the patient is in the system, iDart draws all the patient information, not the episodic information, just the patient information. The downside is that, iDart, as you can clearly see is a standalone on their pc, standalone in that facility. We had it running in xxxx clinic, and the PC crashed, so any information they had on iDart went with the PC. Because it was running there, we did not have the ability to give them their backups."*

The various conditions and shortcomings in limited resources, systems and clinics taken into account, one ARV doctor claimed that:

---

[75] https://www.himss.org/electronic-health-records

"*Under these circumstances, the most reliable patient record is the patient retained card. There are not resources for full EPR in all clinics. Money is needed for more clinics, staff, and medicines".*

I asked one nurse in a MOU section in what way she would say that they were benefiting from the electronic system in their daily work practice and patient management. She answered: "*As of now, not much, because none of the nurses or the doctor have a computer."*

6.2.2 Interface – the coordinative artefacts

Transfer of information between systems, within and between clinics as well as between administrative levels in the health management hierarchy is important, and is also emphasized by the WHO:

> *"A repeated wish from country representatives was that the information system should "ideally be one system". However, most countries will develop paper-based systems in combination with electronic based information systems. Even in countries with advanced information systems, combinations of paper- and electronic-based systems exist. It is arguable that even with a well-developed electronic system, one will need a paper backup system."*
>
> *"What is therefore important is that the transfer of information is standardized, allowing the different systems to "talk" with each other. This is important in terms of an exchange of information between clinics, or from clinic to sub-national or national levels and vice versa." (WHO_EMR meeting report 2004, p.11).*

As described in Ch 2.4.1, the term 'coordinative artefact' has been used in the literature to denote a number of different artefacts, such as the patient folder, the patient card, or any other of the paper forms used to capture, and/or transmit patient information from one instance to another, some of which in this thesis are included in 'the collection of artefacts' in Sec 6.2.1.

In the process of sharing data, standards play an important role, and the concept 'gateway', has been used to describe an interface between standards. I have chosen to use the 'interface' concept in the more general meaning of being "*a point where two systems, subjects, organizations etc. meet and interact*" (ref Ch 2.5.2, p.44). In the following, I will describe some of the coordinative artefacts in the case presented, and their role as 'interfaces' in clinic, and across health care providers. I will particularly focus on artefacts that connect the paper and electronic modules in the health information system, and thus allow sharing of information about a patient in a hybrid HIS, and also transmitting aggregated data to administrative levels. The connections may work from paper to electronic as well as the other way around.

Patient data that needed to be coordinated and shared in HIV/AIDS care and treatment are described in sec 6.1, i.e.: personal ID and clinical information related to HIV/AIDS, like HIV status, CD4, lab results, clinical history, TB status, and X-ray results. The paper as well as electronic modules had standards for capturing data, data that needed to be shared or 'translated' (Braa et al, 2007) between them.

a) Patient ID and clinical data

The most 'revolutionary' artefact, working as an interface, was no doubt **the barcoded sticker** with the unique personal health ID, drawn from the patient master index (PMI). Printed, and then pasted on to a number of paper cards, folders and forms, it helped identifying people almost without changing the standard paper forms (figure 44, p.145). Using **a hand-scanner** and one computer online, it worked as the key to the digital databases. Despite the problems presented by the personnel related to identification, the overall impression was that the barcode label made a huge difference. Most people interviewed emphasized this, and described it as a revolution. By scanning the label, the receptionist would be connected to the electronic patient folder (in PHCIS, PREHMIS, eKapa, iDart), thus getting access to the information captured there, although limited as described before. Demographic data, and the clinic that opened the record, would be available for most clinics online, and the patient´s clinical data only for clinics with eKapa. For clinics offline, there was also the option to scan the folder number, and register that the patient attended this clinic on a specific day, given that a patient ID had been registered previously in hospital or a clinic online, and that the patient brought his card or referral with the barcode label to the clinic.

The two Health Administrations in the Province and The City Health, shared the patient PMI, thus it was possible to identify a person across the two health administrations through the barcode system, but only to get his demographic details. RMR items were also standardized across PHCIS and PREHMIS, only the prefix on the barcode for the software differed (e-mail business analyst, Dec 2010).

b) LAB results

Access to results from tests sent to lab, was crucial for treatment. Most laboratories used the National Health Laboratory System (NHLS). Results from NHLS were communicated either on paper directly from lab to clinic by courier, through fax, or via web-services, where the result could be looked up and then printed (figure 35, p.135). The need for quick response for, for example TB sputum, and also to submit reports to higher-level authorities, the clinics found the fax machine important. Scanning the paper documents, and then transmitting by telecommunication links, was seen as the quickest and most effective way to send and receive information.

Although there was the option to access NHLS online, this had limited functionality. Authorized personnel had the option to look up one patient at a time, and only a patient from their clinic. It was not possible to import/export data between NHLS and eKapa, and as NHLS had their unique way of assigning the patient ID, this was adding complexity to patient identification. The goal was however to be able to have eKapa working with NHLS system, which still would be an option only for the few clinics having the eKapa module installed. One Clinic manager claimed that, keeping up with getting access, and capturing data would not work without the wonderful staff. She had a computer, and they were sent to courses to be computer literate, but they were not all online for PHCIS. She could connect the Internet and get lab results, that was all. She could access PHCIS in the reception with a code, or some of the clerks would help her in. Lab results then needed to be printed and captured in the folders manually, and they were lagging behind, which created problems.

When it was not in the folder, the nurse needed to look it up in the Lab system online once more.

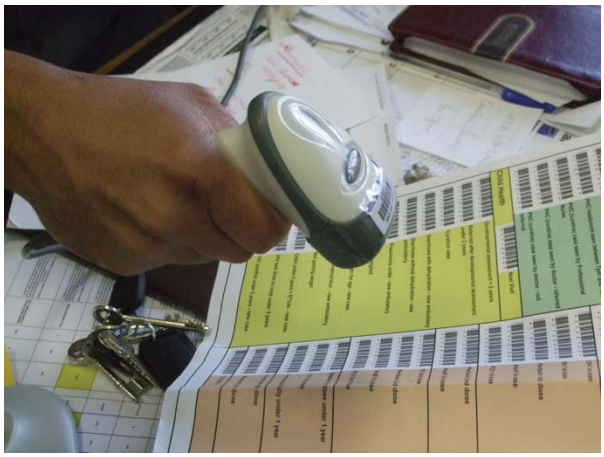


Figure 41: Barcoded patient data elements recorded after visit.

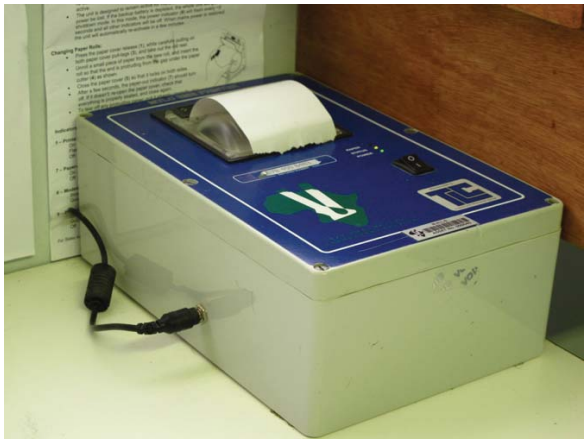


Figure 42: (TB) fax machine

c) Prescriptions

The pharmacy system JAC, was supposed to communicate with PHCIS so that prescriptions would be sent electronically directly to the pharmacy. The system did however require resources that the smaller clinics could not provide, so this would only be an option for the larger hospitals. One CHC in the case study had been selected for the implementation of JAC, but when the technicians arrived for installing the system, it turned out that the requirements for computers as well as personnel far exceeded their capacity, and the 'experiment' was cancelled.

The doctors in the clinics did not have computers; hence there were no electronic prescriptions, and the prescriptions for medication were issued on paper forms (figure 33, p.135), and information entered into the paper folder, or captured in eKapa, where available, by the data clerk.

One pharmacy had the Clinicom HIS installed, for hospital and clinic at the premises, as they served both, and they also served the remote clinics. All medication for chronic diseases was dispensed there, and all prescriptions from the clinics came to them. The medicines to the outreach clinics went with one of the staff members out to the clinics (figure 43, p.145). Normal chronic diseases would go every 2nd month, HIV monthly, as also TB. The pharmacy controlled the stock, and also the stock at the clinics. They did not have an electronic system for this, but used stock cards.

On the patient cards they had the Clinicom stickers, so you could see that they had been to the pharmacy, but not the type of medication. The pharmacist stapled the copy of the prescription to the card. One copy stayed at the pharmacy, one in the paper folder and one on the patient card/folder.

As described in sec. 6.2.1, the electronic medical dispensing system iDart, was implemented in a few clinics only, and would read the barcode label for limited use. Thus, patients brought their prescriptions to the pharmacy physically, with or without a barcode label, depending on the clinic that issued the script.

Figure 43: Folders and medication in Pharmacy, ready for outreach to remote clinics (chronic diseases)

Figure 44: Hybrid collection of artefacts with barcode labels

According to one pharmacist, the new procedures related to ARV treatment, had its drawbacks, as the disease was now (2010) categorized as ‘chronic’, and the health services distributed from the ARV clinics to PHC clinics. Before this new procedure, the pharmacist dispensed ARV medication to the patient, as the pharmacy was located in the same premises as the ARV clinic. They would have seen the patients in person, carrying their folder to the

pharmacy, thus being able to pick up other information that might have been of importance, such as the overall condition of the patient, and if perhaps wrong medicine or wrong doses were prescribed.

Now that the treatment was distributed to the remote clinics, they had to pre-pack and distribute medication (for all chronic patients) to these clinics according to prescriptions only. They only made notes on the prescriptions what they had dispensed, and the nurse in the clinics would enter this information into folders and forms. Stock management and item dispensed was still (2010) done on paper forms (self-developed), to be able to meet the requirements for reports and statistics (figure 27, p.126).

d) X-ray

For an ARV doctor, it was also important to have x-ray results for a complete picture of the patient and treatment. To get this information was often more complicated than achieving other types of information. There were no x-ray imaging systems in the public health, so ARV doctors were dependent on patients bringing their images to the doctor. According to one doctor, this did often not happen, and he explained the importance of having the image as well as the written analysis from the X-ray doctor:

"Even if I see the sputum, and I get the results, I need to get the x-ray to see if there are any neurological changes, and that I don't have. Then they say: the x-ray was taken and it is at the TB clinic. Then I phone the TB clinic and they say, no, we have sent the x-ray back to the hospital, because they don't keep the x-rays at the clinic, they send it back to the central where the x-rays are stored. You end up repeating x-rays, [...]" (ARV doctor 2009).

This doctor was eager to have an electronic system in place for his patients, but realized that an x-ray system still was an unrealistic dream in a near future.

e) Facility, District and HIV/AIDS/TB Program management

To meet the requirements for reporting clinical patient data in aggregated format to (Sub)-District, Programs, National and International Agencies, the clinics used different tools for different purposes. The size of the clinic, and number of patients on ARV for example, influenced the need for structure and technology.

At PHC facility level, data clerks collected individual patient data, collated and compiled monthly reports, to be sent to the facility manager, or in a bigger clinic, to the information manager. They were all using standard forms with a set of selected data elements. In a large clinic with several sub-units, such as ARV, TB, MOU, pharmacy, and X-ray, all units had specific forms for reporting to District and Program management. To follow the development and results within HIV/AIDS and ARV treatment, some sentinel sites had also been selected to do cohort analysis (ref sec 6.1.4, p.127 and figure 48, p. 149).

Clinic managers in the provincial PHC did their reports manually. They reported the RMR[76] form to the (Sub-) District, where the results were entered into the computer systems, for compiling reports to the programs and management respective. The clinics got feedback in graphs, showing how they were doing related to baseline and targets set. For clinics with eKapa installed, the District office could collect the information online. If not, these reports were often sent by fax or using USB sticks.

[76] Routine Monthly Report

For monthly reporting, **City Health** kept the RMR tick-sheet in the paper folder (figure 47, p.148), filled in by the health worker when seeing the patient. After treatment, the folder was returned to the data clerk, who scanned the information using the A3 sheet, where all RMR data elements were barcoded (figures 45-46, p.150) for statistical purpose and reports compiled to District. This it allowed for quick registration of visits and the RMR.

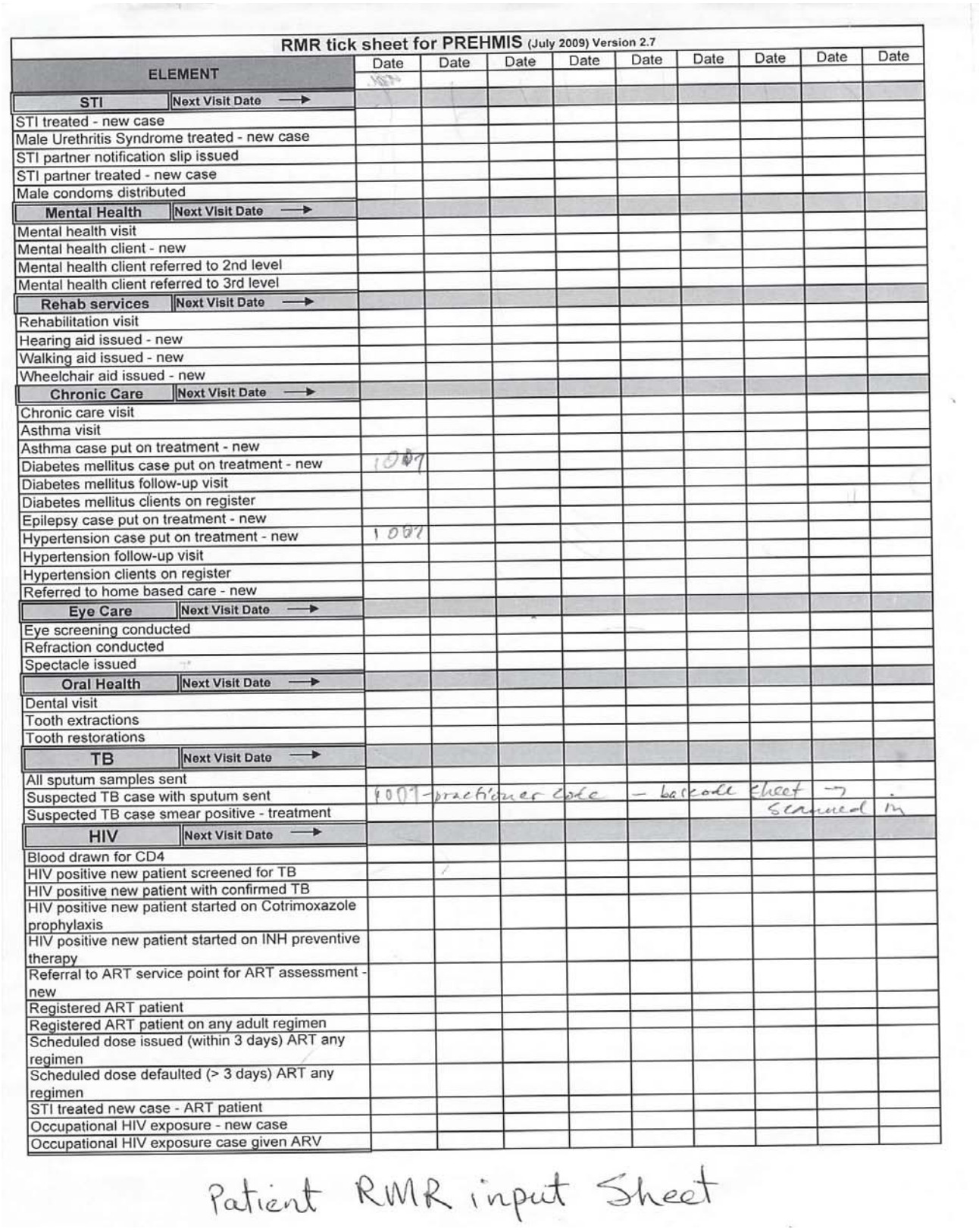
City Health and Province used different forms for registers and reporting, and the ARV and TB registers were not 'speaking'. The data clerk in the combined ARV and TB clinic submitted his ARV report (compiled from eKapa) to the information manager in clinic, while the TB clerk sent his report to Sub-District.

Registers for program management and routine aggregated data were submitted from the clinics to higher levels administration partly on paper forms, using fax or on USB sticks, or from a few facilities, electronically online. In the clinic with ETR.net implemented in the TB section, the TB coordinator from District still retrieved the data onto a USB stick in clinic, and then entered into ETR.net in his office.

Even the Information Manager in a larger Cape Town clinic, with several sub-units, such as ARV/TB and MOU, did all the statistics manually. The reception only, had one computer in his section. He did the headcount calculation on PC, but submitted the results on paper monthly by fax, and he reported only to the Metro District Health Services (MDHS). MDHS then reported to Provincial Department of Health, where it was entered into Sinjani. He knew little about eKapa, iDart or other electronic systems. The MOU section submitted their reports directly to City Health (MOU register, PMTCT, ANC HIV counselling and testing register). Private sector, NGO's, and community projects involved in a number of HIV/AIDS projects, also reported their activities to the facilities/Sub-District on agreed upon data elements, but is not part of this study.

Summing up hybrid health information systems

In Ch 3 Methodology, I describe my search for theory and ways of analysing a system with hybrid components, as presented in Ch 2.5. In table 22 (p.151), I have combined Ulrich's (1995), idea of *"mapping from functional elements to physical components"*, and Parnas (1972), *'Criteria on modular structure of complex systems'*. The **components' 'functions'** being the different categories of health work practices, and the **hybrid modules** using the **interfaces** between (parts of) modules, to meet these information needs, where **'interface'** is of the utmost importance for the functionality of the hybrid system.



RMR tick sheet for PREHMIS (July 2009) Version 2.7

ELEMENT	Date	Date	Date	Date	Date	Date	Date	Date	Date
STI Next Visit Date →									
STI treated - new case									
Male Urethritis Syndrome treated - new case									
STI partner notification slip issued									
STI partner treated - new case									
Male condoms distributed									
Mental Health Next Visit Date →									
Mental health visit									
Mental health client - new									
Mental health client referred to 2nd level									
Mental health client referred to 3rd level									
Rehab services Next Visit Date →									
Rehabilitation visit									
Hearing aid issued - new									
Walking aid issued - new									
Wheelchair aid issued - new									
Chronic Care Next Visit Date →									
Chronic care visit									
Asthma visit									
Asthma case put on treatment - new									
Diabetes mellitus case put on treatment - new	1007								
Diabetes mellitus follow-up visit									
Diabetes mellitus clients on register									
Epilepsy case put on treatment - new									
Hypertension case put on treatment - new	1007								
Hypertension follow-up visit									
Hypertension clients on register									
Referred to home based care - new									
Eye Care Next Visit Date →									
Eye screening conducted									
Refraction conducted									
Spectacle issued									
Oral Health Next Visit Date →									
Dental visit									
Tooth extractions									
Tooth restorations									
TB Next Visit Date →									
All sputum samples sent									
Suspected TB case with sputum sent	1007 - practitioner code - barcode sheet → scanned in								
Suspected TB case smear positive - treatment									
HIV Next Visit Date →									
Blood drawn for CD4									
HIV positive new patient screened for TB									
HIV positive new patient with confirmed TB									
HIV positive new patient started on Cotrimoxazole prophylaxis									
HIV positive new patient started on INH preventive therapy									
Referral to ART service point for ART assessment - new									
Registered ART patient									
Registered ART patient on any adult regimen									
Scheduled dose issued (within 3 days) ART any regimen									
Scheduled dose defaulted (> 3 days) ART any regimen									
STI treated new case - ART patient									
Occupational HIV exposure - new case									
Occupational HIV exposure case given ARV									

Patient RMR input Sheet

Figure 47: RMR tick sheet used as source for scanning RMR elements (PREHMIS)

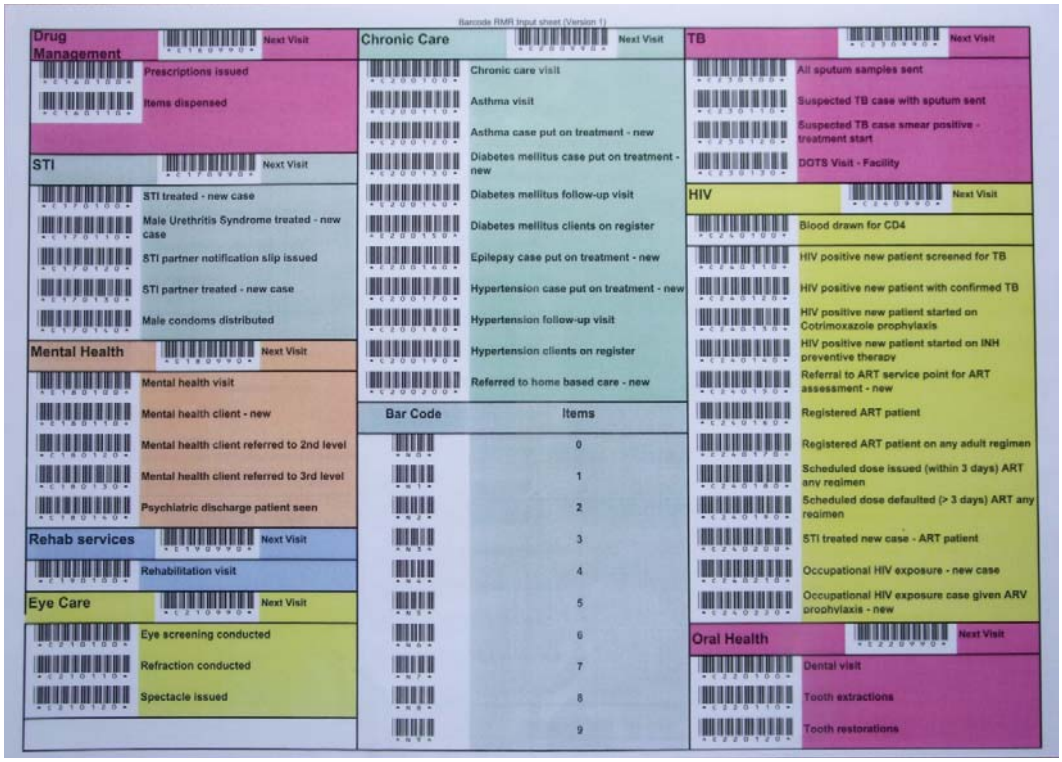
Cohort Analysis Report

Report on Treatment Status/Outcomes for Cohorts on ART — Cohorts are defined by month/year they started ART.

Facility:

	For cohort starting ART by month/year: at baseline then results at 6 months on ART, 12 months on ART, 24 months on ART	Cohort Jan 04	6 mo- July04	12 mo- Jan05	24 mo- Jan06	Cohort Feb04	6 mo- Aug04	12 mo Feb05	24 mo- Feb06	Cohort Mar04	6 mo- Sep04	12 mo Mar05	24 mo- Mar06
X	**Started on ART in this clinic**												
Y	**Transfers In**												
Z	**Number in Cohort**												
H	**Continuing on Original 1st Line Regimen**												
I	**Substituted to Alternative 1st Line Regimen**												
J	**Switched to 2nd Line Regimen**												
D	**Stopped**												
E	**Died**												
F	**Transferred Out**												
G	**Lost to Follow-up (DROP)**												
	Percent of cohort alive and on ART												
	[(H + I + J) / Z * 100]												
	CD4 median or proportion ≥ 200 (optional)												
	Functional Status												
	Proportion Working												
	Proportion Ambulatory												
	Proportion Bedridden												
	Number of persons who **picked up ARVs each month for 6 months**		X	X	X	X	X	X	X	X	X	X	X
	Number of persons who **picked up ARVs each month for 12 months**		X	X	X	X	X	X	X	X	X	X	X

Figure 48: Cohort Analysis Report on ART treatment status and outcome



Figures 45-46: Double-sided print - A-3 form with barcoded items

COMPONENTS Function of a product = 'what it does' (Ulrich)	MODULES Parts of modules (Parnas) Collection of artefacts		
'Work practices'	**Paper**	**Interface**	**Electronic**
Patient identification	Patient held card Patient folder (name or #) National ID book Passport # Referral letter	Clinicom barcode sticker; Handscanner;	Clinicom HIS (PPMI) PHCIS (incl CRADLE) eKapa PREHMIS ETR.net NHLS
Follow-up in clinic: - Appointments - Medication (adherence) - TB/ANC - Other OI - X-ray	Patient held cards (TB/ARV/Clinic); Patient paper folders (TB/ARV) with longitudinal forms, prescription (dispensed drugs noted); more notes; Booklet (MOU)	Barcode sticker Prescription (copy) Referrals (copy) X-ray, with doctors note	Clinicom HIS PHCIS eKapa [CRADLE] PREHMIS NHLS
Follow-up across sites: - Laboratory- tests - Pharmacy-drugs - X-ray - CHC -> ARV clinic - Clinic -> Hospital	Patient held cards (ARV/TB/Clinic); Referral letters Prescription Test results in referral X-ray image+doctors note	Barcode sticker on cards, paper forms, and lab tests; NHLS access online, and/or by phone or fax;	Clinicom HIS PHCIS eKapa PREHMIS NHLS iDart
Registers/reports: - RMR - ARV - TB register - PMTCT /MOU - VCT - Medicine stock	Paper reporting forms - various register forms and books; Locally developed paper systems for medicines stock management; ARV: monthly summary forms, cohort; TB-reg paper form	RMR, PMTCT, medicine and ARV: from paper form to eKapa, fax or USB-stick respectively; TB-reg on USB or fax	eKapa eRegister ETR.net PREHMIS → RMR Local developed software for medicines stock management

Table 22: Hybrid health IS in a modular structure

The next section will analyse the paper and electronic artefacts in terms of what they may provide of relevant information, as well as what are their constraints in the different settings, i.e. the affordances of the artefacts.

6.3 Affordances

In Chapter 2, different views on the concept affordances are presented, from the introduction by Gibson (1979), to a number of researchers within CSCW and other disciplines (Norman 1999; Gaver 1991; McGrenere and Ho, 2000; Bærentsen and Trettvik, 2002), shifting the focus from interaction between animals and the environment (Gibson), to human action in cultural environment (Bloomfield et al, 2010; Kaptelinin et al, 2010). Emphasis by most authors is on information technology, and the question whether artefacts have 'objective' affordances (potentials).

In this section, I will focus on the affordances of the artefacts (the hybrid), from the perspective that both technologies have 'objective affordances' in terms of the

potentials/benefits they offer in meeting the information needs in HIV/AIDS care. The assumption is that, these properties can only be understood in relation to the context, i.e. policies, plans, material and personal resources. In the next sections, a few examples from health workers' daily work situation and challenges will be presented, highlighting some pros and cons of the technologies, as perceived by the actors in the specific contexts.

6.3.1 Vignettes

Vignette #1

One ARV doctor describes his current situation in the ARV clinic (also doing outreach to 8 remote clinics for ARV treatment), and how the available information artefacts affect his daily work with the patients:

> *"He thinks they now have 450 patients on ARV, and (almost) all data and processing is done paper-based. He thinks that they are at the peak of what they can manage manually, with only the two of them to handle all this (i.e. calculate adherence, check for defaulting, see the patients in all the clinics, assess whether ARV should be started, when to give up, and register as lost-to-follow-up). If he could have an EPR like the PHCIS, he could track his patients much easier. And for treatment, he needs to see the x-ray, to see if there are any neurological changes […]".*

He is positive to having EPR in the premises, and he has high expectations as to what the EPR might provide.

> *"Ideally, I would like to put my patients last CD4, their viral load, the liver function's test on, and if this patient gets seen somewhere else, like in Robertson or Worcester or wherever, they can at least see my information"*
> (fieldnotes from interview, Nov 2009)

He points to the limitations with a *paper-based system*, where they to a large extent depend on the patients bringing their cards and referrals. On the other hand, he emphasizes the importance of a number of artefacts, with information that will not be added to the electronic patient record, such as the x-ray, consents forms, hand written reports from home visit, and more. He sees the challenge if all these artefacts should be captured and entered into one system, one way or the other (scanning, access to image systems for x-ray), but he thought a combined solution would make a lot of things much easier to handle.

Vignette #2

Another ARV doctor in a larger ARV clinic, treating up to 5000 patients for ARV a month, describes his work routines:

> *He (or any other medical staff) does not have a computer on his desk, but he uses the paper folder at patients' visits. The folder contains all the information he needs. After treatment, he enters new information, like test results, comments, and medication. The folder then goes to pharmacy, and from there to reception, where they capture the data into eKapa. That is, doctors notes are not captured, only date of visits, and other 'facts'. As he is the Principal Medical Officer, he needs to plan for staff, medicines etc., and he has access to eKapa. He uses the system for statistics, research and projects. They compile weekly list of defaulters, with information about those patients, health status etc., to see what kind of follow-up is needed.*

He would not want a computer on his desk for use during consultations, as he has approximately 5 minutes per patient, but would very much like to have a computer system to enter key clinical information, including x-rays, and scanned consent forms etc., which would save a lot of duplicate work. When I asked who should enter the clinical information into the full EPR, he thinks it should be medical personnel, doctors or nurses, not data clerks. He does however acknowledge that their caseload probably might pose a capacity problem in PHC, with both x-ray and scanned documents included (fieldnote interview, Nov 2009).

Vignette #3

A TB nurse in a smaller clinic, also seeing HIV/AIDS patients for HIV test and CD4 count, worked paper-based mostly, and at our first meetings, she used fax for receiving test results. The clinic then had one computer in the reception, used for locally keeping a register of their patients, but at our later interviews, the clinic had PHCIS implemented, and she described the new situation:

She was very satisfied with the barcode labels, and the option to register the patient electronically, being able to see if he had been to another clinic before, even if there were no clinical details registered. The option to print the barcode stickers, and put them on the patient held cards, the prescriptions and other paper documents, was very useful. She did however not want to have a computer on her desk, as she felt, it would be totally disturbing if she would enter data while treating the patient (fieldnotes interviews, 2009/2010).

Vignette #4

Related to the replacement of the 'Delta 9' Hospital system to 'Clinicom', the information manager in one hospital, with ARV clinic in the premises, explains the problems with the transformation. They had 93,000 folders to transfer, and they had to engage an extra person for 6 months to get the work done. According to the information manager:

"The nurses were not allowed to do the job, because there was more 'admin information' than clinical info (about the patients) to enter and 'admin' was not in their work instructions.

In 'Clinicom', you might get 4-5 folders, because they use different names etc. You can find the duplicates, but it takes time to merge them. Creates extra work" (interview information manager 2010).

These examples from everyday health work practices show that, following patients and capturing relevant health information constitutes a composite whole, where both paper and electronic artefacts play important parts, and there were different views among the health personnel on the use of computers when seeing patients.

6.3.2 Affordances of electronic artefacts

Key electronic artefacts for patient care and treatment in PHC emphasized in the HIS literature, are listed in table 18, p.105. Potential benefits described in the literature are mainly: 1) Patient information being accessible regardless of where you are located, in clinic and across service providers; 2) EPR will reduce redundancy and improve quality of health care services; and 3) have the possibility of multiple uses of data recorded once, to be used

for different objectives; i.e. reporting, statistics, financial and other admin processes (Institute of Medicine, 2003; Gurley and Rose, 2004).

Constraints and limitations are also discussed, with particular challenges mentioned in DC's, related to disease challenges such as the HIV/AIDS pandemic, lack of resources, and security issues, and there seemed to be a general view that affordances should be assessed in relation to context/environment. In the table 23, the potential benefits emphasized in the discourses when using electronic patient records are presented, related to the electronic systems in use in the WC Province, as well as the 'actual information provided', to being able to assess how, or to what extent, they meet the requirements for patient information in health care treatment.

Artefact	'Objective'/ potential benefits	Actual information provided	Limitations / constraints
PHCIS, PREHMIS (patient folder)	Complete patient information, accessible across time and place; multiple use of data recorded once	Name of clinic that created the folder; Clinicom ID #; Demographic data; Date of visit	Lack of clinical data; lack of resources, technological and personal; i.e. no computers in remote areas; unstable or no Internet
eKapa	Patient information HIV/AIDS, across time and place; Multiple use of data, recorded once	Demographic data, visits, clinical information and history; Compiles reports, statistics for management	Lack of resources to taking full advantage of the application; implemented in a few clinics
eRegister (500-2000 patient load)	Works as a step up to eKapa; option to migrate to eKapa when >2000 patients	Aggregated data, useful for management; no individual patient data	Electronic copy of paper register; Need computer and Internet
iDart	Monitor ARV stock and patient drug dispensing – linked to eKapa	Demographic data; reg. patient medication; Calculates adherence	Standalone in pharmacy/ facility; i.e. no backup from Province; Connects to eKapa, but not doctor;
NHLS	Provide lab services to all public sector healthcare providers	Demographic data; clinical information to ARV/TB/PMTCT	Limitations in access to the results, and/or electronic transfer of patient data from NHLS to PHC

Table 23: Affordances of *electronic* artefacts

6.3.3 Affordances of paper artefacts

Sec 6.2.1 presents the collection of artefacts involved in creating a patient record, and gives a detailed description of the paper artefacts, and the role they play in providing patient information.

Table 24, give an overview of the key paper artefacts involved in keeping the patient record for an HIV/AIDS patient, listing the information in the paper artefacts (almost) providing the complete information needed, however with different limitations for use across health care providers.

Artefact	'Objective' / potential benefits	Limitations / constraints
Patient ARV folder	Comprehensive patient information, 'visibility at a glance'	Only available locally; if new patient in clinic, dependant on patient to bring information from, or have to call previous clinic; may temporarily be misplaced
ARV card without barcode label	Not complete, but carries sufficient clinical information (according to ARV doctor)	Depends on patient to bring card, and additional information (referral+)
ARV card, with barcode label	Not complete, but good. Enables link to EPR for ID and visits	Depends on patient to bring; possible to manipulate; need referral, prescript + in addition
Referrals and results after treatment, NHLS, X-ray etc.	Important clinical information; essential for follow-up	Depends on the patient to bring the referral, and the referring instance having filled in the information required; access to NHLS results depends on context
Prescription	Important clinical information; essential for treatment	Depends on patient bringing to pharmacy; and copy archived in paper folder
Hand written reports, consent forms etc.	Complementary information – seen as important by health personnel	Only partly shared, like copies in Pharmacy, some results on ARV/TB cards
ARV/TB- reports, RMR, Cohort analysis	Important reports for routine and resource planning; Convey local statistics to higher levels	Time consuming to prepare; Capacity depends on headcount (500 max on ARV); Depend on fax, USB stick or other ways of transmission

Table 24: **Affordances of *paper* artefacts**

6.4 Affordances of hybrid health information systems

There is clearly a gap between the affordances of most of the electronic systems involved in terms of providing the 'potential benefits', and in presenting the 'complete patient record', thus giving the health worker access to health data important for treatment. From the case data collected, potential benefits seem not to be realized in practice, but the electronic artefacts do contribute positively in a number of ways. To get the information necessary for treatment, paper artefacts are however still crucial. This leads to the question of redundancy and robustness in the health information system. The next sections will focus on data collection and coordination in health care, related to the question whether health data are collected more than strictly necessary, thus being redundant, and leading to inefficiency, or being crucial to achieving a robust and secure system. The role of redundancy related to coordination of information in health work practices will be analysed in section 6.4.1, followed by a security and risk analysis related to the robustness perspective on health information systems and health care in sec 6.4.2.

6.4.1 Coordination of health care – the role of redundancy

The declared aim in health care, both in CSCW and ISD discourses, is to provide quality information, to enable quality health care services. As described in Ch 2.5.3, the focus and view on redundancy to meet this aim differ, ranging from the vision of 'zero redundancy', to redundancy being described in some instances as productive (Landau 1969; Cabitza et al 2005), or even crucial (de Vries and Nyemera 2010).

Ellingsen and Monteiro (2003), introduce different types of information, and categories of redundancy, as elaborated in Ch 2.5.3, claiming the *'essential ones'* to be: 'related, but

different' information (supplementary), facilitating robustness. Cabitza et al (2005), have a similar categorization of the concept. Both models distinguish between data recorded in the same artefact or in different artefacts.

Although the paper folder keeps copies of a number of artefacts (forms) with both duplicated and supplementary kinds of information, the folder will be seen as one artefact in this case.

This section will analyse the collection of artefacts involved in the patient record, paper and electronic, in terms of what information is captured in the artefacts in relation to information needs, i.e. a) identification; b) clinical information and history; c) follow-up/adherence, with a focus on:

- What information is
  - duplicated (redundant)
  - supplementary/additional
- What information is missing – and for whom is this information important
- What is seen as positive redundancy – by whom?

***a) Identification*:**

Demographic data are captured and stored by all artefacts (cards, folders, referrals, prescripts, reports) included in the patient record, paper and electronic, although with different degree of details captured, and to a large extent overlapping. ID problems described Ch 6.1.1, are mostly not related to redundant (duplicated) information, or relating to one technology in particular, rather to lack of information caused by a mix of reasons, such as these situations mentioned previously:

- People did not bring the required identification, as
- they were either deliberately cheating to not being recognized;
- had simply forgot or lost their patient retained cards;
- or some people did not have a SA ID (e.g. NGO workers from overseas);
- Confusion related to mix of names; (family vs first name, spelling names differently, babies registered with 'baby' + mothers name), or unclear date of birth at registration (both technologies);
- EPR is down and temporary numbers leads to duplicate records;
- Different electronic systems use different system for generating ID numbers, which may increase the time and difficulty in recognizing the person.

Solving the problem of identification often included using a combination of paper artefacts, electronic databases, and human knowledge and experience ('articulation work'), and multiple registrations of demographic data were clearly a necessity. Such multiple registrations of the same information in different artefacts would be seen as 'duplicated' and redundant, using the models of Cabitza et al (2005), and Ellingsen and Monteiro (2003), but at the same time it is seen as an important and valuable kind of redundancy by the health workers. Some of the difficulties listed above may be improved, but probably not completely solved, as one cannot completely disregard technological failure or human error. As being able to identify the right person is crucial for treatment and follow-up ARV treatment, these are facts that need to be taken into consideration, and 'backup' in terms of having parallel alternatives proved a good way of reducing risk.

b) Clinical information and history

As described in Sec 6.2.1, the basic electronic systems (PHCIS, PREHMIS) captured a rather limited amount of the information needed for a clinician in HIV/AIDS care and treatment. The eKapa provided clinical information, but was at the time of my study implemented only in five ARV clinics in the capital, and even if implemented, capacity problems made it difficult to utilize the full functionality of the module, thus additional sources were crucial.

The patient held ARV card, with or without a barcode label, was an important resource. Unlike some more simple PHC clinic cards, the ARV card would function as a minimum record, and provide the core medical information (type of ART, CD4 count, viral load, regimen changes, TB treatment or OI, previous dates of visits), important for the clinicians to know. Discussing the various options with an ARV doctor, he stated that, the patient held cards were a very good way of transferring data between practitioners where there are resource constraints. Although there was no additional information in terms of reports or doctor or nurse's notes, the information carried by the ARV card was seen as bringing the most important information for a clinician.

> *"It contains the information necessary for a clinician when the patient comes for a visit; demographic data, places they have been visiting, type of visit and test results, and it follows the patient wherever he/she is. With the Clinicom barcode sticker on it, the patient will be identified everywhere in WC"* (email ARV doctor 2010).

The paper folder kept a volume of documents with important details related to patient trajectory, used in various situations of treatment and follow-up, details that were nowhere else captured, but by most ARV doctors and nurses described as crucial knowledge. Important information not kept in the paper folders, was e.g., the x-ray images, but a description of the results. Thus, the paper folder in the clinics, with the long-term form and documents, was closest to meeting the information needs for the health worker, although only available in clinic or information accessible via phone call to previous sites.

It was however not unusual that the paper folder was missing in the archive, for different reasons: the patient may have carried the folder from the doctor/nurse to the X-ray or other stations in a larger clinic, and forgot to bring with him to the reception; the data clerk in the reception was lagging behind when updating the folder after the last visit, and it would be difficult to locate at the next visit.

In these cases, the basic electronic systems would provide some information, (eKapa more), and the clinician had the option to print a copy, for adding notes, and then use as a temporary patient folder until the original folder reappeared, what usually happened, according to one data clerk. If, on the other hand, the electronic system was down, which happened rather regularly, either because the Internet connection or the electric power was down, the paper tools were invaluable. According to the frameworks of Ellingsen & Monteiro (2003), and/or Cabitza et al (2005), this involved 'duplicated' and 'redundant' data (same data in different artefacts), as well as 'supplementary' (additional or slightly different representation) data in different artefacts. In the situations described, both technologies only partly met the requirements of providing a complete record. Adding the fact that both technologies also might fail in important situations, the combined solution seemed important for backup and providing crucial patient information in time and place. This reality was also emphasized in

the TIER.net strategy, as described in Ch 4.5.1 and Ch 5.1.5. In a TIER.net User Guide (UCT 2011), it is acknowledged that,

> *"[…] there is likely to always be a mix of system across tiers, and the focus should be on **achieving scale and balance rather than a one-size fits all solution**" (bold added).*

Despite this view on what is a realistic scenario, the ultimate goal, as published by Osler et al (2014), will still be *'a paper-less facility with data entered into software directly by the health care provider*':

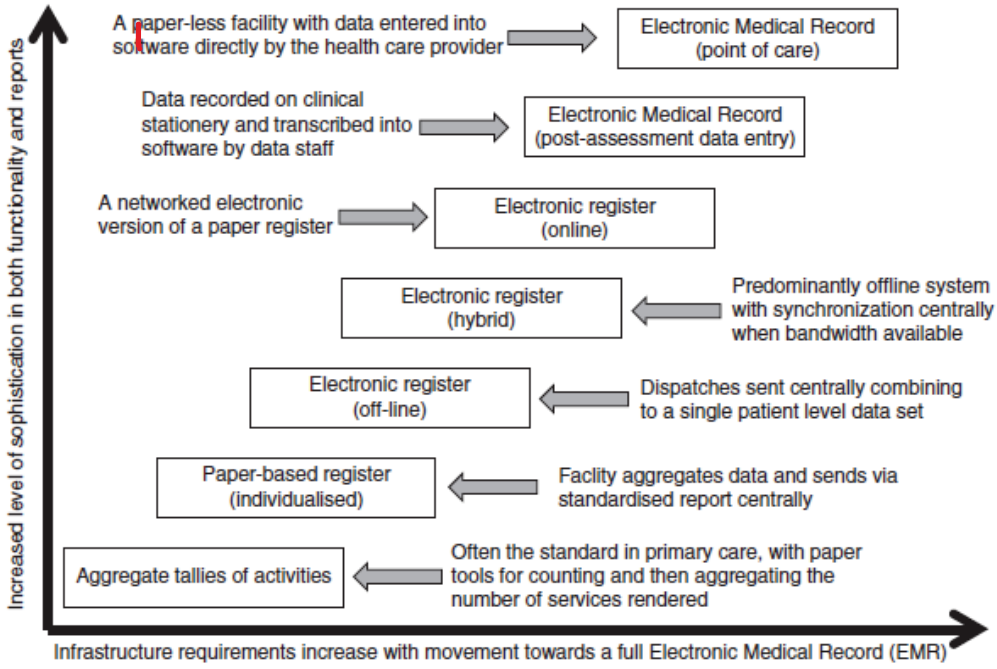


Figure 49: Different candidate tiers of a multi-tier monitoring system (Osler et al, 2014)

Lab results were an important part of the clinical information needs. Most clinics used NHLS labs for analysis, but results were not always easy to access, as mentioned in Ch 6.1.3. Lack of integration between the electronic systems, and delays and backlog in capturing the printed results retrieved from NHLS, often led to duplicate printing. Integration with NHLS repository would reduce the duplicate printing, and certain initiatives to find solutions for this were initiated (information manager 2009)[77]. Even if/when this functionality between electronic systems is established, there would still be the problem with lack of resources and access in many areas and clinics.

As the TB and HIV/AIDS diseases and treatment were close related, information in the TB treatment card and folder was also important for the health workers. The TB treatment card (figure 40, p.140) did however not carry any HIV/ARV information, which was commented on by one ARV doctor. She suggested that the TB card should hold information about the

[77] WC Government Health: Annual report 2014-2015 (p. 52), claims this is solved by NHLS together with the other e-systems now using Clinicom ID#

patient being HIV tested or not, and the CD4 count, as a minimum. Another ARV clinic described how they managed the patient cards in cases where the patient was treated for both diseases: they would staple the ARV and TB cards together, and when the TB treatment was finished (after 6 months), they would remove the TB card, and the patient would keep it. If a patient came from a PHC clinic with a clinic card, they would only use this to identify the person, and then issue a new ARV card. She did not think it would be possible to combine ARV and TB cards, as there was too much information to be covered, and TB was a curable disease, while HIV/AIDS was chronic. She thought the ARV card contained sufficient information for her, if somebody was coming from another area. If the patient were moving from another place to their area, he would need to bring a referral letter (Clinic manager, 2010). The TB clinic patient folder (figure 31), did however have a separate section with HIV status and ART treatment notes

c) Follow-up/adherence

To follow up a patient over time, i.e. see to that he keeps his appointment, and to control the adherence to medication were important parts of the medical treatment. As described in sec 6.1.2, the clinics had different ways of solving the challenges, depending on resources available, and location. To secure adherence was not necessarily, or only, a matter of technology and available information. For the majority of clinics, the tools and technology available contributed only partly to achieving the goal of continuous treatment, and this called for combined solutions. As adherence to therapy was a most important issue, all means and creativity were used to achieve this goal, and required a combination of tools and people, including health personnel as well as the patients. Paper tools (cards), electronic systems (appointment modules) combined with printouts, phone calls, and/or home visits were used to keep track of the patients. Following the categories from Ellingsen and Monteiro (2003), and Cabitza et al (2005), information needed to follow-up a patient in most clinics would be seen as 'redundant' and 'duplicated' as a number of non-integrated tools had identical information. The health workers considered however this information important, to be able to cope with the reality, and thus redundancy was *'playing a positive role'* in this context.

The table 21, p.140, shows that, the paper patient folder for an HIV/AIDS patient *in clinic*, will cover the overall information needs, given that the patient has had all his treatment and visits in this clinic, and that results from tests and x-ray for example, have been delivered to the clinic and entered into the folder. In a completely paper-based system, you will depend on manual, routines for coordinating information, and relate on the patient to bringing his patient held card, a referral letter or an x-ray. Should he have been to hospital or another online unit, the barcode sticker will add information about previous visits in other clinic or hospital, and the option to call for additional information.

6.4.2 Robustness - Security and risk analysis

To decide when and how redundancy in the modules, or in CSCW terms, the 'collection of artefacts', play a positive or negative role, will depend on the wider context as well as information needs in the sites in question. If some kind of redundancy in certain contexts is considered desirable, there is also the question of how to keep the desirable redundancy, while reducing its drawbacks. These questions cannot be answered on a general basis, but should also be evaluated in relation to the robustness in the systems.

In any IS domain security will be an important issue, and keeping personal health data safe is of great concern (UNAIDS 2007, 2008). Because of the sensitive character of the HIV/AIDS disease in particular, UNAIDS addresses the importance of security; including protection of data as well as non-availability. In their report, "Guidelines on Protecting the Confidentiality and Security of HIV Information", it is emphasized that; *"Security must address* ***both protection of data from inadvertent or malicious inappropriate disclosure, and non-availability of data*** *due to system failure and user errors"* (UNAIDS, 2007 bold added).

The findings from this case study describe how manual and electronic artefacts collect and coordinate patient information, where redundancy exists in various ways. As apparent from the case description of how patient data are captured, stored and shared in the facilities, a variety of tools and sub-systems are used at different service points capturing patient data; partly overlapping, partly adding and/or complementing existing information.

I find that Currall's (2006), connotation of 'robustness' rather than 'redundancy', is appropriate when discussing information security and risk analysis in information systems in this particular setting. This includes an analysis of how information needs are covered in the components (including redundancy), and how the components work together (coordination), as well as exploring potential risks of missing important information. Currall emphasizes that,

> *"[...] things will go wrong"*, and "*You need to understand the threats, where they come from, what they mean and the effects they can have. In addition, you need to understand both the role that technology can play in providing solutions and also the problems that technology brings with it" (ibid, 2006).*

Sec 6.4.1 has described in more detail how the involved components and artefacts have captured, shared and coordinated to meet information needs, and also where gaps and/or overlap may occur for various reasons. Having this reality as a point of departure, it seems appropriate to conduct a risk analysis as described by Currall (2006), and point to situations where there might be a need for certain types of redundancy, for robustness and security reasons.

Repeating the three elements of a risk that needs to be analysed (Ch 2.5.4, p.50):

1) a contingency (a future event or circumstance that is possible but cannot be predicted with certainty);
2) a consequence or impact (with some measure of how big), and
3) a likelihood of occurrence;

I find it useful to combining his points 1) and 3), i.e.:

1) A contingency, and 3) How likely are certain threats to happen?

From the findings, we know that a number of threats are likely to happen, within the paper components as well as within the electronic ones:

- patient retained cards are forgotten or falsified;
- people with an HIV positive test do not want to be recognized;
- patient records/folders a misplaced in archive or left in other station in clinic, without being returned to the reception;

- multiple reasons for problem with identification also in EPR;
- electric power is lost for days, without backup alternatives, or Internet being very slow or down; both cases leading to huge backlog;

To point 2) Consequences or impact (how big)? How do you measure 'how big' when it might be a question of life or death? Consequences may relate to:

a) Non-availability, such as missing artefacts, or missing details in artefacts, i.e. lack of important patient information when needed for adequate treatment, like HIV status, type of medication if on ART, and other OI, not available when needed, may have severe consequences; at worst it is a matter of life or death, and thus, always causes 'big impact'.

b) Unwanted disclosure of sensitive information may lead to 'lost-to-follow-up' an important issue in fighting the HIV/AIDS, as resistance to accept the diagnosis is huge, something emphasized by all medical personnel.

c) Lack of 'seamless' dataflow between components, both within and across the technologies. The single artefacts are not designed to 'seamless' transfer complete information from one artefact to the other, which requires extra work. The TB card or the simple PHC clinic card does not give sufficient information about ARV, thus there will be necessary to call the clinic that first opened the e-folder, which of course requires extra work for the data capturers to catch up, and for the health personnel to collect the missing information, if accessible at all. EPR with limited clinical information needs to be complemented by ARV patient card and/or folder.

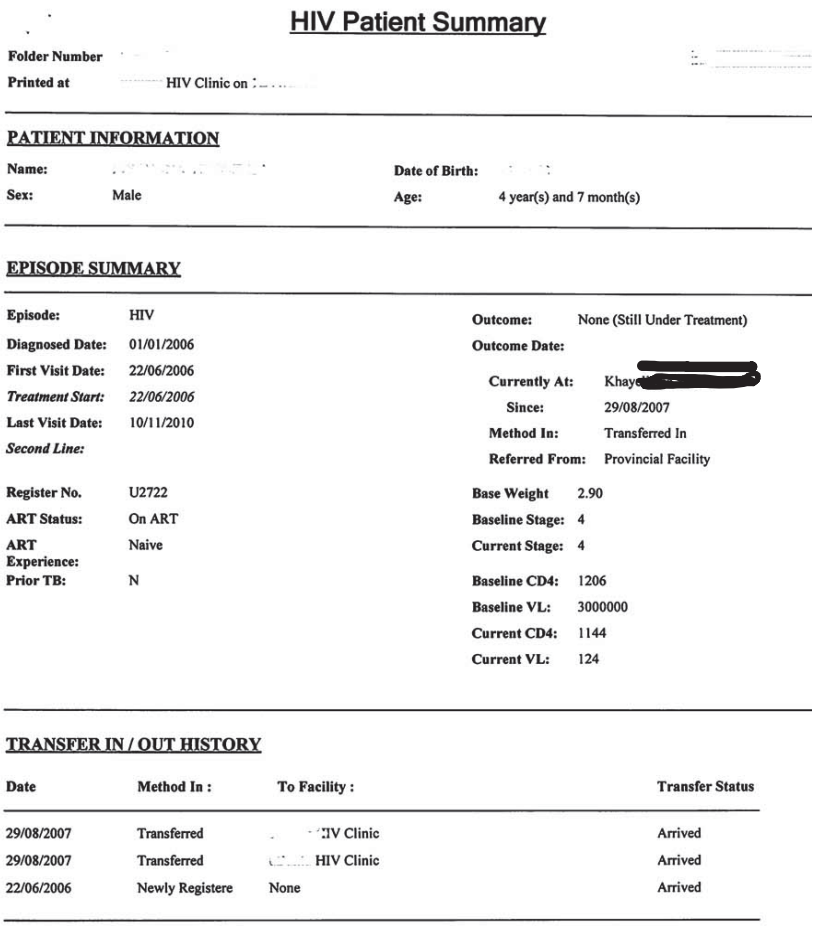
Related to the threat of non-availability, Currall (2006), emphasizes the importance of having a backup strategy:

> *"[...] which ensures that there is an adequate number of copies stored securely in more than one location, [...]",* and: "*[...] you need to plan on that basis and have appropriate tools to monitor the situation and to recover from the problems".*

The conclusion being that, paper as well as electronic artefacts will have different advantages at different levels and settings, and for different users in the HIS management and treatment hierarchy. For a doctor or nurse/a clinic manager/and ARV program manager, the properties of the health information systems will have different benefits/utility depending on the context in which they serve. A pure paper-based system has its limitations. With the barcode label added to the card, the utility of the patient cards, folders and forms increases, enabling communication between paper and electronic systems, facilitating identification of the patients, and to some extent also clinical history, where the electronic artefacts are in place. Quoting Berg (1997), we may say that: *"the organization of the hybrid produces the net effect: [...].*

In the Western Cape Department of Health, this was taken care of in various ways. In the cases of non-availability in both technologies, the hybrid reality to some extent solved the problems, i.e., paper artefacts (and local knowledge) did the job when the electronic system was down, and/or if the paper folder was missing, the EPR supplied a brief

summary/minimum record (figure 50) for the health worker to use, until the paper folder reappeared. This would however not replace a complete folder with documents and reports.



HIV Patient Summary

Folder Number
Printed at HIV Clinic on

PATIENT INFORMATION

Name: **Date of Birth:**
Sex: Male **Age:** 4 year(s) and 7 month(s)

EPISODE SUMMARY

Episode: HIV
Diagnosed Date: 01/01/2006
First Visit Date: 22/06/2006
Treatment Start: *22/06/2006*
Last Visit Date: 10/11/2010
Second Line:

Register No. U2722
ART Status: On ART
ART Experience: Naive
Prior TB: N

Outcome: None (Still Under Treatment)
Outcome Date:
Currently At: Khaye
Since: 29/08/2007
Method In: Transferred In
Referred From: Provincial Facility

Base Weight 2.90
Baseline Stage: 4
Current Stage: 4

Baseline CD4: 1206
Baseline VL: 3000000
Current CD4: 1144
Current VL: 124

TRANSFER IN / OUT HISTORY

Date	Method In :	To Facility :	Transfer Status
29/08/2007	Transferred	IV Clinic	Arrived
29/08/2007	Transferred	HIV Clinic	Arrived
22/06/2006	Newly Registere	None	Arrived

Figure 50: HIV patient summary - eKapa (2010)

If the electronic system was down, the paper tools were invaluable. The patient held ARV card would function as a minimum folder, with demographic information, type of ART, regimen status, TB or other infections, CD4 status, viral load, important for the clinicians to know. Unlike some more simple PHC clinic cards, the ARV card would provide the core medical information (CD4 count, HIV RNA, regimen changes, TB treatment and more), and previous dates of visits (ref figure 38/39, p.139), but no additional information like doctor's or nurse's notes, for example.

Summing up Affordances Redundancy and Robustness

The previous sections have analysed the components involved in creating and keeping a longitudinal patient record for an HIV/AIDS patient, related to what kind of information is captured, and to what extent data is registered more than once in the artefacts involved. The focus has been on how the artefacts meet the information needs for health workers, and on security and robustness related to availability of key data. Table 25 give a brief overview of information captured in the most central artefacts, paper ***and*** electronic.

Information	Modules/Artefacts								
	Paper					Electronic			
	ARV card	TB card	PHC card	Paper folder in clinic	TB folder	PCHIS	PREHMIS	eKapa (HIV&TB)	NHLS (lab)
ID + folder #	x	x	x	x	TB-reg#	X	X	X	
Previous treatment sites	x	x		referral clinic	referral clinic	X	referral clinic	X	
Demographic	x	x	x	x	x	X	X	X	x
Appointments	x	x	x	x		X	X	X	
CD4/HIV viral load	x		*optional (may reveal HIV status)	x	x			x	x
Clinical notes		x		x	x			visit summary	
Medication	x			x	x			x	x
ART history	x			x	x			x	x
TB sputum	x	x			x			x	x
TB treatment and history	x	x			x				
OI[78]	x			x	x			x	x

Table 25: Type of information in the collection of artefacts

Looking at the major electronic patient records (right side of table 25), what is most striking is the relatively modest coverage of the clinical information needs for a health worker at PHC and ARV clinic level, as the eKapa module was only an option for a few larger clinics. The lack of integration/coordination between some of the electronic systems, such as between NHLS/ETR.net and PREHMIS/PHCIS, also lead to unnecessarily cumbersome coordination of clinical data, as well as statistical data.

As a consequence, the need for additional information and artefacts was obvious. There was a clear discrepancy between the Health Informatics view on "*redundancy seen as unnecessary storing same information more than once"*, and the robustness/security perspective put forward by Currall and others. For a returning patient in one clinic, the paper folder would provide a more comprehensive picture, but not necessarily provide all the important information. Results from e.g. x-ray, would depend on the patient bringing the picture and/or description from doctor, getting results from NHLS might be delayed, and for an ARV clinic to treat a new patient, it was a prerequisite that the patient brought the referral from the PHC clinic. Once registered as an HIV/AIDS patient, the patient retained card worked however as one of the most important information carriers, in clinic as well as between service providers (with or without the barcode label).

Important when coordinating information are standards to sharing data between artefacts. This requirement also applies when different technologies are cooperating. The unique patient ID and the barcode stickers were important tools to connect paper and electronic components and conveying information. Although the TB monitoring system had their own system for assigning patient # and folder #, they also added the Clinicom barcode sticker on their TB paper folders and cards, where this label was issued. HIV/AIDS and TB also had

[78] Opportunistic infections

developed standards for clinical data and reporting, so you would find the same terms and concepts in paper cards and folders, referral letters etc. What were not easily standardized were handwritten notes and reports from e.g. home visits.

Analysing redundancy in different cases highlights the importance of context, and there seems to be an agreement among the authors discussing 'redundancy' that, it should always be assessed in relation to context (Ellingsen and Monteiro, 2003; Cabitza et al, 2005; de Vries and Nyemera, 2010). The context in my case differs from the cases presented by Ellingsen and Monteiro (2003) and Cabitza et al (2005), in a number of ways, i.e. HIS in a hospital in western settings vs HIS in Primary Health Care clinics in SA, in terms of available resources as well as the use of technologies. There are however a number of similarities in how patient information is captured and shared. Ellingsen and Monteiro (2003), claim that hybrid information systems represent a particular configuration, combining different technologies to achieve a common goal. They describe how the health workers cope with non-integrated IS by taking advantage of the paper forms: '*sifting through'* the documents kept in the paper folder, "*redundancy of information is worked around"* (ibid, p.86).

Although acknowledging the positive sides of the paper artefacts involved in the folder, the authors conclude that, "*the benefits (robustness) do not compensate for the amount of work involved in maintaining the redundancy".* On the other hand, they do argue for the positive redundancy when redundancy is 'supplementary', as *"these benefits, we argue, tend to override the costs associated with maintaining supplementary information* (ibid, p.88).

I would argue that, to meet the goal of providing the information needed to the health care services, the results from the case study confirm the need for hybrid and flexible solutions, and highlights the importance of redundancy as a means to succeed in achieving robust systems. The paper version of the patient record constitutes a particular instance of the hybrid IS category. The patient folder contains a number of forms with partly identical, partly supplementary information, collected from different service providers, together giving a 'complete' picture of the patient's health status, and should be categorized as 'supplementary' information, thus positive, and important for clinical personnel.

In this particular case, limited resources, and the HIV/AIDS context, the questions of security and risk adds important factors, when concluding about positive or negative redundancy. The need for redundancy in terms of 'supplementary information' was confirmed, as was also the need for backup in unstable environments (power supply, internet down + paper folders get lost, patients don't bring their cards). The electronic and the paper components functioned as backup for one another, increased security and reduced risk, and the hybrid solution contributed to a more robust health information system. Even if information is seen as redundant according to Ellingsen and Monteiro (2003), i.e. identical information in different, non-integrated information sources, they may provide a reserve (DeVries and Nyemera, 2010), and being a principal reason for robustness of work: "because if one component fails for lack of knowledge, the whole system does not grind to halt" (Hutchins, 1995).

6.5 The hybrid patient record - a summary

Table 26, is summing how up how I have used the conceptual framework in sorting and ordering the collected case data, and later as a tool for analysis of how the informational artefacts have met the information needs in a hybrid system:

Action/ function	Technology	Collection of artefacts	Coordinative artefacts	Affordances of paper and electronic artefacts	Affordances of Hybrid system
Patient ID	Paper	Patient held card Paper folder archive (name) [Passport, National ID-booklet]	Prescription Referral Patient card	+Patient ARV card comprehensive info, -depend on patient to bring. Folder complete, but might temp. be missing	Patient ID is captured in all artefacts, paper and electronic. ID problems relate to a mix of reasons, and can happen at all levels, thus certain degree of redundancy contribute to robust-ness and security
	Electronic	PHCIS, PREHMIS, iDart, eKapa, NHLS, ETR.net	Barcode label Handscanner	+ most useful for coordination, - systems use diff. ID#, and possible to manipulate	
Follow-up (time) In clinic	Paper	Patient card, patient folder incl. clinical notes and paper forms and reports	If barcode label on card, issued by other unit, person might be reg in local data base for identification	+Folder flexible, complete info, -depends on patient to bring card; manual system for follow-up over time	Patient held card and folder allow access to patient info on site, but folder may be missing; With barcode label, and EMR in clinic, access to data-bases, and follow-up, but no clinical data (except for eKapa). The technologies complement each other and work as backups
	Electronic	PHCIS, PREHMIS, eKapa, iDart	Barcode label Handscanner	+Quick ID for reg and follow-up when online; - lack of clinical data (except eKapa); -Power down leads to backlog and extra work ++	
Follow-up (time and space) Across providers	Paper	Patient held card, referral, prescript, test results printed	Patient held card, referral, prescript, test results printed	+The artefacts provide the info needed, -depend on the patients to bring; -depend on available communication between providers (fax, phone, post)	The combination of paper cards, the various referrals, and printed results carrying comprehensive patient information, together with the barcode label, enabling ID of the person, where an EPR is implemented, provides the best possible result,
	Electronic	PHCIS, PREHMIS, eKapa, NHLS	Barcode label, hand scanner, x-ray, fax	+Quick ID for reg and follow-up when online; -lack of clinical data (except eKapa); -Power down leads to backlog and extra work	
Reports Programs Cohorts	Paper	Paper forms: RMR, ARV, TB, PMTCT/MOU registers, cohort analysis report	tick sheets;	+Useful in day-to-day work practices; -capacity depends on headcount; -time consuming for compiling reports	The paper forms for statistical data are well incorporated for the data collection in clinics, is however time consuming to prepare. The solution with barcoded data items, captured by data clerk, from paper folder after patient visit, saves preparation of some of the required reports from clinic to admin levels.
	Electronic	eKapa, ETR.net, Sinjani, DHIS	A-3 form with barcoded data items, Handscanner, eKapa online, fax, USB	Provides required statistics to higher levels; A3 form enable quick registering; otherwise need to be prepared manually in clinic before submitted (except ETR.net in one clinic)	

Table 26: The hybrid patient record in HIV/AIDS care and treatment

Chapter 7 Contributions and conclusion

In this chapter, I reflect on the findings, and elaborate on the empirical and theoretical contribution to the aims and research question, as presented in the previous chapters. **The research scope and aims** of the study have been:

- **to understand and give a rich description** of the health work practices and challenges in coordinating patient information in the context of HIV/AIDS in a developing country context;
- **to contribute to the discourse** around design of health information systems in this context, with a focus on the need for hybrid solutions, and to suggest principles for designing hybrid HIS;
- as a result, during the research process, I came to: **reflect on the visions and policies at higher levels,** and how they are guiding the development and implementation of these systems.

Giving a rich description and contributing to the CSCW and HIS discourse

The overarching principle for patient-related health information systems would be: to meet the information needs for all users, i.e. health service providers at all levels. In the discourses, ICT and EPR have been suggested to being the answer to the challenges in keeping and sharing a patient record, reinforced by the HIV/AIDS pandemic, to coping with this disease and challenges. The solution does however bring new challenges, such as: the need for power, equipment, knowledge, and infrastructure for electronic communication.

Through this case study of health information systems within HIV/AIDS care and treatment in primary health care in a developing country context, I contribute to our understanding of the challenges and the conditions under which these systems work. The findings give a detailed description of health work practices, information needs, and how the different technologies and artefacts in this process collect data and coordinate information, thus creating a longitudinal patient health record, while at the same time providing aggregated data for higher level management. Instead of considering these working hybrid solutions to be temporary solutions, as is often the case in the discourses, I suggest recognizing hybrid health information systems as viable alternatives.

Contribution to theory - Hybrid health information systems

The findings in this case describe the paper and electronic artefacts involved, and their roles in coordinating patient information. In discussing information systems design in Chapter 2, I have introduced the term ‘hybrid’ or ‘hybrid systems’. Definitional characteristics for a hybrid system, as presented by Clarke (2005), relate to functionality (*creating new potentials*), flexibility (*to cope with differences in circumstances*), and adaptability (*the capacity to change its elements over time*) (table 7, p.53). I found these characteristics to be applicable in health information systems, particularly in the context of this case study, but also in other settings.

For the design of a hybrid system, I have included the concepts of ‘redundancy’, related to the analysis of the robustness of the system, and ‘affordances’ for analysing the strengths and weakness of an artefact in a certain context. ‘Redundancy’, has in the CSCW and ISD literature been discussed with a variety of views and recommendations, to whether it should

be completely removed, or rather to be valuable in certain cases. I have argued for, and have described how allowing a certain amount of redundancy in the system, creates a robust *hybrid health information system* to coordinating patient information over time and across space. Related to vulnerability, and the questions of confidentiality and availability of sensitive health information, a security and risk analysis is also recommended, as elaborated in section 2.5.4.

In the hybrid combination of technological artefacts, the barcode label plays an important role, serving as a *'coordinative artefact'*. In conveying information between the paper and electronic modules, the barcode label contributes to meeting one of the characteristics of hybrid systems as introduced by Clarke (2005), i.e.,*'creating new potentials'*. These outcomes would mostly not be achieved in a 'pure' paper or a 'pure' electronic system. In table 26 (p.165), I give some examples of how the *hybrid* collection of artefacts in the system, benefits from the positive affordances of the technologies, and how this hybrid 'total' provides the best possible result related to information needs in the context.

Visions, policies and principles for design of hybrid systems

In the Introduction chapter, I question whether integrated EPR's might be the answer to meet the information needs in patient health care, and I ask if there should be a re-vision of the policies and goals for health information systems and the role of ICT in DC; bearing in mind the implications that higher level visions and policy have for planning and implementation at lower levels. HIV/AIDS as a global challenge has priority in many ways, related to focus in health care and management in international as well as national health policies. This has implication for e.g. investments in computer systems. The issue of competition for resources is also brought forward in the report "Everybody's business" by WHO (2007). The Province of the Western Cape has, by introducing the ETR.net multi-tier monitoring system, adapted to the current reality, and has provided recommendations, as to when to choose a paper-based system, an eRegister or an EMR (Osler and Boulle, 2010), although with the ultimate aim of *"a paper-less facility with data entered into software directly by the health care provider"* (figure 49, p.158).

I have introduced the idea of a hybrid health information systems design not just as a temporary working solution, while striving towards the vision of an integrated electronic system, but I contend that hybrid HIS in DC's would be satisfactory as vision; guiding plans to achieving the goals for health care delivery at higher managerial levels, with important implications for lower level planning, cost, design and implementation.

Answering the research question

"What are the principles for designing comprehensive hybrid health information systems in a developing country context?"

There is no standard configuration for hybrid systems. Each environment is unique and needs specific considerations and solutions. Ford and Ford (1994) discuss different logics in relation to organizational change, looking for new perspectives or frames for thinking about, understanding and explaining change. Referring to Horn (1983), they define logics as

> *"[…] points of view that refer to the underlying assumptions, deeply held, often unexamined, which form a framework within which reasoning takes place. They*

provide lenses through which we view everything [….]. When a person is 'operating in' a particular logic, he or she takes its rules and boundaries for granted"
(Ford and Ford, 1994, p.758).

Based on the idea of hybrid health information systems, I have developed a framework to discuss the idea of designing hybrid information systems, which involves a change in reasoning (visions), followed by a change in planning, design and implementation of the health information system, using the definition of logics from Ford and Ford: *"a framework within which reasoning takes place"*. I suggest that the design principles in information systems design need to reflect the contexts and services in which the systems are supposed to serve, based on different logics.

The research question was followed up by some reflections and principles for the design of hybrid systems; principles, which should be based on **analysis of the affordances** of the technologies (ref examples tables 23-24, p 156/7), i.e., what are their benefits and constraints, assessed in relation to the following:

Context:	*a) the level of headcount, (e.g. how many patients may be handled in a paper system);* *b) type of information needs, (medical, aggregated data);* *c) resources available (material and personnel, infrastructure).*
Flexibility:	*Shared standards, and interface between the technologies/artefacts, should allow mutual exchange of data elements in the information flow;* *and facilitate stepwise development when context changes.*
A 'minimum' record:	*Define a 'minimum' of key/essential patient data, shared in both technologies.*
Robustness:	*Type and level of redundancy needs to be considered in relation to contextual factors, i.e. resources available, confidentiality, security and risk analysis.*
Visions and plans:	*do have implications for practice. Prioritizing between more clinics and personnel, versus computers and infrastructure is challenging, but needs to adapt to reality, and should be based on a risk analysis and a cost-benefit analysis.*

Table 27: Design principles hybrid health information systems

Contribution to methodology

In their review of CSCW research, Fitzpatrick and Ellingsen (2012), present four suggestions for how CSCW researchers can broaden their research, among them:

- To focus on multi-site workplace studies, place these practices within their larger socio-technical context, such as political and policy-making context, and systems and workplace design;
- Asking how to conduct such studies over a substantial amount of time; they suggest *"to follow the patient trajectory around the multiple settings in which their care is provided, and to do this over more extended periods of time";*

- in discussing the challenge of practical impact for CSCW studies, they refer to *"a hybridized form of ethnography"* as suggested by Martin et al (2005).

I have contributed to these calls by conducting a longitudinal case study, including workplace studies, and searched to see the situation in health work practices in relation to the policies and ICT efforts in low-income setting. The choice of method, a serial and/or periodic ethnographic field study, might share some of the characteristics of '*the hybridized form of ethnography'* (Martin et al, 2005), to meet *'the challenge of practical impact'*. I had the opportunity to meet with the informants, and partly observe, both at managerial and health work practice levels, over a time span of two years, thus achieving some of the benefits usually related to 'classic' ethnographic studies, as described by Crang and Cook (2003).

> *"Here, interactions, which are much more like informal conversations can usually be developed in which both parties feel more able both to reveal their often undecided, ambiguous, and contradictory feelings about the matter in hand, and to challenge each other about these in an atmosphere of mutual respect and trust." (ibid, p. 46).*

Limitations of the research

The research presented in this thesis is an interpretive case study, taken from a specific context, with specific challenges, aiming at contributing to rich insights. The time span of the case study covered field data collected 2009 – 2010, and email further until 2012. These data might be considered outdated, related to the general development and digitization worldwide.

To keeping up with the recent development, I have however read relevant literature related to the health IS-field in public documents and research. This includes WHO factsheets on HIV/AIDS, and SA National and Provincial strategic plans and documents, covering plans and achievements up to 2018. I find that, the knowledge achieved in this study may still be relevant, not only in SA, which might have expanded their digitized systems broader, but also in other low-income countries, as well as in a western setting.

Seen in relation to cases from developed country contexts presented in the CSCW and ISD literature, I find that, 'specific implications' drawn from this case study, may have relevance, and being valuable, beyond the HIV/AIDS and developing country context.

We know from case studies and media in western countries, that infrastructure may be unstable at times, and patient records in hospital, and/or prescriptions for medication in pharmacies, may be inaccessible over some time; even hacking of health information systems is a realistic scenario. To meet these situations, the electronic systems, combined with a paper-based backup system may be useful as a safety net. Applying the principles for analysis and design as suggested in this thesis, might provide more robust systems, and provide a broader empirical foundation for further planning and development.

Conclusion

My research interest and focus in this study has not been on success or failure of the health information system, or on identifying challenges in implementation of one (or many) integrated information systems, but on how computer technology, together with the existing

technologies, as hybrid systems can be designed to meet the challenges when keeping a patient record related to a person with a chronic disease (the longitudinal record), in a resource-constrained setting.

References

Aanestad, M, and Jensen, T.B. 'Building Nation-Wide Information Infrastructures in Healthcare through Modular Implementation Strategies'. *The Journal of Strategic Information Systems* 20, no. 2 (June 2011): 161–76.

Albrechtsen, H., et al 'Affordances in Activity Theory and Cognitive Systems Engineering'. Risø National Laboratory, Roskilde, August 2001.

Alfven, T.et al. 'A Decade of Investments in Monitoring the HIV Epidemic: How Far Have We Come? A Descriptive Analysis'. *Health Research Policy and Systems* 12, no. 1 (2014): 62.

Alvesson, M. and Sköldberg, K. *Reflexive Methodology. New Vistas for Qualitative Research*. London, UK: SAGE Publications Inc., 2000.

Asangansi, I. 'Understanding HMIS Implementation in a Developing Country Ministry f Health Context - an Institutional Logics Perspective'. *Online Journal of Public Health Informatics* 4, no. 3 (2012).

Ash, J.S.et al; E. 'Some Unintended Consequences of Information Technology in Health Care: The Nature of Patient Care Information System-Related Errors'. *J Am Med Inform Assoc* 11 (2004): 104–12.

Avgerou, Chrisanthi. 'IT as an Institutional Actor in Developing Countries'. In *The Digital Challenge: Information Technology in the Development Context*, 46–62. London UK: Ashgate Publishing, 2004.

Avison, D. and Myers, M.D. 'Information Systems and Anthropology: An Anthropological Perspective on IT and Organizational Culture'. *Information Technology & People* 8, no. 3 (1995): 43–56.

Avison, D. and Young, T. 'Time to Rethink Healthcare and ICT?' *Communication of the ACM* 50, no. 6 (2007): 69–74.

Bærentsen, K.B. and Trettvik, J. 'An Activity Theory Approach to Affordance', 51–60. Århus, Denmark: ACM, 2002.

Baldwin, C.Y.and Clark,K. 'Modularity in the Design of Complex Engineering Systems'. In *Complex Engineered Systems*, 175–205. Understanding Complex Systems. Springer Link, 1998.

Baldwin, C.Y., and Clark, K.B. 'Managing in an Age of Modularity'. *Harward Business Review* 75, no. 5 (October 1997): 81–93.

Balka, E. et al, 'Steps Toward a Typology for Health Informatics'. San Diego, California, USA: ACM New York, USA, 2008.

Bansler, J. and Havn, E. 'Technology-Use Mediation: Making Sense of Electronic Communication'. *Scandinavian Journal of Information Systems* 16 (2004): 57–84.

Bardram, J.E., and Bossen, C. 'A Web of Coordinative Artifacts: Collaborative Work at a Hospital Ward', 168–76. Sanibel Island, Florida, USA: ACM, 2005.

Bend, J. *Public Value and E-Health*. London, UK: Institute for Public Policy Research, 2004.

Bentley, R. et al. I. 'Ethnographically-Informed Systems Design for Air Traffic Control', 123–29. Toronto, Canada, 1992.

Berg, M. 'Accumulating and Coordinating: Occasions for Information Technologies in Medical Work'. *Computer Supported Cooperative Work* 8 (1999): 373–401.

Berg, M. *Health Information Management*. Routledge Health Management Series. New York, NY: Routledge, 2004.

Berg, M. 'On Distribution, Drift and the Electronic Medical Record', 141–56. Lancaster, UK: Kluwer Academic Publishers, 1997.

Berg, M. 'Practices of Reading and Writing: The Constitutive Role of the Patient Record in Medical Work'. *Sociology of Health & Illness* 18, no. 4 (1996): 499–524.

Berg, M. *Rationalizing Medical Work*. Inside Technology Series. Cambridge, Massachusetts: Massachusetts Institute of Technology, 1997.

Berg, M. and Goorman, E. ‘The Contextual Nature of Medical Information’. *Int Journal of Med Inf* 56 (1999): 51–60.
Berg, M. and Toussaint, P. ‘The Mantra of Modeling and the Forgotten Powers of Paper: A Sociotechnical View on the Development of Process-Oriented ICT in Health Care’. *Int Journal of Med Inf* 69 (2003): 223–34.
Bjørn, P. and Balka, E. ‘Health Care Categories Have Politics Too: Unpacking the Managerial Agendas of Electronic Triage Systems’. Limerick, Ireland, 2007.
Black, A.D. et al. ‘The Impact of eHealth on the Quality and Safety of Health Care: A Systematic Overview’. *PLoS Medicine* 8, no. 1 (January 2011): e1000387.
Blaya, J., et al. ‘E-Health Technologies Show Promise in Developing Countries’. *Health Affairs* 29, no. 2 (February 2010): 244–51.
Blomberg, J. and Karasti, H. ‘Reflections on 25 Years of Ethnography in CSCW.’ *Computer Supported Cooperative Work* 22, no. 4–6 (2013): 373–423.
Bloomfield, B., et al., T. ‘When Is an Affordance? Bodies, Technologies and Action Possibilities’. *Sociology* 44, no. 3 (June 2010): 415–33.
Bodart, C. and Shrestha, L. ‘Identifying Information Needs and Indicators’. In *Design and Implementation of Health Information Systems*, 270. Geneva, Switzerland: World Health Organization, 2000.
Boulle, A. et al. ‘Antiretroviral Therapy and Early Mortality in South Africa’. *Bulletin of the World Health Organization* 86, no. 9 (September 2008): 678–87.
Boulle, A. and Ford, N. ‘Scaling up Antiretroviral Therapy in Developing Countries: What Are the Benefits and Challenges?’ *BMJ Postgrad Med J* 84, no. 991 (2008): 225–27.
Bowker, G.C., and Star, S. Leigh. *Sorting Things Out*, 1999.
Braa, J. et al. ‘Developing Health Information Systems in Developing Countries: The Flexible Standards Strategy’. *MIS Quarterly* 31, no. 2 (2007): 381.
Braa, J. and Hedberg, C.. ‘The Struggle for District-Based Health Information Systems in South Africa’. *The Information Society* 18, no. 2 (2002): 113–127.
Braa, K. and Sandahl, T.I. ‘Introducing Digital Documents in Work Practices - Challenges and Perspectives’. *Group Decision and Negotiation* 9 (2000): 189–203.
Bredemeyer, D., and Malan, R. ‘Architecture Definitions’. *Artículo, Bredemeyer Consulting Págs* 3, no. 4 (2001).
Buckingham et al. *Information Systems Education: Recommendations and Implementation*. Cambridge: Cambridge University Press, 1987.
Buse, K. et al. *Making Health Policy*. 2nd ed. Berkshire, England: Open University Press, McGraw-Hill Education, 2005.
Button, G. and Harper. ‘The Relevance of “Work-Practice” for Design.’ *Computer Supported Cooperative Work: An International Journal* 4 (1996): 263–80.
Byrne, E. and Sahay, S. ‘Generalizations from an Interpretive Study: The Case of a South African Community-Based Health Information System: Reviewed Article’. *South African Computer Journal* 38 (2007): 8–19.
Cabitza, F. et al. ‘When Once Is Not Enough: The Role of Redundancy in a Hospital Ward Setting’, 158–67. Florida, USA: ACM, 2005.
Cabitza,F. et al. ‘Repetita Iuvant: Exploring and Supporting Redundancy in Hospital Practices’. *Computer Supported Cooperative Work* 28 (2019): 81–90.
Cabitza, F. and Simone, F. ‘“...And Do It the Usual Way”: Fostering Awareness of Work Conventions in Document-Mediated Collaboration’. In *Proceedings of the Tenth European Conference on Computer Supported Work*, 119–38. Limerick, Ireland: Springer, 2007.
Calloway, L. and Knapp, A. ‘Using Grounded Theory to Interpret Interviews’. New York: Pace University, School of Computer Science and Information Systems. [On-line], 1995.
Carstensen, P. H., and Schmidt, K. ‘Computer Supported Cooperative Work: New Challenges to Systems Design’. In *Handbook of Human Factors*, 24. Tokyo, Japan, 1999.

Chawani, M.S., et al. ‘Balancing Work Practices and Protocols in the Design of EMR Systems: The Case of Developing an EMR System for Antenatal Care Services in Malawi’. *European Journal of Information Systems in Developing Countries* 63, no. 1 (2014): 1–26.
Chetley, A. et al. ‘Improving Health Connecting People: The Role of ICTs in The Health Sector of Developing Countries.’ HealthLink.org, 2006.
Chetley, A., and Davies, K. ‘Improving Health, Connecting People: The Role of ICTs in the Health Sector of Developing Countries’. HealthLink.org, 31 May 2006.
City of Cape Town. ‘5 Year Plan (IDP) for Cape Town’. Draft to Council. Cape Town, South Africa, 24 March 2007.
Clarke, R. ‘Hybridity - Elements of a Theory’, 10 May 2005.
Coiera; E. ‘Building a National Health IT System from the Middle Out’. *J Am Med Inform Assoc* 16 (2009): 271–73.
Conger, J.A. ‘Charismatic and Transformational Leadership in Organizations: An Insiders’ Perspective on These Developing Streams of Research’. *Leadership Quarterly* 10, no. 2 (1999): 145–79.
Crang, M, and Cook, I. *Doing Ethnographies*. Norwich: Geobooks, 2003.
Currall, J. ‘Security and the Digital Domain’. In *Record Keeping in a Hybrid Environment: Managing the Creation, Use, Preservation and Disposal of Unique Information Objects in Context*, 47–68. Information Professional Series. Chandos Publishing, 2006.
Daviaud, E., and Chopra, M. ‘How Much Is Not Enough? Human Resources Requirements for Primary Health Care: A Case Study from South Africa’. *Bulletin of the World Health Organization* 2008;86 (2008): 46–51.
de Vries, W.T., and Nyemera, B.W. ‘Double or Nothing: Is Redundancy of Spatial Data a Burden or a Need in the Public Sector of Uganda?’ *Information Research* 15, no. 4 (2010).
Detmer, D.E., and Steen, E.B. ‘The Computer-Based Record: Patient Moving from Concept toward Reality’. *Int Journal of Bio-Medical Computing* 42 (1996): 9–19.
Dick, R.S., and Steen, E.B. *The Computer-Based Patient Record: An Essential Technology for Health Care*. Washington DC: National Academy Press, 1991.
Dourish, Paul. ‘Implications for Design’. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 541–550, 2006.
Dourish, P. and Bellotti,V. ‘Awareness and Coordination in Shared Workspaces’. In *Proceeding of CSCW ’92*. Toronto, Canada: ACM New York, USA, 1992.
Dourish, P. and Bly, S. ‘Portholes: Supporting Awareness in a Distributed Work Group’. In *CHI’92 Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 1992:541–47. Monterey, California, USA: ACM New York, USA, 1992.
Eisenhardt, K.M. ‘Building Theories from Case Study Research’. *The Academy of Management Review* 14, no. 4 (October 1989): 532–50.
Ellingsen, G., and Monteiro, E. ‘A Patchwork Planet: Integration and Cooperation in Hospitals’. *Computer Supported Cooperative Work* 12 (2003): 71–95.
Ellingsen, G., and Monteiro, E. ‘Seamless Integration: Standardization across Multiple Local Settings’. *Computer Supported Cooperative Work* 15 (2006): 443–66.
Ellingsen, G., and Monteiro, E. ‘The Organizing Vision of Integrated Health Information Systems’. *Health Informatics Journal* 14 (18 August 2008): 223–36.
Fitzpatrick, G. ‘Integrated Care and the Working Record’. *Health Informatics Journal* 10, no. 4 (2004): 291–302.
Fitzpatrick, G., and Ellingsen, G. ‘A Review of 25 Years of CSCW Research in Healthcare: Contributions, Challenges and Future Agendas’. *Computer Supported Cooperative Work*, 21 June 2012.
Flyvbjerg, Bent. ‘Five Misunderstandings About Case-Study Research’. *Qualitative Inquiry* 12, no. 2 (April 2006): 219–45.

Ford, J.D., and Ford, L.W. ‘Logics of Identity, Contradiction, and Attraction in Change’. *The Academy of Management Review* 19, no. 4 (October 1994): 756–85.
Foster, R.S. ‘Human Factors in Health Information Systems: The Western Cape Experience’. Department of the Premier, Provincial Government of the Western Cape, 2007.
Fraser, H.S.F. et al. ‘Implementing Electronic Medical Record Systems in Developing Countries’. *Informatics in Primary Care* 13 (2005): 83–95.
Fraser, H.S.F, et al. ‘Evaluating the Impact and Costs of Deploying an Electronic Medical Record System to Support TB Treatment in Peru’, 264–68. Washington DC, USA: Proc AMIA Symp 2006, 2006.
Fraser, H.S.F, et al. ‘An Information System and Medical Record to Support HIV in Rural Haiti’. *BMJ* 329 (13 November 2004): 1142–46.
Gaver, W.W. ‘Technology Affordances’, 79–84. New Orleans, Louisiana, USA: ACM New York, USA, 1991.
Geertz, Clifford. *The Interpretation of Cultures*. New York: Basic Books Inc., 1973.
Gibson, J.J. *The Ecological Approach to Visual Perception*. Boston, MA, USA: Houghton-Mifflin, 1979.
Gilson, L. and Raphaely, N. ‘The Terrain of Health Policy Analysis in Low- and Middle-Income Countries: A Review of Published Literature 1994-2007’. *Health Policy and Planning* 23 (2008): 294–307.
Golden-Biddle, K. and Locke, K. *Composing Qualitative Research*. 2nd ed. SAGE Publications Inc., 2007.
Greenhalgh, T. et al. ‘Tensions and Paradoxes in Electronic Patient Record Research: A Systematic Literature Review Using the Meta-Narrative Method’. *The Milbank Quarterly* 87, no. 4 (2009): 729–88.
Grills, Scott. *Doing Ethnographic Research: Fieldwork Settings*, 1998.
Grimson, J., Grimson, W., and Hasselbring, W. ‘The SI Challenge in Health Care’. *Communication of the ACM* 43, no. 6 (June 2000): 49–55.
Grisot, M. ‘Foregrounding Differences: A Performative Approach to the Coordination of Distributed Work and Information Infrastructures in Use’. PhD Thesis, University of Oslo, 2008.
Grudin, J. ‘Computer Supported Cooperative Work: History and Focus’. *IEEE Technology and Society Magazine*, 1994.
Gurley, L., and Rose, B. ‘Advantages and Disadvantages of the Electronic Medical Record’. *American Academy of Medical Administrators Executive*, Spring 2004.
Hammersley, M., and Atkinson, P. *Ethnography: Principles in Practice*. Routledge, 2007.
Hannan, T.J., ‘The MOSORIOT Medical Record System (MMRS) Phase I to Phase II Implementation: An Outpatient Computer-Based Medical Record System in Rural Kenya’, 619–22. London, UK: IOS Press, 2001.
Hanseth, O. et al. ‘Reflexive Standardization: Side Effects and Complexity in Standard Making’. *MIS Quarterly* 30 (2006): 563–81.
Hanseth, O. and Lundberg, N. ‘Designing Work Oriented Infrastructures’. *Computer Supported Cooperative Work (CSCW)* 10, no. 3–4 (2001): 347–372.
Hanseth, O. and Lyytinen, K. ‘Theorizing about the Design of Information Infrastructures: Design Kernel Theories and Principles’, November 2003, 36.
Hanseth, O. and Monteiro, E. ‘Understanding Information Infrastructure’, August 1998.
Hanseth, O. et al. ‘Developing Information Infrastructure: The Tension Between Standardization and Flexibility’. *Science, Technology, & Human Values* 21, no. 4 (October 1996): 407–26.
Harries, AD et al. ‘Scaling up Antiretroviral Treatment in Resource-Poor Settings.’ *The Lancet*, no. June 3;367(9525): 1870-2 (2006).

Harrison, D. ‘An Overview of Health and Health Care in South Africa 1994 - 2010: Priorities, Progress and Prospects for New Gains’, December 2009.
Hartswood, M. et al. ‘Making a Case in Medical Work: Implications for the Electronic Medical Record’. *Computer Supported Cooperative Work* 12 (2003): 241–66.
Haux, R. ‘Medical Informatics: Past, Present, Future’. *Int Journal of Med Inf* 79 (2010): 599–610.
Health Metrics Network/World Health Organization. ‘Framework and Standards for Country Health Information Systems’. Geneva, Switzerland: WHO, June 2008.
Heath, C., and Luff, P. ‘Collaborative Activity and Technological Design: Task Coordination in London Underground Control Rooms’. Amsterdam, Netherlands, 1992.
Heath, C. and Luff, P. ‘Documents and Professional Practice: “bad” Organisational Reasons for “Good” Clinical Records’, 354–63. Boston, MA, USA: ACM, 1996.
Hevner, A.R. et al. ‘Design Science in Information Systems Research’. *MIS Quarterly* 28, no. 1 (March 2004): 75–105.
Hinman, A.R. et al. ‘Principles and Core Functions of Integrated Child Health Information Systems’. *Journal of Public Health Management Practice*, no. November (Suppl) (2004): S52–56.
Hughes, J. et al. ‘Faltering from Ethnography to Design’. In *Computer Supported Cooperative Work ’92*. Toronto, Canada: ACM New York, USA, 1992.
Hughes, J. et al. ‘Moving Out from the Control Room: Ethnography in System Design’, 429–39. Chapel Hill, NC, USA: ACM New York, USA, 1994.
Human Sciences Research Council: ‘South African National HIV Prevalence, Incidence and Behavior Survey, 2012’. Survey. Cape Town, South Africa: Human Sciences Research Council, 2014.
Hutchby, I. ‘Technologies, Texts and Affordances’. *Sociology* 35, no. 2 (2001): 441–456.
Hutchins, E. *Cognition in the Wild*. Massachusetts, US: MIT Press, 1995.
Institute of Medicine of the National Academies. ‘Key Capabilities of an Electronic Health Record System’. Letter Report. Washington DC, USA: National Academy of Sciences, USA, 2003. 49.
Jacob, M. et al. ‘Modelling of Business Systems Using Hybrid Simulation - a New Approach’. Pretoria, South Africa, 2010.
Jacucci, E. et al. ‘Standardization of Health Information Systems in South Africa: The Challenge of Local Sustainability’. *Information Technology for Development* 12, no. 3 (Summer 2006): 225–39.
Janssen, M. and Hjort-Madsen, K. ‘Analyzing Enterprise Architecture in National Governments: The Case of Denmark and the Netherlands’. Waikoloa, HI, USA: IEEE, 2007.
Jazayeri, et al. ‘An Electronic Medical Record System to Support HIV Treatment in Rural Haiti’, page 878, 2003.
Jensen, T. B. ‘IS Adoption From a User Perspective: A Case Study of How Health Care Professionals Experience and Make Sense of an Electronic Patient Record Adoption’. PhD Thesis, University of Aarhus, Aarhus School of Business, 2007.
Jensen, T. B. and Aanestad, M. ‘Hospitality and Hostility in Hospitals: A Case Study of an EPR Adoption among Surgeons’. *European Journal of Information Systems* 16, no. 6 (2007): 672–680.
Jones, M. ‘Learning the Lessons of History? Electronic Records in the United Kingdom Acute Hospitals, 1988-2002’. *Health Informatics Journal*, 2004, 10(4) ed. 39.
Kaptelinin, V. and Nardi, B. ‘Affordances in HCI: Toward a Mediated Action Perspective’, 967–76. Austin, Texas USA: ACM, 2012.
Kaptelinin, V. ‘Activity Theory: Implications for Human-Computer Interaction’. *Context and Consciousness: Activity Theory and Human-Computer Interaction* 1 (1996): 103–16.

Kaptelinin, V. and Bannon, L. ‘Interaction Design beyond the Product: Creating Technology-Enhanced Activity Spaces’. *Human–Computer Interaction* 27, no. 3 (2012): 277–309.
Kaptelinin, V. and Nardi B. ‘Affordances in HCI: Toward a Mediated Action Perspective’. In *CHI’12*. Austin, Texas USA: ACM New York, USA, 2012.
Klein, H, and Myers, M.D. ‘A Set of Principles for Conducting and Evaluating Interpretive Field Studies in Information Systems’. *MIS Quarterly* 23, no. 1 (1999): 67–94.
Knaup, P. et al. ‘Electronic Patient Records: Moving from Islands and Bridges towards Electronic Health Records for Continuity of Care’. *IMIA Yearbook of Medical Informatics*, 2007.
Knoblauch, H. ‘Focused Ethnography’. *Forum Qualitative Social Research* 6, no. 3 (September 2005).
Kreps, D., and Richardson, H. ‘IS Success and Failure - The Problem of Scale’. *The Political Quarterly* 78, no. 3 (September 2007): 439–46.
Krickeberg, K. ‘Principles of Health Information Systems in Developing Countries’. *Health Information Management Journal* 36, no. 3 (2007): 8–20.
Landau, M. ‘Redundancy, Rationality, and the Problem of Duplication and Overlap’. *Public Administration Review* 29, no. 4 (August 1969): 346–58.
Langlois, R. N. ‘Modularity in Technology and Organization’. *Journal of Economic Behavior & Organization* 49, no. 1 (2002): 19–37.
Lee, A.S., and Baskerville, R.L. ‘Generalizing Generability in Information Systems Research’. *Information Systems Research* 14, no. 3 (September 2003): 221–43.
Leiner, F. et al. *Medical Data Management. A Practical Guide*. Health Informatics (Formerly Computers in Health Care. New York: Springer, 2002.
Lippeveld, T, and Spohr, M. ‘Third International RHINO Workshop - Information for Action: Facility and Community Focus’. Proceedings. Chiang Rai, Thailand: MEASURE, 26 March 2006.
Lippeveld, T. ‘Routine Health Information Systems: The Glue of a Unified Health System’. In *Keynote Address at the Workshop on Issues and Innovation in Routine Health Information in Developing Countries, Potomac, March*, 14–16, 2001.
Lippeveld, T., Sauerborn, R. and Bodart, C. *Design and Implementation of Health Information Systems*. World Health Organization Geneva, 2000.
Little, SJ. et al. ‘Antiretroviral-Drug Resistance among Recently Infected with HIV’. *New England Journal of Medicine* 347, no. 6 (August 2002): 385–94.
Lucas, H. ‘Information and Communications Technology for Future Health Systems in Developing Countries’. *Social Science & Medicine* 66 (14 March 2008): 2122–32.
Luff, P. et al. *Workplace Studies: Recovering Work Practice and Informing System Design*. University Press, Cambridge, UK, 2000.
Lynge Nielsen. *Classifications of Countries Based on Their Level of Development: How It Is Done and How It Could Be Done*. International Monetary Fund, 2011.
Maher, D. ‘The Power of Health Information - the Use of Cohort Monitoring in Managing Patients with Chronic Non-Communicable Diseases’. *Tropical Medicine and International Health* 17, no. 12 (December 2012): 1567–68.
Mamlin, B.W. et al. ‘Cooking up an Open Source EMR for Developing Countries: OpenMRS - A Recipe for Successful Collaboration’, 529–33. Washington DC: American Medical Informatics Association, 2006.
Manchester, G.W. et al. ‘Primary Care Health Information System: A Hybrid Electronic-Paper Medical Record System’. *Journal of Ambulatory Care Management* 15, no. 3 (1992): 13–29.
Mars, M., and Seebregts, C. ‘Country Case Study for E-Health South Africa’. For Bellagio Conference, 2008.

Martin, D. et al. ‘Timing in the Art of Integration: “That’s How the Bastille Got Stormed”’. In *GROUP ’05 Proceedings of the 2005 International ACM SIGGROUP Conference on Supporting Group Work*, 313–22. Sanibel Island, Florida, USA: ACM New York, USA, 2005.
Martin, D. and Sommerville, I. ‘Ethnography and the Social Structure of Work.’ In *Structure for Dependability: Computer-Based Systems from an Interdisciplinary Perspective.*, 169–88. London: Springer Verlag, 2006.
McDonald, et al, and the INPC Management Committee. ‘The Indiana Network For Patient Care: A Working Local Health Information Infrastructure’. *Health Affairs* 24, no. 5 (September 2005): 1214–20.
McGrenere, J., and Ho, W. ‘Affordances: Clarifying and Evolving a Concept’. In *Proceedings of Graphics Interface 2000*. Montreal, Canada, 2000.
Medical Protection Society. ‘Retention of Medical Records’, *www.mps-group.org*
Menachemi, N. and Brooks, R.G. ‘Reviewing the Benefits and Costs of Electronic Health Records and Associated Patient Safety Technologies’. *Journal of Medical Systems* 30 (2006): 159–68.
Mikkelsen, G., and Aasly, J. ‘Concordance of Information in Parallel Electronic and Paper Based Patient Records’. *Int Journal of Med Informatics* 63 (2001): 123–31.
Miles, K. and Huberman, A.M. *Qualitative Data Analysis*. 2nd ed. California, US: SAGE Publications Inc., 1994.
Millen, David R. ‘Rapid Ethnography: Time Deepening Strategies for HCI Field Research’. In *Proceedings of the Conference on Designing Interactive Systems*, 280–86. Brooklyn, New York: ACM New York, USA, 2000.
Millennium Summit of the United Nations. ‘United Nations Millennium Declaration’, September 2000.
Mønsted, Troels Sune, Fossum, Kristoffer, and Aanestad, Margunn. ‘Managing Redundancy: A Practice Perspective on Emergent Standardization in a Hospital Unit’. San Francisco, CA, US, 2018.
Monteiro, E. et al. ‘From Artefacts to Infrastructures’. *Computer Supported Cooperative Work (CSCW)* 22, no. 4–6 (August 2013): 575–607.
Mostert-Phipps, N. et al. ‘A Socio-Technical Approach to Continuity of Care and Electronic Records in the South African Context’. Cape Town, South Africa: IOS Press, 2010.
Mursu, A. ‘Information Systems Development in Developing Countries. Risk Management and Sustainability Analysis in Nigerian Software Companies’. PhD Thesis, University of Jyväskylä, 2002.
Myers, M.D. ‘Qualitative Research in Information Systems’. *MISQ Discovery*, June 1997.
Myers, Michael D. ‘Investigating Information Systems with Ethnographic Research’. *Communication of the Association for Information Systems* 2, no. 23 (December 1999).
National Department of Health, SA. ‘Annual Performance Plan 2013/14 -2015/16’, 2013.
National Department of Health, SA ‘Human Resources for Health South Africa. HRH Strategy for the Health Sector: 2012/13 - 2016/17’. Strategic Plan. Witwatersrand, SA, 11 October 2011.
National Department of Health, SA. ‘The National Strategic Framework for EHR.Za Implementation in South Africa’, July 2007.
National Department of Health, SA. ‘The Primary Health Care Package for South Africa - a Set of Norms and Standards’, March 2000.
National Department of Health, SA. ‘The South African Antiretroviral Treatment Guidelines’, 24 March 2013.
National Department of Health, South Africa. ‘eHealth Strategy South Africa’. National Department of Health, SA, 2012.

National Department of Health, SA. 'The HIV & AIDS and STI Strategic Plan for South Africa 2007-2011'. Strategic Plan. National Department of Health, March 2007.
National Department of Health, SA. 'The Operational Plan for Comprehensive HIV and AIDS Care, Management, and Treatment for South Africa'. Operational Plan. National Department of Health, 2007.
National Department of Health, SA. 'White Paper for the Transformation of the Health System in South Africa', 1997.
Noormohammad, S.F. et al. 'Changing Course to Make Clinical Decision Support Work in an HIV Clinic in Kenya'. *Int Journal of Med Informatics* 79 (2010): 204–10.
Norman, D.A. 'Affordance, Conventions, and Design'. *Interactions* 6, no. 3 (June 1999): 38–42.
Norman, D.A. *The Design of Everyday Things*. Basic books, 2002.
Nygren, E. and Henriksson, P. 'Reading the Medical Record. I. Analysis of Physicians' Ways of Reading the Medical Record'. *Computer Methods and Programs in Biomedicine, Elsevier Science Publishers* 39 (1992): 1–12.
O'Brien, J. et al. 'At Home with the Technology: An Ethnographic Study of a Set-Top-Box Trial'. *ACM Transactions on Computer-Human Interaction (TOCHI)* 6, no. 3 (September 1999): 282–308.
Oomman, N. et al. 'Following the Funding for HIV/AIDS: A Comparative Analysis of the Funding Practices of PEPFAR the Global Fund and World Bank MAP in Mozambique Uganda and Zambia.', 2007. http://www.healthaffairs.org/doi/10.1377/hlthaff.24.5.1214
Orlikowski, W.J., and Baroudi, J.J. 'Studying Information Technology in Organizations: Research Approaches and Assumptions'. *Information Systems Research* 2, no. 1 (March 1991): 1–28.
Orlikowski, W.J., and Iacono, C.S. 'Research Commentary: Desperately Seeking "IT" in IT Research - A Call to Theorizing the IT Artifact'. *Information Systems Research* 12, no. 2 (June 2001): 121–34.
Osler, M., and Boulle, A. 'Three Interlinked Electronic Registers (TIER.Net) Project', September 2010.
Osler, M. et al. 'A Three-Tier Framework for Monitoring Antiretroviral Therapy in High HIV Burden Settings'. *Journal of the International AIDS Society* 17, no. 18908 (2014).
Østerlund, C. 'Mapping Medical Work: Documenting Practices across Multiple Medical Settings'. *Journal of the Center for Information Studies* 5 (2004): 35–43.
Øvretveit, J. et al. 'Improving Quality through Effective Implementation of Information Technology in Healthcare'. *Int Journal for Quality in Health Care* 19, no. 5 (August 2007): 259–66.
Parkhurst, J.O., and Lush, L. 'The Political Environment of HIV: Lessons from a Comparison of Uganda and South Africa'. *Social Science & Medicine* 59 (2004): 1913–24.
Parnas, D. et al. 'The Modular Structure of Complex Systems'. *IEEE Transactions on Software Engineering* SE-11, no. 3 (March 1985): 259–66.
Parnas, D. 'On the Criteria To Be Used in Decomposing Systems into Modules'. *Communication of the ACM* 15, no. 12 (December 1972): 1053–58.
Pearson, L.B. *Partners in Development: Report of the Commission on International Development*. New Orleans, Louisiana, USA: Praeger Publisher, 1969.
Provincial Government of the Western Cape. 'The Western Cape Antiretroviral Programme. Monitoring Report, June 2006'. Monitoring Report. Cape Town, South Africa, 2006.
Provincial Government Western Cape, Department of Health. 'Annual Performance Plan 2009/2010'. Provincial Government Western Cape, February 2009.
Rasebotsa, N, Samuelson, M., and Thomas, K. *Nobody Ever Said AIDS: Poems and Stories from Southern Africa*. Cape Town, South Africa: Kwela books, 2004.

Rawolle, M. ‘The Motivating Power of Visions’. Friedrich-Alexander-Universität, 2010.
Reddy, M., Dourish,P. and W. Pratt. ‘Coordinating Heterogeneous: Information and Representation in Medical Care’. In *Proceedings of European Conference on Computer Supported Cooperative Work*, 239–58. Bonn, Germany: Springer Link, 2001.
Rotich, J.K. et al. ‘Installing and Implementing a Computer-Based Patient Record System in Sub-Saharan Africa: The Mosoriot Medical Record System’. *Journal of the American Medical Informatics Association* 10, no. 4 (August 2003): 295–303.
Sahay, S. and Walsham, G. ‘Building a Better World: Frugal Hospital Information Systems in an Indian State’. Thirty Fifth International Conference on Information Systems, Auckland, New Zealand, 2014.
Sandhu, J. S. ‘Serial Hanging Out: Rapid Ethnographic Needs Assessment in Rural Settings’. In *Human-Computer Interaction. Interaction Design and Usability*, edited by Julie A. Jacko, 614–23. Lecture Notes in Computer Science 4550. Springer Berlin Heidelberg, 2007.
Sanner, T.A. et al. ‘Grafting: Balancing Control and Cultivation in Information Infrastructure Innovation’. *Journal of the Association for Information Systems* 15, no. 4 (April 2014): 220–43.
Sauerborn, R. ‘Using Information to Make Decisions’. In *Design and Implementation of Health Information Systems*, 270. Geneva, Switzerland: World Health Organization, 2000.
Schmidt, K. *Cooperative Work and Coordinative Practices*. Springer, 2011.
Schmidt, K. and Simone, C. ‘Coordination Mechanisms: Towards a Conceptual Foundation of CSCW Systems Design’. *Computer Supported Cooperative Work (CSCW)* 5, no. 2–3 (1996): 155–200.
Schmidt, K. and Wagner, I. ‘Ordering Systems: Coordinative Practices in Architectual Design and Planning’. In *GROUP’ 03 Proceedings of the 2003 ACM SIGGROUP Conference on Supporting Group Work*, 274–83. Sanibel Island, Florida, USA, 2003.
Schmidt, R. et al. ‘Identifying Software Project Risks: An International Delphi Study’. *Journal of Management Information Systems* 17, no. 4 (Spring 2001): 5–36.
Schneider, H., and Stein, J. ‘Implementing AIDS Policy in Post-Apartheid South Africa’. *Social Science & Medicine* 52 (2001): 723–31.
Sellen, A.J. and Harper, R.H.R. *The Myth of the Paperless Office*. Cambridge, Massachusetts: MIT Press, 2002.
Shekelle, P. et al. ‘Cost and Benefits of Health Information Technology’. *Agency for Healthcare Research and Quality (US),* April 2006. 32.
Shidende, N. H. ‘Distributed Collaborative Practices in Resource Restricted Settings’. PhD Thesis, University of Oslo, 2015.
Siika, A. M. et al. ‘An Electronic Medical Record System for Ambulatory Care of HIV-Infected Patients in Kenya’. *Int Journal of Med Informatics* 74 (2005): 345–55.
Silverman, D. *Interpreting Qualitative Data. Methods for Analysing Talk, Text and Interaction*. Second. London UK: SAGE Publications Ltd., London, 2001.
Skorve, E. ‘Patient Safety, Resilience and ICT. A Reason for Concern?’ In *Information Technology in Health Care: Socio-Technical Approaches 2010*. IOS Press, 2010.
Skorve, E. ‘Shaping Information Infrastructures: Complexity and Management in the Context of a Clinical IS Implementation’. PhD Thesis, University of Oslo, 2013.
Smith, M. et al. ‘Integrated Health Information Systems in Tanzania: Experience and Challenges’. *The Electronic Journal of Information Systems in Developing Countries* 33, no. 1 (2008): 1–21.
South African National AIDS Council. ‘National Strategic Plan on HIV, STIs and TB 2012 - 2016’, 2011.

Star, S. L. and Griesemer, J.R. 'Institutional Ecology, "Translations" and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology'. *Social Studies of Science* 19, no. 3 (August 1989): 387–420.
Steel, G., et al. 'Development of a Multi-Method Tool to Measure ART Adherence in Recource-Constrained Settings: The South Africa Experience'. Submitted to the US Agency for International Development by the Rational Pharmaceutical Management Plus Program. Arlington, VA: Management Sciences for Health, 2007.
Strauss, A. and Corbin, J.M. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Second. SAGE Publications Inc., 1998.
Streeck, J. and Mehus, S. *'Microethnography: The Study of Practices'*. Lawrence Erlbaum, 2005.
Suchman, L. 'Do Categories Have Politics? The Language/Action Perspective Reconsidered'. *Computer Supported Cooperative Work* 2, no. 3 (n.d.): 177–90.
'Third International RHINO Workshop, Information for Action: Facility and Community Focus — MEASURE Evaluation'.
Thoresen, K. 'Computer Use'. PhD Thesis, University of Oslo, 1998.
Tierney, W. et al. 'Experience Implementing Electronic Health Records in Three East African Countries'. *Stud Health Technol Inform* 160, no. Pt 1 (2010): 371–375.
Tierney, W. et al. 'Viewpoint: A Pragmatic Approach to Constructing a Minimum Data Set for Care of Patients with HIV in Developing Countries'. *Journal of the American Medical Informatics Association* 13, no. 3 (2006): 253–260.
Tough, A. and Moss, M. *Record Keeping in a Hybrid Environment*. Oxford: Chandos Information Professional Series, 2006.
Ulrich, Karl. 'The Role of Product Architecture in the Manufacturing Firm'. *Research Policy* 24 (1995): 419–40.
UNAIDS. 'Confidentiality and Security of HIV Information', 2008.
UNAIDS. 'GUIDELINES on PROTECTING the CONFIDENTIALITY and SECURITY of HIV INFORMATION: Proceedings from a Workshop'. Geneva, Switzerland: UNAIDS, 15 May 2007.
UNAIDS 'South Africa Global AIDS Response Progress Report 2012'. UNAIDS Global AIDS Response Progress Report, 2012.
UNAIDS. 'Treating 3 Million By 2005: Making It Happen. The WHO Strategy'. WHO Library Cataloguing-in-Publication Data, 2003.
United Nations. 'The Millennium Development Goals Report 2012'. New York, US, 2012.
United Nations, General Assembly. 'Political Declaration on HIV/AIDS: Intensifying Our Efforts to Eliminate', 2 June 2006.
University of Cape Town, ZA. Centre for Infectious Diseases Epidemiology and Research. 'Tier.Net HIV Electronic Register - User Guide'. University of Cape Town/CIDER, 2011.
Uslu, A. M., and Stausberg, J. 'Value of the Electronic Patient Record: An Analysis of the Literature'. *Journal of Biomedical Informatics* 41, no. 4 (2008): 675–682.
Van Damme, W., Kober, K., and Kegels, G. 'Scaling-up Antiretroviral Treatment in Southern African Countries with Human Resource Shortage: How Will Health Systems Adapt?' *Social Science & Medicine* 66 (2008): 2108–21.
Van Maanen, J. 'The Fact of Fiction in Organizational Ethnography'. *Administrative Science Quarterly* 24, no. 4 (December 1979): 539–50.
Van Maanen, J. *Tales of the Field: On Writing Ethnography*. Second Edition. University of Chicago Press, 2011.
Walsham, G. *Interpreting Information Systems in Organizations*. Information Systems. Chichester, W. Sussex, England: John Wiley & Sons Ltd, 1993.
Walsham, G. 'Interpretive Case Studies in IS Research: Nature and Method.' *European Journal of Information Systems* 4, no. 2 (1995): 74–81.

Walsham, G. ‘Learning about Being Critical’. *Information Systems Journal* 15, no. 2 (2005): 111–117.
Weick, K.E. ‘Impermanent Systems and Medical Errors: Variety Mitigates Adversity’. In *Making Sense of Organizations: The Impermanent Organization*, Vol. 2. Wiley & Sons Ltd, UK, 1995.
Weick, K.E. *Making Sense of the Organization: The Impermanent Organization*. Vol. 2. Wiley & Sons Ltd, UK, 2009.
Weick, K.E. ‘The Collapse of Sensemaking in Organizations: The Mann Gulch Disaster’. *Administrative Science Quarterly* 38, no. 4 (December 1993): 628–52.
Were, M.C. et al. ‘Creation and Evaluation of EMR-Based Paper Clinical Summaries to Support HIV-Care in Uganda, Africa’. *Int Journal of Med Inf* 79 (2010): 90–96.
Western Cape Department of Health. ‘2020 The Future of Health Care in the Western Cape’, November 2011.
Western Cape Department of Health. ‘Annual Report 2008/9’, August 2009.
Western Cape Department of Health. ‘Annual Report 2011-2012’, August 2012.
Western Cape Department of Health. ‘Comprehensive Service Plan for the Implementation of Healthcare 2010’, May 2007.
Western Cape Department of Health. ‘Five-Year Strategic and Performance Plans 2005/2006’, March 2005.
Western Cape Department of Health. ‘Routine Monitoring of Antiretroviral Treatment: Guidelines and Examples’, May 2004.
Western Cape Department of Health. ‘Strategic Plan 2010/11-2014/5’, February 2010.
Western Cape Department of Health ‘Healthcare 2010: Health Western Cape’s Plan for Ensuring Equal Access to Quality Health Care’. Cape Town, South Africa, 2003.
Western Cape Department of Health. ‘Western Cape AIDS Spending Assessment Brief (2007/08-2009/10)’, April 2013.
Western Cape Government Health. ‘2020 The Future of Health Care in the Western Cape’. Cape Town, South Africa, November 2011.
Western Cape Department of Health. ‘Annual Report 2016-2017’, 2017.
Western Cape Department of Health. ‘Annual Report 2017-2018’. Annual Report. Cape Town, South Africa, ISBN: 978-0-621-46607-2
Western Cape Government: Health Directorate: Communications. ‘Annual Performance Plan 2013/14’. Western Cape Government, February 2013.
Whiting-O’Keefe, Q.E. et al. ‘A Computerized Summary Medical Record System Can Provide More Information Than the Standard Medical Record’. *The J of the Am Med Ass* 254, no. 9 (6 September 1985): 1185–92.
WHO. ‘WHO Workshop Electronic Medical Records & Knowledge Sharing for ART Scale Up in Sub-Saharan Africa, Nairobi Kenya’. Geneva, Switzerland, 30 August 2004.
WHO. ‘WHO | Global Health Sector Strategy on HIV/AIDS 2011-2015’. http://who.int/healthsystems/strategy/en/
WHO. ‘WHO | Health Policy and Systems Research - A Methodology Reader’. http://www.who.int/alliance-hpsr/resources/reader/en/
WHO. ‘WHO | HIV Patient ART Monitoring Meeting’. http://www.who.int/hiv/pub/me/artmonitoring/en/
WHO. ‘WHO | Statement on HIV Testing and Counseling: WHO, UNAIDS Re-Affirm Opposition to Mandatory HIV Testing’. http://www.who.int/hiv/events/2012/world_aids_day/hiv_testing_counselling/en/
WHO. ‘WHO | WHO Health Systems Strategy’, http://who.int/healthsystems/strategy/en/
WHO. ‘Everybody’s Business: Strengthening Health Systems to Improve Health Outcomes: WHO’s Framework for Action.’, 2007.

WHO. ‘Management of Patient Information. Trends and Challenges in Member States’. Geneva, Switzerland: World Health Organization, 2012.
WHO. ‘Patient Monitoring Guidelines for HIV Care and Antiretroviral Therapy (ART)’. Guidelines. Geneva, Switzerland, 2006.
WHO. ‘WHO Policy on Collaborative TB/HIV Activities: Guidelines for National Programmes and Other Stakeholders’, 2003.
Wilson, R. ‘Using Computers in Health Information Systems’. In *Design and Implementation of Health Information Systems*, 198–212. Geneva, Switzerland: World Health Organization, 2000.
Winthereik, B.R., and Vikkelsø, S. ‘ICT and Integrated Care: Some Dilemmas of Standardising Inter-Organizational Communication’. *Computer Supported Cooperative Work* 14 (2005): 43–67.
Winthereik, B.R., de Bont, A. and Berg, M. ‘Accessing the World of Doctors and Their Computers: “Making Available” Objects of Study and the Research Site through Ethnographic Engagement’. *Scandinavian Journal of Information Systems* 14, no. 2 (2002): 47–58.
World Health Organization. ‘Declaration of Alma Ata. International Conference on Primary Health Care’. Declaration. Alma Ata, USSR: World Health Organization, 12 September 1978.
World Health Organization. ‘WHO 58th World Health Assembly Report’. Geneva, Switzerland: WHO, 16 May 2005.
Yao, S. ‘Taxonomizing Hybridity’. *Textual Practice* 17, no. 2 (1 July 2003): 357–78.
Yin, R. *Case Study Research: Design and Methods.* Third. Vol. 5. Applied Social Research Methods. California, US: SAGE Publications Inc., 2003.
Yin, R. *Case Study Research: Design and Methods*. Second. Applied Social Research Methods. SAGE Publications Inc., 1994.
Yukl, G.A. *Leadership in Organizations*. 4th ed. Upper Saddle River: Prentice Hall, NJ, 1998.
Zachman, J. P. ‘1992 IBM Systems Journal- Extending and Formalizing the Framework for Information Systems Architecture’. Zachman International | Enterprise Architecture.

Appendix

Semi-structured interview guide Western Cape 2009 sent to the Western Cape Department of Health

1a Health worker: Clinical practice and data collection - new HIV patient

- Describe **routines** for data collection when a new patient comes for HIV testing, consultation or treatment
  - paper and/or computerized data collection
  - forms used, storage etc;

- Minimum **requirements** for data to collect? (from Sub-District, National – Provincial Department of Health)

- **Local needs** - Have data elements been added locally?

- Do the collected data give **useful information** for you in your work?

- Do you have **suggestions for improvement**? Data/information that you would like to add or remove?

- **Confidentiality** – security: How is the patient folder/record stored? Who has access to it? How is **patient information shared** between health workers within the clinic?

- If **no computer system** in use: do you think that use of computers would make the data collection and analysis more effective and useful? In what way?

- **If computers**: what are the advantages / problems?

- What kind of feedback do you get on performance and/or reporting?

1b Clinical practice and data collection - HIV/AIDS patient 'follow-up'

- How are **patients identified**? In manual systems and/or computerized:
  - by name, id-number?

- How do you **track / follow-up patients** who have been tested HIV+
  - for example, if they do not show up for appointments / do not adhere to medical treatment (ARV)?

- **Sharing of patient information** between health care providers (clinic, hospital, pharmacy, testing, blood-bank), - what are the **routines**?

- **Relationship between health workers, data managers and program mangers**

2. Data clerk/information officer:

- **Data collection, collation, reporting, routines:**

  requirements from Sub-District, Province, National Health Department – software, forms, frequency etc.

- **Integration -** Links between Preventive Mother To Child Transmission, Antenatal Care and TB programs and HIV/ART programs (and more)?

- Do you think the **existing routines cover the needs** for information both ways, i.e. for reporting 'upwards' and for patient management?