



Integrated Health
Information Architecture
Power to the Users



Integrated Health Information Architecture Power to the Users

Design, Development and Use

Jørn Braa • Sundeep Sahay



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*Dedicated to
Unni & Diego...
and
for a better world for all*



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Preface

HISP: Time, Space and Architectures

Chance brought together the radical Norwegian union based participatory design tradition, with grass root level anti-apartheid politics in 1994, when a Norwegian informatics researcher was invited to participate in South Africa's Reconstruction and Development Plan (RDP). This potent hybrid of traditions within this unique context of the fervour post-apartheid reform, led to the birth of Health Information Systems Pilot Project – HISPP. The Plan received external funding through Norwegian Agency for Development Cooperation (NORAD), to support pilot projects first in Western Province and then other provinces. Later, another Norwegian activist joined the team, contributing to the development of the first version of the District Health Information System (DHIS) on MS Office platform, which in 1998 was implemented in two provinces, and by 2000, became the de facto national standard. As the project scaled in momentum, the team dropped one 'P' from original HISPP and proclaimed it as the programme – HISP. This book is being written after about 15 years of the initial establishment of HISP, and its evolution as a 'network' involving different people, institutions, technologies and activities spreading across more than 20 countries. DHIS has now evolved into an architecture from just being a standalone software system. This journey – over time, space and technology – has provided the context and empirical experiences for our thoughts to evolve, and provides the basic foundation of this book. We describe in brief, this journey.

The Origins: South Africa and Standalone DHIS (1995-2000)

HISP found its origins in South Africa, where HISP had learnt and created its own unique approach to 'Health Information Systems' (HIS). It was there, the term 'information for local action' was born and moved beyond rhetoric to actually having a grounded meaning and purpose. The notion of an 'integrated database' from the perspective of information flows in a district, converging to a central point in a district, was understood. This integration approach represents the essence of the data warehouse approach, something which many countries are trying to achieve today – 15 years on – with limited degrees of success. In this context, integration had a purpose – the political aim to rectify the 'bads' of apartheid in the health services which were inequitable, fragmented according to race, and centralised. Technology, the DHIS Version 1 (DHIS1), was one of the tools deployed for enabling this political integration. There were deliberately constructed features of flexibility and local control inscribed in the software design with the aim of empowering users. This process of design was not a one-time task of freezing requirements and development, but an ongoing process of

evolution in context. Given the background of the team members as social and political activists in the anti-apartheid struggle, the approach was grounded necessarily in the framework of a larger ‘learning through action’ and ‘empowerment’, especially political empowerment of both people and areas that had been systematically excluded during apartheid. This undoubtedly resonated with the African National Congress (ANC) government policy of reform and upliftment.

DHIS development was based on rapid prototyping with new ‘builds’ being sometimes released on a weekly or even daily basis. The informal mechanisms for reporting bugs and requesting new functionality – all tightly integrated with user support – proved popular and encouraged users to provide feedback to the development



team. This combined with the rapid deployment of new or corrected versions astounded many users, whose prior experience had involved long waits for responses to their requests, if they ever came. Requests for new functionalities were moderated by the HISP team depending on the number of users making requests and the team capacity, while recording all relevant requests. The methodology used was informal and to a certain degree, based on user improvisation. Thus, any proactive user, regardless of his or her place in the hierarchy, had full access to the development team representing

a meritocratic approach. This approach was arguably more effective than formal processes, given the formal and conflict-ridden operating environment which demanded hierarchy.

The important role that standards play in developing integrated systems, was another key learning from the South African experience. Apartheid was about fragmentation according to race, type of service, and the system of ‘homelands’. A consequence of this was that the absence of a comprehensive national standard for data collection, and each province used different datasets, definitions, and standards. The cornerstone of the strategy to address this challenge was to develop a HIS, including a system of national standards to measure and monitor the extent to which, this policy is being achieved while pinpointing the areas where more resources and efforts are needed. Implementing standards required an approach which did not try to make one shoe fit all, but there was a ‘hierarchy of standards’, where each level (for example, a province) had the freedom to define their own standards as long as they aligned with the standards of the level above. This hierarchy was implemented in the DHIS and used to prototype, negotiate, and implement provincial and national data standards. This approach helped lower tensions between various organisational units such as provinces and health programmes, as freedom to define their own information needs was granted to the locals, while the national level was satisfied by the universal compliance to their reporting requirements.

The social systems approach to Integrated Health Information Architecture (IHIA), which we argue for in this book, helps one to understand the marriage between the political and social climate of post-apartheid, providing the context for DHIS to be born and evolve into a national standard by the year, 2000. A sophisticated technical solution without compatibility with the political context – for example, being centralised rather than decentralised – would probably not have been as effective

a solution. A social systems approach emphasises the engagement of users in the process of technology design and development. While the participatory design helped in developing the DHIS software and getting the generic data models right, DHIS used as a tool for prototyping helped to get the wider information system right, such as the datasets, indicators, and reports. This could only be achieved by using the DHIS as LEGO bricks to build the system.

The seeds of the architectural approach, which we discuss in this book, were sown in South Africa during these formative years of the nineties. Some key concepts which took root were:

1. Principles of flexibility and user control are essential features of HIS.
2. Standards are the key to a national HIS, and the principle of hierarchy of standards provides an effective way of their implementation.
3. Principles of minimum and essential datasets are important in focusing the HIS on providing data on 'what is needed most', and not on what people believe may be important in future.
4. Integration of the information flows – involving convergence of all the local information flows into a central point in a district framework – is the key to an effective district-based health system.
5. Rapid prototyping is effective as a tool to build communication and interaction between the users and developers, and to ensure that strong public health related domain knowledge is inscribed in the software.

While DHIS was successfully launched within South Africa, the same principles of geographical scaling were attempted in other countries too. This presented various challenges, of which some issues are discussed here.

Networking Efforts: HISP in South Africa and Beyond (2000-2006)

Scaling of both geographical and across areas of focus such as software and education, were the key efforts made from the year 2000 onwards. Growth of Masters programmes and involvement of PhD students became important and focal activities around which the scaling of HISP was attempted.

The intensive and evolutionary participatory development processes that HISP followed in South Africa, took DHIS from district pilots to a country-wide standard, involving increasingly refined prototypes being tested in close collaboration with the users whose focus was on using information for local action and management. The ANC government's reform goals of decentralisation and local empowerment were 'inscribed' into the design. For example, the hierarchy of standards and the use of Excel pivot tables, made drilling down and local use of information, easy. While the iterative design process produced a close fit with the needs for sweeping reform, the system accumulated both rigidities and a messy architecture overall. This proved problematic when it was subsequently introduced in countries such as Mozambique, India, Vietnam, and Cuba. A few anecdotes are presented.

In Cuba, HISP was initiated in October 2001, through the efforts of two Masters students working under the guidance of the Cuba's National Statistical Office. The Masters students, who had been trained in the Scandinavian tradition, had read about the success of the South African experience. They started their efforts in two pilot provinces

by attempting to develop minimum datasets while defining indicators to support local action. Minimum datasets and indicators for local action were alien concepts in Castro's centralised health system, where all indicator reports needed to be sent to Havana, even on a daily basis. The students' training efforts involving a participatory methodology was met by resistance at the national level, who expressed dislike for the concept of the local workers getting more skilled in the system than them. Institutionally, the HIS in Cuba was dominated by the statistical cadre, whose needs for information use were not so much to support local action, but statistical reporting. The statistical structure inspired by the Soviet legacy, encouraged centralisation, with data flowing to the national database for making prospective 5-year macro-level national



plans. Such a focus impeded processes to encourage local and active use of information, which required participation of local users.

Similarly, in India, where HISP efforts were initiated in the year 2000, breakthroughs in promoting the notions of 'information for local action' were difficult to achieve. Contributing to this was the very strong centralised mandate, at both the state and national levels, and also the extreme fragmentation and multiplicity of reporting channels. Institutional inertia was significant, with many reports that were

identified from the health programmes that were terminated long before. Attempts to try and deal with data redundancies in one state through the design of 'minimum datasets' was not allowed to go through by the state authorities who gave instructions that HISP should not be allowed to change anything. Many years later, in the year 2008, the situation did change as HISP became an active participant in the national level reform effort to redesign datasets, indicators, and information flows. The invitation to participate in these national level efforts, while coming largely through personal contacts (as is most always the case in India), helped open up opportunities to work at the local level in various states. An approach primarily focused on building grass root level participation, without the permissions from the top, would arguably have ended up in a failure in the Indian context.

In Mozambique, we found that the use of the 'learning by doing' approach, which had been so popular and effective in South Africa, to be relatively ineffective. The 'pivot table' based reporting approach, provides users with the flexibility to create the reports they locally require, and promotes a 'learning by doing' approach that potentially strengthens empowerment. Attempts to adopt the 'pivot table' approach was met with resistance as users wanted pre-designed reports, which could be generated with the click of a button and sent up the reporting hierarchy. The failure of the HISP team to provide such functionality in the application contributed significantly to the limited uptake of the systems in the three provinces, where HISP was piloting the project.

These different examples from varying contexts, helped to drive home the realisation, that context matters, and approaches to design and development of HIS must be broad-based and flexible enough to adapt. Scandinavian traditions of development, found a happy partner in post-apartheid South Africa, where the political focus was on local empowerment. In Cuba and India, local empowerment was largely a concept foreign to the culture, where the focus was on centralisation. This was a result of legacies of Soviet's statistics-based planning and the British bureaucracy, in the

respective countries. Politics was important, though there were apparent differences in how they played out on the ground. In both Cuba and India, the political buy-in was required, not as a form of user empowerment, but to get the permissions from the top to try out and scale things in the field. In hindsight, if permission had been obtained from Fidel Castro in Cuba and the Health Commissioner in India, the results could have been markedly different.

How does one deal with the limits of scaling efforts, both in terms of the technical systems and approaches to their development and implementation? HISP points to the solution in terms of consciously trying to cultivate networks within which, collaborative action can be fostered and shared, to address the twin problems of scale and sustainability. In the public health system, the normative goal is to provide equitable services to all. Hence, the problem of scale becomes a unique one of 'all or nothing', since data from limited sites will always be inadequate to the district manager, who needs data on the entire coverage of the catchment area, under the district including all its sub-units. However, if the HIS is not at a scale to be useful to the health system, then the managers will neither take ownership of the system nor invest resources, making the system unsustainable. A pilot will remain a pilot, and it would not scale if learning from the pilot is not linked to other facilities, systems, people and institutions to which it needs to scale. Without these inter-linkages, there will be no critical mass of interested people and resources, which will make the system unsustainable. Further, networks are never apolitical, and there are always negotiations around who gets included and who does not. A key agenda of HISP has been to work with marginalised contexts, and include them in the network.

HISP conceptualised as a 'network of action', comprises of various entities, including Universities, Ministries of Health, international agencies like WHO and NORAD, and in-country implementing agencies like HISP SA and HISP India. The network is never static and there are always new memberships, such as ongoing attempts by HISP, to forge partnerships with other open source software development groups such as OpenMRS and iHRIS. Network members play different roles from managing software development, co-ordinating educational linkages, or fund raising. Some nodes play co-ordinating and other implementing roles, influencing either local, national, or global levels depending on their interests, agendas, capacities and resources.

Reflecting back, as efforts were made over time to scale to different geographies, there was the encountering of very different time, space and cultural contexts, with significantly different politics (as compared to South Africa, which was our reference frame). As in the case of South Africa, there is always a deep and intimate relation between the politics, technology, and the user needs and pull. With respect to politics, in India and Cuba, HISP was not positioned 'high enough' in the hierarchy to get the required support to scale completely. With respect to the technology, the first version of the DHIS, which was used successfully in South Africa, had limits primarily because of a messy database architecture which had grown in a relatively ad hoc manner over time. It could not be scaled easily to other settings as evidenced by the difficulties faced initially in its internationalisation. Not being compatible with the web, provided another set of serious constraints to the technology, in how much it could be expanded.

While DHIS related project implementation was not so successful in the early 2000s, positive results were achieved by HISP in supporting the establishment of Masters programmes in Health Informatics (in Mozambique, South Africa, and so on), and

having more students engaged in PhD programmes from the South. From the social systems perspective, which was so integral to our thinking, we found out that the same was something which was not easily understood by students coming from more traditional engineering and medical backgrounds. Challenging their existing thinking, while incorporating a strong action research approach, which does not see a divide between action and research, are some of the struggles that we are grappling with, even today. Not being able to bridge this gap has adversely influenced implementation efforts in various settings such as in Ethiopia.

Web-based Networking: Embracing a New Technological Paradigm (2006-2010)

The years following 2005, saw HISP or at least a large part of it embrace the new technological paradigm offered by the Web. In response to the demand for moving HISP to an Internet enabled web-based platform, the development of second version of the DHIS (DHIS2) was initiated. This development took place under the leadership



of the University of Oslo, but aimed at distributing development activities to a number of countries in the network, in order to bring software development closer to the contexts of use. A stack of 'bleeding edge' Java-based technologies was selected for DHIS2, and in parallel, a distributed development platform similar to those employed by many FOSS projects was set up. However, re-implementing DHIS as a modular web application proved quite difficult. Also, the radical break in technologies, as well as, an overemphasis on the new online communication platform presented a formidable obstacle to the

involvement of existing technical staff in various sites globally, such as in India, Ethiopia, and Vietnam.

It was only in January 2006, that the first instance of DHIS2 was deployed in Kerala, India; even at which point, many important functionalities were lacking. The system improved significantly through early use in India and Vietnam, and later in the Republic of Sierra Leone, as well as through the involvement of new software developers recruited locally. While engaging with the global source code, their main task was to support local implementations, in the process of bridging the divide between users and developers. Some of the principles of HIS learnt in South Africa were very relevant to the efforts in India and Sierra Leone. The technologies and the new web-based paradigm brought about important differences, for example in Republic of Sierra Leone.

Sierra Leone provides an interesting example in the making of architecture. While principles of intensive and rapid development of new functionalities required by the 'context of use' learnt in South Africa were relevant here; the DHIS2 was used as a 'plastic' to create the architecture, while allowing different groups of users with multiple views of data, transmitted through the Internet in ways that were relevant to them. The HMN Framework, which represented the global vision of the architecture, was instantiated through the DHIS2. An architecture, which is being developed by teams of

developers situated in their respective contexts of use, undoubtedly will have to deal with problems of coordination and synchronisation. When DHIS2 was first introduced in the field in the year 2006, the HISP India team members, who had several years of experience with DHIS1, found it hard to make it useable in their context. At the time, no report generation or graphing tools were in place and also DHIS1 was largely ill-equipped to process large amounts of data collected in India. Workarounds and ad hoc 'hacks' were used to produce the needed reports. In addition to this, the technology was changed to Java-based frameworks at the same time, which was not well known among the Indian team, leading to a knowledge gap between the global and Indian teams. For example, although the data model was quite similar to the DHIS1, DHIS2 had an additional data abstraction layer, thus using the Java Application Programming Interface (API) instead of directly accessing the database. The Indian team found this hard to comprehend. In addition, to achieve optimal speed, they chose to bypass the API and access the database directly, in order to get quick results and fill in the gaps in functionality in the DHIS2 application. This resulted in some 'hard-coded' but well performing reports.

Initially, the objective for the DHIS2 distributed development was to bring the design and development of the software closer to the users. Experience teaches us that the potential forking of branches and code bases is a complex problem to overcome. There is a significant advantage for developing countries to pool together resources and best practices, while developing a shared code base for DHIS2. But, the levels included in designing DHIS2 needs to be re-explored, starting with the distinction between software and system. In many ways, the DHIS2 development has seen a separation of the coding from the actual context of use. A team of 4-7 Java programmers in Vietnam have been a part of the global HISP network since 2006 and have become very proficient. The procedures being established now, is to centralise the core development and outsource (or what we call 'opensource') tasks to Vietnam, while strengthening the DHIS2 implementers in all the regions. These procedures ensure communication between implementers and 'coders' through the DHIS2 'gate keepers'.

The explicit change from stand-alone to networked user applications, within health systems in many developing countries, also signifies the increasing momentum in the use of open source technologies. While earlier, HISP spread through students and educational programmes, which are typically time and resource intensive, these new developments allowed countries to technically adopt systems or what we call 'HISP technologies', with limited prior preparation. For example, this was achieved by training and dissemination through regional workshops in West Africa with 8 participating countries. The shift in the networking dimension represents a fundamental challenge to locally focused participatory design approaches. Now, the landscape changes both technologically and in terms of geographical spread. While Microsoft-based technologies with its relative simplicity and more widespread use has enabled more direct participation of users, the web-based technologies undoubtedly place layers of complexity in between. Users, in the initial period, will not be able to directly engage with design issues, and their participation would need to be mediated by intermediaries such as HISP team members, who span the domains of both technology and use.

Integrated Health Information Architecture: The Focus

While providing a broader aspect of the Integrated Health Information Architectures (IHIAs), the book's analysis is grounded concretely and deeply in the experiences of the HISP network and evolution of the DHIS2 over the last 15 years, in which both the authors have been personally involved.



The journey described so far has involved the birth of HISP in South Africa, the growth of participatory design and DHIS, and with it, the core ideas of the IHIA. While the DHIS was sufficient in the context of South Africa, technological and methodological limits were experienced as efforts were made to scale outside the country. The technological shifts that had emerged helped to provide the impetus for HISP and other global actors to co-operate on developing architecture of interoperable systems.

Thanks to HMN and their HMN Framework; which represents an overall country HIS Systems architecture design, integration of data using a data warehouse approach and interoperability between systems have helped to describe key features of such an architecture to a large extent.

Over the last year or so, and much accelerated in recent months, extensive focus was set on:

- Health information architecture and interoperability.
- Developments around expanding the scope of HIS.
- Include patient based systems such as OpenMRS, and human resource information systems such as iHRIS.

Discussions on how these systems should speak to each other, and the standards of data exchange are important contemporary topics. Thus, the HMN and WHO had taken a strong role in defining the Public Health Information Toolkit, consisting of a suite of applications and also the SDMX-HD standards for data exchange. With this move from individual to multiple systems, the nature and methods of the underlying approach to build them also need to be redefined. The book seeks to explore some of these issues in how architectures can be conceptualised, designed and used. The point of departure taken in this book is to focus on information needs, software applications, and data exchange, rather than just the technology that typical architecture discussions tend to focus on. At the level of information needs, the focus is on understanding what the users want, and then analyse from which system or part of the architecture, the information will feed in. The architecture approach thus helps to provide information of a greater granularity that individual users need, which also places the onus on the implementing staff to be capable of understanding the deep impact of the nature of decision making, information requirements, and the supporting systems that provide this.

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