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Health Information Systems Programme

Participatory Design within the HISP network

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This chapter seeks to contribute to the ongoing debates in the domain of Participatory Design by discussing the various trends and questions within the context of the Health Information Systems Programme (HISP) initiative ongoing over nearly two decades. The focus in this chapter is to discuss issues of Participatory Design during the course of the design, development, implementation and scaling of the DHIS software within an action research framework in the context of the public health sector in various developing countries. Further, we discuss Participatory Design with respect to changes over time in technological and political contexts and the challenges following from that; from stand-alone MS Office to cloud computing and fully open source technology – enabling local Participatory Design!

In this chapter, we try to describe this rather complex HISP movement over time following three broad phases; 'traditional' Participatory Design; pilots and networking Participatory Design, and Participatory Design and web technologies. After this historical reconstruction, we describe and discuss current trends and challenges, focusing on the new area of cloud computing and the need for integration with other systems.

We elaborate on practical challenges and potentials of doing Participatory Design in the context of developing countries and in a longitudinal perspective. The reader will learn about Participatory Design in a global development perspective and about the importance of networking Participatory Design projects and to share software, lessons and resources across countries 'South–North–South' as a way to achieve sustainability and scalability. Rapid spread of communication technologies such as mobile Internet is currently changing the context for Participatory Design in developing countries. The chapter provides the reader with analysis and discussion on the potential for Participatory Design and empowerment of users in developing countries in the new area of cloud computing and in an environment where multiple systems need to be integrated.

The emerging cloud-based infrastructure represents both an opportunity and a threat. While users even in rural Kenya may now feel empowered by having instant access to own and other data, global actors are aggressively promoting their own software-based services. To counteract the latter, the challenge is to enable development of local capacity to master the new technologies, for which Participatory Design may provide both the means and the end.

Introduction

This chapter seeks to contribute to the ongoing debates in the domain of Participatory Design by discussing the various trends and questions within the context of the Health Information Systems Programme (HISP) initiative ongoing globally over the last 15 or so years (see Braa et al. 2004). The empirical basis for this chapter is provided by the efforts – technical, educational and political – in developing and evolving the HISP network with a key focus on the design, development, implementation and scaling of the DHIS (District Health Information Software) within an action research framework for the public health sector in developing countries.

HISP can be described as a global research, development and action network around health information systems (HIS) for the Global South, enabled through South–South–North collaboration. The network is by no means homogeneous and static, nor in harmony following a single goal, including how Participatory Design techniques have been and should be used. HISP was initiated through the efforts of a few as a bottom-up Participatory Design project in South Africa in 1994/5, and has today evolved into a global and thriving network spread across multiple countries and contexts. This development has been non-linear and followed different trajectories, experiencing successes and setbacks, as well as radical technological changes: the Internet and mobile network revolutions in Africa and Asia and the shift from stand-alone desktop application to networked web applications. HISP evolution has gained further impetus through increased focus on global health, including on the achievement of the Millennium Development Goals (MDGs). During times of rapid policy, technological and other changes, HISP has all along tried to be 'on top of' the changing environment, but has many times been victim to changing policies; as an example, being literally thrown out of Ethiopia after years of work as a result of political decisions at the national level. At no point in time have the HISP actors been able to foresee moves into the future, as the context of funding and politics has been constantly changing and uncertain. Maybe the only consistent element in the history of HISP has been a stubborn willingness to apply participatory approaches in designing HIS in cooperation with various levels of users in a variety of contexts.

A key focus of the application of Participatory Design techniques has been around the design and development of the DHIS software. The DHIS is a tool for collection, validation, analysis and presentation of aggregate statistical data, tailored to supporting integrated health information management activities. It is designed to serve as a district-based country data warehouse to address both local and national needs. DHIS is a generic tool rather than a pre-configured database application, with an open meta-data model and a flexible user interface that allows the user to design the contents of a specific information system without the need for programming. DHIS development has evolved over two versions. The first – DHIS v1 – has been developed since 1997 by HISP in South Africa on MS Access, a platform selected because it was at that time a de facto standard in South Africa. The second – DHIS v2 – building on the v1 data model is a modular web-based software package built with free and open source Java frameworks, developed since 2004 and coordinated by the University of Oslo.

The flexible and modular DHIS software application has all along been the pivotal element in the HISP approach; both as a tool with which to communicate design to users and as a software application suite which may provide results from day one and thereafter expand while in full production, as more functionalities, datasets and other elements are added.

This chapter attempts to describe this rather complex movement over the last 15 years of the HISP network and its associated dimensions of software development and, Participatory Design processes in a multiplicity of contexts. We have interpretively developed a historical reconstruction of this movement to depict the following three broad phases of HISP development. In

addressing the first phase (1995–2000), we discuss HISP in relation to 'traditional' Participatory Design based primarily on the experience in South Africa. In the second phase (2000–6), which was characterised by pilot projects and 'networking Participatory Design', we focus on how networks of action were created outside South Africa, also encompassing educational programmes. In the third phase (2006–10), development of the fully open source and web-based DHIS platform gained momentum and challenges were experienced in applying distributed Participatory Design and scaling HISP during a time of significant technological change, including rapid spread of Internet and mobile networks in developing countries. Finally, we discuss the future direction for HISP and Participatory Design in the age of cloud computing. In our coverage of HISP, we highlight the important role that context plays in each country, which we illustrate through cross-country comparisons.

Phase 1: HISP and traditional Participatory Design

The term 'traditional Participatory Design' is used to depict basic principles of the Scandinavian Participatory Design tradition as related to user participation in system design, workplace democracy and empowerment, which was the source of inspiration for the initial HISP researchers coming from Oslo. These principles found a welcome home in post-apartheid South Africa, where the focus was on 'making right the wrongs of the past', equity in health services delivery and development and empowerment of those communities and population groups that had suffered under apartheid.

HISP was initiated in South Africa at the advent of democracy in 1994 as a part of the new ANC government's reconstruction and development programme (RDP). As a legacy of apartheid, the health services were inequitable, fragmented according to race, centralised with no local decentralised management structures contributing to the marginalisation of the black majority. The restructuring plan was based on a decentralised system of health districts including their supporting HIS. HISP started out as collaboration between, on the one hand, public health researchers and activists with background from the anti-apartheid struggle, and on the other hand, informatics researchers with background from the Scandinavian Participatory Design and action research tradition. Given this background, HISP became part of the larger development process (see Braa and Hedberg 2002 for a detailed presentation of HISP in South Africa). Two key arguments underlined the HISP process in supporting health sector reform:

1 The political empowerment argument: general exclusion of deprived areas and regions from economic, social, health-wise and technological development as depicted by the quest for equity in health services delivery, or the 'digital divide' – the need for development and empowerment. This political empowerment argument was core to the ANC government's policy to uplift and empower the black majority who had suffered during apartheid.
2 The practical learning through hands-on participation argument: individual and institutional users had limited experience with practical information technology applications, requiring a participative learning approach to overcome the differences in understanding and knowledge between users and developers through a practical hands-on approach.

These two arguments reflected the decades-old dichotomy in the Participatory Design tradition between the political agenda of the early Scandinavian action research and Participatory Design projects and the subsequent more pragmatic technically oriented Participatory Design projects. Both have been important in the development of HISP. See the influential *Computers and Democracy – A Scandinavian Challenge* (Bjerknes et al. 1987), and Chapter 2 of this volume for

background on the Scandinavian projects. HISP started as a research project with the explicit objective to bring learning from the Scandinavian Participatory Design and action research tradition to Africa and to explore to what extent these lessons could be useful in developing African Participatory Design approaches. Two Scandinavian Participatory Design perspectives – and projects – were explicitly formulated as hypotheses for what would also be useful approaches in Africa. First, the broad political empowerment perspective of the Norwegian Iron and Metal project, which was not about design as such, but aimed at empowering workers through learning in questions regarding technological changes and threats to the workplace (Nygaard 1979). Second, the more focused design for empowerment perspective of the UTOPIA project, which developed and applied practical Participatory Design approaches as a way to empower skilled workers to participate in developing technical alternatives 'controlled' by themselves (Bødker et al. 1987). On the public health side, both HISP and the wider health information community in South Africa at that time were influenced by the concept of 'information for action' and in applying action-led, as opposed to the traditional data-led (Sandiford et al. 1992), approaches to the design and development of HIS. We now discuss the South African case.

The South African HISP case

During apartheid (1948–93), the health services were extremely fragmented according to race, type of service and the system of 'homelands'. As one consequence of this fragmentation, there were no comprehensive national standards for data collection, and each province used different datasets, definitions and flows. A cornerstone of the ANC reform strategy was the development of an HIS including a system of national standards to measure and monitor the extent to which this policy was being achieved and to pinpoint areas where more resources and efforts are needed.

The initial focus in the HISP pilot districts was on identifying information needs and supporting interim district management teams. Paper-based systems for registering patients, pregnant women for control, babies for immunisation, etc., made up the primary data sources, from which data was aggregated and reported 'upwards' using a plethora of paper forms belonging to, or defined by, different health programmes or health structures. In the absence of local governance and managerial structures, systems were centralised and fragmented and all flows of data were leading out of the district to different head offices, with no feedback. The RDP was to change this into a decentralised structure empowering the local level with new health districts as basic building blocks, as reflected in Figure 10.1 showing the proposed HIS design in Atlantis, one of the HISP pilot districts.

The information for action approach was a hot topic within the health reform process during the 1990s and was applied according to what was labelled the 'information cycle', which may be outlined as follows: set targets for the health services, for example improve immunisation coverage among infants; define information and indicators to measure achievements of your targets; collect and analyse the needed data; assess the situation and compare achievements, i.e. indicators, against targets; then act if targets are not met; then redefine targets. The approach to implement this action-led approach in the health services was to identify key indicators and to develop minimum datasets of essential data that could be used to calculate these indicators. An example of an indicator is 'Measles immunisation coverage under one year', which may be calculated based on number of measles vaccines divided by number of infants. The process of developing effective indicators and datasets was at the core of the process of developing the new HIS, and even very central in the wider health reform, as it was directly linked to the debate of what targets to prioritise. Obviously, therefore, this was not an easy process as each part and sub-part of the health services tended to have their own and often conflicting views. A rather

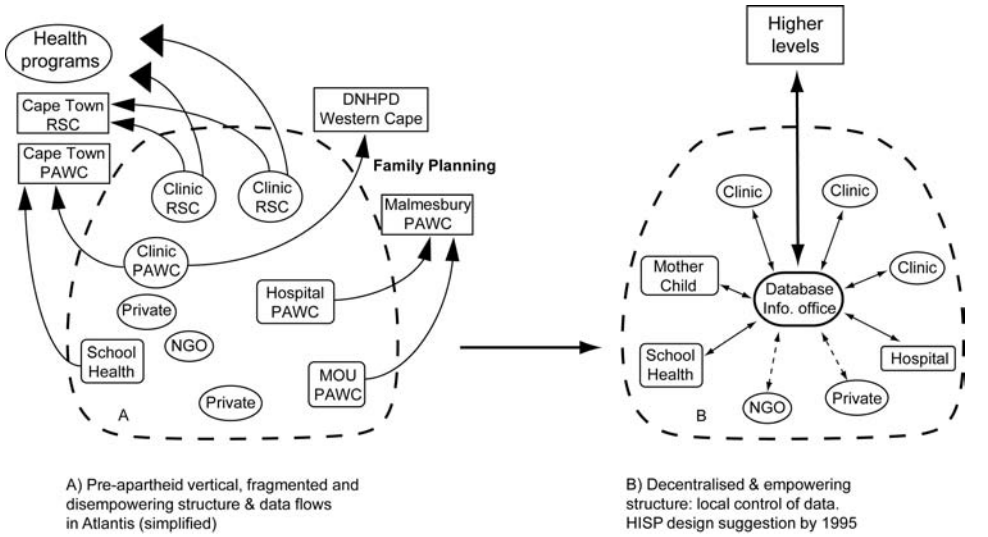

Figure 10.1 Design for integration in South Africa, 1995

intensive process of workshops and draft proposals went on during 1995–6 without much result before, in 1997, the first version of the DHIS software was used to pilot datasets in all health facilities in the four HISP pilot districts.

At the end of 1997, after about nine months of intensive negotiations driven by local managers in collaboration with the HISP team and informed by the pilots, the first essential dataset was implemented in all local government health facilities in the Cape Metropole (including HISP pilot districts). Later, after rounds of revisions, a unified dataset was implemented in the whole of Western Cape Province which subsequently inspired the neighbouring Eastern Cape Province to do the same in 1998. The datasets being implemented in the two provinces were very different, but the fact that they were implemented, something that had never been achieved before, was widely regarded as a breakthrough. Implementing datasets using DHIS represented something new in that users now had immediate access to the data, as compared with the traditional upward reporting with no feedback apart from through annual statistics.

The first version of the DHIS software was instrumental in developing, testing and piloting the datasets and it was subsequently used to capture and analyse monthly data at all levels of first Western and then Eastern Cape Province. This application went through a series of very rapid prototype cycles over the next six months, and towards the end of 1998 the DHIS stabilised in use in the Western Cape and Eastern Cape Provinces. We see here that the Participatory Design process went on at two interconnected levels: the wider participatory process of developing the datasets and the HIS, using the DHIS as a means of engaging users and stakeholders at all levels, and the more narrow Participatory Design process of developing DHIS as a software application, engaging the 'activists'.

Results from the Eastern and Western Cape presented in a national conference in 1999 also inspired other provinces to adopt this route, leading to the DHIS and the HISP approach becoming national standards in 2002. Key to this was the HISP formulated hierarchy of standards, where each level (e.g. 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 in the Participatory Design process to prototype, negotiate and implement

provincial and national datasets, which ended up being quite different from province to province. Such differences were accepted within the national system because the national standards were included as sub-sets of the provincial standards.

The development of the DHIS during these formative early years 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. Requests for new functionalities were moderated by the HISP team depending on the number of users making a request and team capacity, but all relevant requests were logged in. The development process emphasised performance and progress over established prototyping models using formal and structured processes of well-established user groups, channels of communication, and mechanisms for conflict resolution. Such formal processes may not have been effective in a conflict-ridden operating environment. The methodology used was thus more informal and to a significant degree based on improvisation, whereby any interested or innovative user, regardless of his or her place in the hierarchy, had full access to the development team representing a meritocratic approach. Access was either direct or indirect via the DHIS facilitators and users were encouraged to use their preferred channels.

HISP South Africa was formed as an independent NGO in the late 1990s and has since then made a living out of supporting DHIS and related activities in the region.

Learning from the first period

The focus during this early period was on identifying information needs and supporting interim district management teams as seen in the intervened participatory processes of (a) developing datasets and data standards for primary health care and (b) developing the DHIS software application supporting the implementation and use of these datasets. Through the use of DHIS, users such as interim district management teams had immediate access to their information, processed as indicators that could be applied to measure achievements according to targets, thus making it possible to implement the 'information cycle', which until then had been difficult to try out in practice. This concrete hands-on access to own information provided by DHIS, combined with users' constant urge for better information, analytical tools and graphs, made up the engine of the Participatory Design approaches applied in HISP, which may best be characterised as 'eternal' participatory and exploratory prototyping, or evolutionary Participatory Design. There is never a 'finished' system in the HISP case. Owing to the changing environment and massive demands for improvements in the health sector, the target system and the requirements will always be changing and extended.

Phase 2: First wave of HISP extension: Participatory Design in 'network of actions' (2000–6)

This period is characterised by networking, across countries and also across educational processes. The gradual expansion of HISP has been enabled through the establishing of Participatory Design-based pilot projects in countries and linking them with educational programmes – both Master's and doctoral studies – and then the linking of these programmes across countries. The circulation of PhD and Master's students across and within countries has been the means with which learning, software and best practices have been spread in the network. This networked action was

aimed at enabling the creation of capacities to carry out shared development and application of software between multiple country pilot projects. A challenge has been around adapting traditional Participatory Design to multi-country contexts, and finding the balance between education and practical action.

While, in South Africa, the HISP work continued and still continues, carried out by an independent HISP-NGO, both the PhD and Master's programmes have been based at or coordinated from the University of Oslo. Students became the major HISP advocates and developed smaller Participatory Design projects in their respective countries. This period was also characterised by efforts to build collaborative networks between countries, universities and local health authorities. While reasonable success was obtained in establishing and expanding the educational programmes, arguably far less success was obtained in country implementations of the HISP initiative. Three such examples are discussed, which also aid reflection on some of the limits of the traditional Participatory Design approach.

Cuba

In Cuba, HISP was initiated in October 2001 when Cuban delegates visited Norway in search of possible collaboration, which led to a subsequent collaboration between Ministerio de Salud Pública (MINSAP), the Cuban Ministry of Public Health, and the University of Oslo. In June 2002, one faculty member with two Master's students went to Cuba to initiate processes in collaboration with the Dirección Nacional de Estadísticas (DNE) (the national statistics office). A Norwegian donation of 11 computers in May 2002 made it possible to start, and a further donation of 60 computers contributed to the scaling process.

In two pilot provinces – Matanzas and Sanctí Spíritus – a situation study was initiated to understand the information flows, datasets and the work practices which contributed to the prototype design of local and province database applications. All existing data was paper based, and the HISP aim was to make data available locally for analysis and management. Two provincial statistical health offices, six municipal offices, two polyclinics and a municipal hospital were chosen as pilot sites within these two provinces. Subsequently, in September the two Oslo students started training the staff based on a participatory methodology aimed at empowering them by building their capacity to define and use data locally. The trainees were encouraged to participate in the design process to help tailor the system to their needs and build local ownership. This process of local empowerment, however, was in conflict with the centralised and vertical way of organising things in Cuba. The sharing and dissemination of information horizontally and locally using Excel pivot tables created a new opportunity of breaking the stranglehold of the statistical offices, creating interest and enthusiasm among other horizontal offices. However, the 'uncontrolled' horizontal interaction and data-sharing was immediately reported by somebody to Havana and all local HISP activities were closed down immediately after. In hindsight, this local focus can be seen as being in conflict with the centralised structure of Cuba, in which the national level complained of having lost control of the development process and demanded a centralised approach, expressing dislike for what they saw as the local workers becoming more skilled in the system than they were themselves. As a result, HISP had to refocus their efforts to a centralised development as the DNE in November 2002 froze all local activities.

Reflecting on the use of the Participatory Design approach in Cuba, it is obvious that the legacy of 40 years of strong central planning could not be overcome overnight. Coupled with the centralisation was a strongly compartmentalised system which impeded cooperation, for example between the statistics and information technology departments. These parallel structures at the national level were mirrored, though to a lesser extent, at the province level and

below, making it relatively more possible to conduct meetings at provincial and local levels. National programmes and corresponding datasets, in line with the strong Soviet statistical legacy, were designed at the national office, unknown even to the senior directors, as decisions were made by MINSAP, Havana. Another factor stifling Participatory Design was the dominance (in numbers and power) of the statisticians in the health system, and the fact that HISP was under DNE control. The Cuban system had a large number of statisticians, even five to each polyclinic (covering about 5,000 population), who were responsible for collecting and processing data, and sending daily reports on infant and maternal mortality to Havana. The statistical structure inspired by the Soviet legacy encouraged centralisation, with data flowing to the national database for making prospective five-year national plans, impeding local and active use of information.

India

In 2000, HISP India was invited by the Chief Information Technology Advisor of the Chief Minister of Andhra Pradesh to initiate a project in one district of Chittoor. Being introduced through the political rather than the health department channel subsequently had adverse implications for HISP, and made it vulnerable to the vagaries of local politics. Initially a situation analysis was conducted aimed at understanding the organisational structure and health information flows by visiting various facilities in the district, interviewing relevant functionaries and conducting participant observations. A key aim was to rationalise the data flows and develop a 'minimum dataset' representing the least number of data items to be collected by different health facilities to satisfy all reporting needs. There were high levels of redundancy, with some data collected repeatedly to comply with different programme needs, including some that had been terminated many years earlier (Puri et al. 2004). By September 2001, the 1,200 data elements had been reduced to 400, and reports restructured to 10 (Puri et al. 2004).

Despite the obvious improvements with this new design, the Health Commissioner did not give HISP official permission to implement these changes, as formats were also being revised at the state level, accompanied by the development of a new software (called FHIMS) funded by a World Bank project (Raghavendra and Sahay 2006). After extensive persuasion enabled through HISP political allies, the Commissioner consented to sanction one computer and to send a letter to the district to permit a DHIS pilot in one health facility. However, neither the computer nor the letter ever reached the district, and staff revealed that over the phone the Commissioner had instructed that HISP should not be allowed to introduce any changes. Subsequently, HISP manoeuvred an opportunity to make a presentation to the Chief Minister and his senior advisors. The Chief Minister appreciated the HISP efforts and sanctioned 12 computers, one for each of the nine clinics in Kuppam (the electoral constituency of the Chief Minister) and the rest for the district office. DHIS implementation was initiated in these facilities.

A small window of opportunity to initiate local processes was thus given to HISP, albeit reluctantly by the Health Department, which did not want interference to its well-funded FHIMS project. In defining the datasets, HISP ensured that all data elements were included (even though some were seen to be not relevant), removing only the duplicates. HISP thus ensured there was no transgression regarding the lack of state permission to make changes, while being able to gain buy-in from the health staff, who benefited because their data-reporting load was reduced, and who also enjoyed the direct interaction with HISP in helping them learn about computers.

The HISP team continued to have a base in Kuppam for about four to five years, benefiting greatly from this experience. First, this became for them a 'deep learning' site where through engaged action they learnt about the micro-level workings and challenges of a peripheral health facility, including its HIS, and how these may be addressed. Second, this engagement led to

customisation of the DHIS which was user-friendly, locally relevant and sensitive to user capacities and their sense of 'ownership' of it. This local bottom-up approach was supplemented with a top-down engagement with the politics of multiple systems, and the combined efforts over time contributed to the scaling of the system from 12 primary health centres (PHCs) to 45 in the first phase, then 82 PHCs in the entire district and then all district capitals in the state (covering about 1,300 PHCs). Seeing this success, even the state authorities (grudgingly) allowed DHIS to be integrated with FHIMS and to support its implementation, as FHIMS had not delivered the required results. However, in the end the vagaries of Indian politics took over, and with a change of the political guard with the elections in 2005, the HISP support network at the state level was lost and the initiative was terminated by the new functionaries. This demonstrated the limits of the combined top-down (for political buy-in) and bottom-up (for system learning) Participatory Design approach, which required greater top-level support in order to scale.

Mozambique

A brief example is presented regarding the attempt to adopt the 'pivot table'-based reporting approach of DHIS, used successfully in South Africa. The design assumption behind such an approach was that users should be given the flexibility to create their local reports, and that a 'learning by doing' approach would enhance user capacity and their sense of empowerment. However, this strategy led to a roadblock, as users wanted pre-designed reports which could be generated with a click of a button and sent up the reporting hierarchy. The failure of HISP to provide such functionality in DHIS contributed significantly to the limited uptake of the systems in the three provinces where HISP was piloting the project.

These different examples drove home the realisation that context matters and Participatory Design approaches need to be broad-based. The implication of context matters was that Participatory Design depends largely on the time, space and cultural conditions in which it evolves. The Scandinavian tradition of Participatory Design evolved through the 1970s found a welcome home in post-apartheid South Africa, where the focus was on local empowerment. In Cuba and India, local empowerment was largely an alien concept, as the political structures focused on centralisation due to reasons of legacies of Soviet statistics-based planning and British bureaucracy respectively. Participatory Design approaches and the evolving systems and practices in both cases could not be scaled beyond a point to be useful to the health system. The learning from South Africa about the importance of politics was reinforced, albeit with a difference. While in both Cuba and India, political buy-in was required, this was not to support user empowerment but to get permissions to try out and scale things in the field. The system design focus was found to be too limited, also requiring the building of broader education and training capacities.

HISP response to these challenges: 'networks of action'

A network, as contrasted to a hierarchy defined in terms of hierarchical relationships, refers to different people or institutions linked together with respect to specific activities or tasks. A collaborative network of action then refers to creating linkages for the purposes of collaboration through specific action around, in our case, HIS development, implementation and scaling (Braa et al. 2004). There are challenges in contextualising systems to local settings while cultivating local learning processes, institutionalising and sustaining them. The other challenge is of making one working solution spread to other sites and of ensuring its successful adaptation there. Scaling involves not only the spreading of technical systems but also the necessary learning processes, including questions of who learns and how.

In the public health system, which has a normative goal of providing equitable services to all, the problem of scale becomes a unique one of 'all or nothing', since data from only some of the sites will be useless to the district manager, who needs data on the entire catchment area under the district, including all its sub-units. And if the HIS is not at a scale to be useful, then managers will not take ownership of the system, nor will they invest resources, making the system unsustainable. This represents a vicious cycle where pilots are allowed to start, but are never used and supported because they are 'only pilots', leading to them fading away – as pilots. This implies that for interventions to be successful they need to both spread and also sustain. This is a particular challenge for HISP since the DHIS approach is about comparing and analysing statistical data which require data coverage. The 'networks of action' approach is articulated as a potential move towards addressing this challenge of scale and sustainability.

HISP conceptualised as a 'network of action' comprises various entities including universities, ministries of health, international agencies like WHO and Norad, and, in country, implementing agencies like HISP South Africa and HISP India. The network is never static and never apolitical and new partnerships are always being developed. The basic strength of a network is that it allows the possibility of learning in a collective, which is more effective than in singular units. Experience in HISP, however, is that collaboration between universities and other actors will always have a certain transaction cost, and that the perceived benefit will need to be higher than these costs or else the collaboration will die.

Reflecting on achievements during this phase, which has been largely exploratory and one emphasising learning, while there was an expansion in the scope of work to multiple countries and across different dimensions, success with respect to project implementation and scaling was limited to a few sites, e.g. India and Zanzibar. Much greater success was achieved on the education front, building a larger awareness and creating greater political visibility to HISP. A pertinent question to probe is the reason for this limited success in project implementation. This requires an analysis of the relation between the politics, technology and user needs and pull. With respect to politics, the general inference can be that HISP was not positioned 'high enough' in the hierarchy to get the support required for full-scale implementation. While local-level support was developed and cultivated through engaged and continuous participatory action, these could not be scaled and sustained, raising the paradox of how to develop local-level learning while being part of the national mainstream.

With respect to technology, the period around 2004–5 was when DHIS 2 development was initiated, the open source Java technologies being used were still new and not yet widely accepted, and so the first DHIS 2 versions started out slowly and were not triggering much interest. In South Africa, where the user base was more mature and DHIS 1 stabilised, the HISP team was reluctant to engage with DHIS 2 and new web-based technologies. At the same time, the MS Office-based DHIS 1 used in South Africa was no longer seen as representing a new paradigm, meaning that HISP was no longer seen as a technology innovator. User drive and pull is important if Participatory Design must succeed, otherwise there is little at stake for local ownership to develop. The new technological paradigm based on web and open source technologies of the next phase made DHIS 2 into an attractor, and a new area of user drive and pull developed.

Phase 3: New technological paradigm: Participatory Design in open source web-based environments (2006–10 onwards)

This phase is characterised by the explicit change from stand-alone to networked applications within health systems in developing countries. This trend is coupled with another important movement signifying the increasing momentum of open source technologies. While HISP had from the start been founded on an open source philosophy, the new situation was that these

technologies had matured to such an extent that the entire web-based technology stack could be provided as Free and Open Source Software (FOSS). While, earlier, HISP spread through students and educational programmes, which are typically time and resource intensive, these new developments allowed countries to technically adopt what we call 'HISP technologies' with limited prior preparation. For example, a training and dissemination workshop in West Africa encouraged eight participating countries to decide to adopt DHIS 2. The shift in the networking dimension represents a fundamental challenge to locally focused Participatory Design approaches, as now the landscape changed to the whole country or whole region and was not limited to a pilot site. The FOSS trend introduces a new stack of technologies requiring very different capacities for participation, while changing the landscape of who participates and how.

The development of DHIS 1 involved an intensive three-year evolutionary Participatory Design with an ongoing scaling process in South Africa, where increasingly refined prototypes were tested in close collaboration with users whose capacity to use information was constantly enhanced. The ANC government's reform goals of decentralisation and local empowerment were 'inscribed' into design, for example through the hierarchy of standards and the use of Excel pivot tables which made local views of data possible. While the iterative design process produced a close fit with the reform needs, the system accumulated both rigidities and a messy architecture overall. This proved problematic when the system was introduced in Mozambique, India, Vietnam and Cuba after the turn of the millennium. In 2004 this spurred the development of a completely revised and internationalised version of DHIS 1, including a full remodelling of the database. The developer team was still in Cape Town, and employed the same technology (MS Access), but users were now in Botswana and Zanzibar, requiring Participatory Design to be enabled through extensive travelling of project staff, supplemented by e-mail communication. This contributed to the birth of DHIS 1.4, still running today in South Africa.

At the same time, however, requirements for moving to a web-based platform were mounting, triggering yet another revamp of the software. Development of DHIS 2 began in 2004 under the leadership of the University of Oslo, but aimed at distributing development activities to multiple 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 DHIS 2, based on a distributed development platform typically employed by many FOSS projects. This process was challenging as it involved a radical break in technologies as well as an over-emphasis on the new online communication platform. The new flexible but complex architecture in effect hindered Participatory Design efforts, taking over a year and a half before DHIS 2 could initially be deployed, first in Kerala, India, in January 2006, when much important functionality was lacking. The system improved significantly through early use in India and Vietnam and later also in 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, while also contributing in more limited terms to core development.

After the first pilot in Kerala in 2006, use of DHIS 2 gradually spread to other states, and was then taken up in 2008 by the National Rural Health Mission (NRHM) to support a national implementation. Simultaneously, Health Metrics Network (HMN) chose to use DHIS 2 in Sierra Leone (see below). Political support in both cases, of NRHM in India and HMN in Sierra Leone, was fundamental for the support of larger adoption of DHIS 2.

Sierra Leone

Sierra Leone, a relatively small country in West Africa, is one of the poorest countries in the world and was ravaged by civil war 1992–2002. The public health system suffered from loss of

personnel and destruction of infrastructure, but was gradually being rebuilt with considerable support from a variety of international donor agencies. The rapid growth of relatively uncoordinated health initiatives created a situation of fragmented HIS, typical for most developing countries. In 2008 each facility reported data every month on 17 different paper forms, with nearly 50 per cent overlap of data across the forms.

Given this fragmented HIS, key challenges were to provide relevant information for decision-making and to diminish the workload of staff responsible for collecting and reporting data. The strategy selected was to use DHIS 2 as a tool to integrate the various data through a participatory prototyping strategy involving all 'owners' of data collection tools alongside the various levels of users. All paper forms and data elements included in these were identified and sorted out in order to identify duplications of data forms and data elements. As a result, a coherent integrated data warehouse was built, where one data element in the database could be related to a field in several data collection forms. In order to satisfy the 'form owners', each paper form was included in the data entry screen, while the duplicate data elements were integrated 'behind the scenes' in the data warehouse. Data already captured would then appear as already included in the data entry form.

In January 2008, this integration approach was implemented in 4 of the 13 districts, and in the rest of the country from six months later. Intensive training was carried out to support each district to capture their data in DHIS and export it to the national DHIS by the use of memory sticks. This process was established in all districts, and for 2008 a rather extensive national dataset became available for analysis. All stakeholders were included in this process, which convincingly documented the existing problems of overlapping data collection forms, inconsistent data definitions and poor data quality. At the same time, through actually implementing the process, it was documented that it was possible to achieve shared datasets in a national repository. This participatory learning process sparked an increased interest in revising the current collection forms, and during 2009 a series of meetings took place among the key stakeholders to negotiate a new set of harmonised data collection forms. As a result, since January 2010 a new set of completely rationalised and harmonised forms have been in use. Sierra Leone has become HMN's 'best practice' example of how even a poor African country can develop an integrated HIS.

Community-level Participatory Design – rationale and experience

As an effort to document their disadvantageous situation and thereby to better argue for improved health services, the traditional chiefdom structures in Sierra Leone were eager to use the new system. In Mayamba district, the seven different chiefdoms compete to produce the best-quality data on health services and produce tables ranking their achievements, in both their local and their national contexts.

The Sierra Leone case demonstrates the need and value for multi-level teams, including members from Oslo, West Africa, national ministries and the global HMN. Political support came both from HMN, urgently needing to show some successes, and also the Ministry, eager to reform their existing systems. This heterogeneous team and interests contributed to an intense period of Participatory Design contributing to the design of the entire HIS as well as the DHIS 2 application. While the situation of fragmentation was similar to that in South Africa, the strategy to reform was different, aiming not at a consensus-based minimum set of 'essential' data but a technologically driven shared data warehouse solution. The Participatory Design involved a three-step approach; first, implement the current system with optimally 'harmonised' datasets in order to give hands-on experience to users and to provide a platform for prototyping; second, use the prototype to demonstrate what a revised HIS could look like; and third, revise

the system, including the paper forms and data standards. While DHIS 2 provided the 'plastic' and easily formable prototyping tool, political support of the HMN made it practically possible.

India

After the initiation of the first instance of DHIS 2 in a clinic in Kerala in early 2006, DHIS 2 increased to full-scale implementations in the states of Gujarat and Kerala. Following these 'best practice' state implementations, HISP was invited to the national stage by NRHM to support their efforts of reform. Examples of working in various states from 2000 were drawn upon by HISP as their empirical base to highlight the challenges in the existing systems and provide recommendations for reform. In 2008, the national HIS was redesigned, including new standards which represented, among other things, a drastic reduction of the actual data elements to be reported. DHIS 2 was then quickly customised to the revisions, and provided states with a low-cost and easy-to-use system which for the first time gave states access to their own data. Further, the flexibility of DHIS 2 to create bridges with other systems, including those at the national level, contributed to its rapid uptake in about 25 states, leading to *The Lancet* terming it the largest open source implementation in the health system in developing countries (Webster 2011).

However, this rapid scaling came at a cost, as in responding to local demands the HISP India team could not effectively coordinate with the global DHIS 2 shared core code base, leading to a 'forking' of two not fully compatible branches. For example, the HISP India team had prior experience with DHIS 1, and the DHIS 2 technologies were foreign to them. The absence of graphing facilities in the early DHIS 2, and being confronted with large volumes of data, forced the Indian team to develop workarounds and ad hoc 'hacks' to produce the needed reports. While the DHIS 2 data model was similar to that of DHIS 1, it had an additional data abstraction layer requiring the use of the Java Application Programming Interface (API) instead of directly accessing the database. The Indians found this hard to comprehend, and chose to bypass the API and access the database directly in order to get quick results, leading to 'hard-coded' but well-performing reports. Another example of forking is provided by the Indian effort to develop a dashboard module to enable graphical analysis of data and indicators in charts. While this module proved very effective in showing local users their data, the code remained incompatible and outside the global code repository, because it used too many local workarounds and hacks. Also, since the Sierra Leone implementation was simultaneously also moving at a fast pace, the global team had created an 'executive dashboard', as coordination was more problematic and time-consuming than making from new. Only in 2010, when processes were reasonably more stable, were the two code bases merged and a seemingly permanent structure for future coordination established.

While the initial objective of DHIS 2 distributed development was to bring the software closer to the users, practically this was a complex problem to overcome. This led to the reformulation of development strategy, based on a clearer distinction between software and system, with two sets of implications on Participatory Design processes. In-country emphasis should be on the system rather than the software, while across countries there need to be shared Participatory Design processes contributing to the development of the global DHIS 2. Obviously, these processes mutually feed into each other; globally distributed solutions grow out of local designs and use, and DHIS 2 as a global toolbox is utilised in local design processes. To what extent design is participatory will depend on how implementers mediate requirements between users and core developers. This raises new skill demands on implementers, requiring them to be proficient in customising the system locally in cooperation with users, and needing knowledge of the DHIS 2 to an extent that they can specify new requirements to the developers. Two

levels of 'gate-keeping' are required at the national and global levels, possible through a certain level of dictatorship.

In many ways, DHIS 2 development has seen a separation of coding and system, as for example seen in Vietnam, which primarily only contributed to core development. The procedures being established now therefore aim to centralise core development and to try to outsource tasks to Vietnam, while strengthening DHIS 2 implementers globally, including processes of communication between implementers and 'coders' through DHIS 2 'gate-keepers'. For a more thorough discussion of the DHIS 2 project and challenges related to distributed Participatory Design, see Titlestad et al. (2009).

Current trends and looking forward: Participatory Design in the cloud and architecture

Various technological shifts are opening up challenging new arenas for Participatory Design in HISP. First, the rapid improvement of the mobile networks is enabling online web-based services and cloud computing in developing countries, raising the question of how Participatory Design will play out with respect to empowerment of disadvantaged communities, and enabling local control and ownership when the system is located 'far away in the cloud'. HISP is currently (in 2011) exploring these issues in Kenya and has found that, first, online easy access to own data combined with access to health data for other areas for comparison has the potential to empower local communities; and second, Participatory Design approaches are needed in order to release such an empowering potential, even in the age of cloud computing. Third, new web-based open source technologies have provided the impetus for HISP and other global actors to cooperate on developing an architecture of interoperable systems. The HMN and their framework of a national HIS architecture, have helped to identify challenges and approaches to integration, standards and interoperability. This trend further raises the challenge of changing Participatory Design approaches based on single systems to support multiple interoperable and integrated systems, or architecture. We now discuss the twin challenges of cloud computing and architecture on Participatory Design approaches.

Participatory Design in the cloud

In Africa, the Internet has not been and is still not perceived by many as sufficiently robust or reliable to support web-based data solutions for routine data reporting. The norm to date has been to capture routine data in stand-alone databases, and to report data electronically by e-mail attachments or physically to the level above. This places significant challenges on human capacity and synchronisation of multiple stand-alone databases, making the HIS fragile and complicated. Building a web-based data warehouse on a central server is simpler technically, and ironically would be more appropriate for Africa even in terms of human resources.

During 2011, DHIS 2 has been rolled out countrywide in Kenya based on a central server solution. Initially, the plan was to implement stand-alone instances in districts around the country – the traditional African way – but a field visit to Machako in October 2010, a district and hospital not far from Nairobi, changed the course of action. During a test of the DHIS 2 online server in the information office, everything went well until a power cut left the line dead. As it was a hospital, the generator started and power came back, but the Internet was gone as it would have to be restarted somewhere down the line. The team were just about to conclude that the Internet was still not available when a Japanese volunteer suggested using his 'dongle', the modem for the Internet over the mobile network. This worked fine, as mobile networks

are not affected by power cuts. Immediately after this revelation, Internet modems were tested around the country. The solution worked, and the decision was taken to go for a central server solution, probably the first time for such a countrywide public sector project in Africa. However, the server in the Ministry of Health could not be used, as the connectivity was poor in the building and the server set-up not reliable. As a temporary solution, therefore, a commercial server was rented – through a London-based company, meaning cloud computing for real, although politically it was not yet acceptable to locate national health data outside the country. The Coast Province was selected as a pilot, and the system rolled out in January 2011 to all districts and hospitals, as a start. All users were provided a modem and a budget for airtime. The network was working, but the bandwidth was limited in many places, and the cost of the airtime was restrictive. In order to address a multitude of problems, the DHIS 2 lab was literally moved to Kenya; the lead developer and others took part in building a local team and engaged in rapid prototyping cycles on site with the users, first in the Coast Province to support the pilot, and later, from April 2011, to support the rollout to all eight provinces. In fact, 'rapid prototyping' changed its meaning; working on an online server meant that the system changed for all users according to their input, if possible on one day, or overnight.

A system based on Excel spreadsheets that were submitted to an FTP server was already in place. The users were thus well accustomed to computers, the data to report and the Internet. The system was initially set up based on the existing paper forms used for reporting from facilities to the district; data entry screens were made to mimic the paper forms reasonably well. A very active period of agile Participatory Design followed the implementation; standard reports were designed and GIS was set up; users' input ranged from the 'small' request for the same functionality as they had in Excel with regard to data entry, such as being able to use the arrows to navigate the data entry screen, to larger issues such as the need for online messaging enabling users to communicate with the developers and with each other. The messaging system developed following these requests have proven crucial in the countrywide deployment of DHIS 2. It was also necessary to optimise DHIS 2 for the low bandwidth in remote areas. The more serious user input, however, was the need to be able to capture data and work on it offline.

The new HTML5 standard has the potential to improve the robustness of Internet and cloud-based technologies in Africa as it allows for offline data entry, with browsers implementing this standard now including more memory or in fact a small database. The first version of such a 'semi-online' feature was implemented in DHIS in late August 2011. The user can now capture data offline by using the memory in the browser and 'flush' the data (i.e. transfer to the server) when online. This is a very useful feature in Africa since the Internet is not available everywhere and all the time. The following message was posted on the DHIS 2 message system by a user after the new feature of offline data capture had been included:

> 2011–09–13
>
> Hi, this is wow! I have realised that I can now work with a lot of easy without any interruptions from network fluctuations since some of us are in the interiors where we have lots of challenges with the network. this is so good, a big Thank you.

Offline data use in a cloud-based infrastructure is the other important feature needed to optimise the system in areas with poor Internet access, which has been addressed in the following way: a small 'super lightweight DHIS 2' application installed locally is used to download data from the user's own area and other areas specified by the user, including the indicators and aggregates generated by the system, which is then used to generate Excel pivot tables used for data analysis.

Outputs are generated when online, downloaded in Participatory Design pdf format and archived in the offline application. As the Excel pivot tables are not easy to update or 'refresh' online regardless of bandwidth, the offline local 'datamart' represents an improvement to 'fully online' web browsing (see Figure 10.2).

The innovative approach to addressing the rather fragile Internet situation in Kenya illustrates how innovations are generated through participatory processes, implementation, use and practical problem-solving. Participatory Design and innovation may thus be seen as being an embedded part of the scaling process. Note that this is particularly enabled through a central server approach, as changes are distributed instantly and widely to all users in Kenya and all users of DHIS 2 globally. The use of open source applications within a framework of collaborative networks enables innovations in Kenya, such as the semi-online approach, to be fed back to the global community.

The project in Kenya was funded by DANIDA from 2010 and by USAID from the end of 2011, and has so far been through three phases totalling 12 months: three months' exploration and pilots in selected districts; three months' piloting in the Coast Province and gradual inclusion of other advanced user groups eager to participate; and six months' countrywide training, province by province. This rapid deployment has been made possible by the cloud-based infrastructure. Furthermore, the 'one server' deployment has made it much easier to manage the continuous participatory development of the system 'while in full production', as new features are added every day. For example, during the last part of 2011, all HIV/AIDS reporting from a USAID-funded project will be added to the system (more than 1,000 reporting units) and a

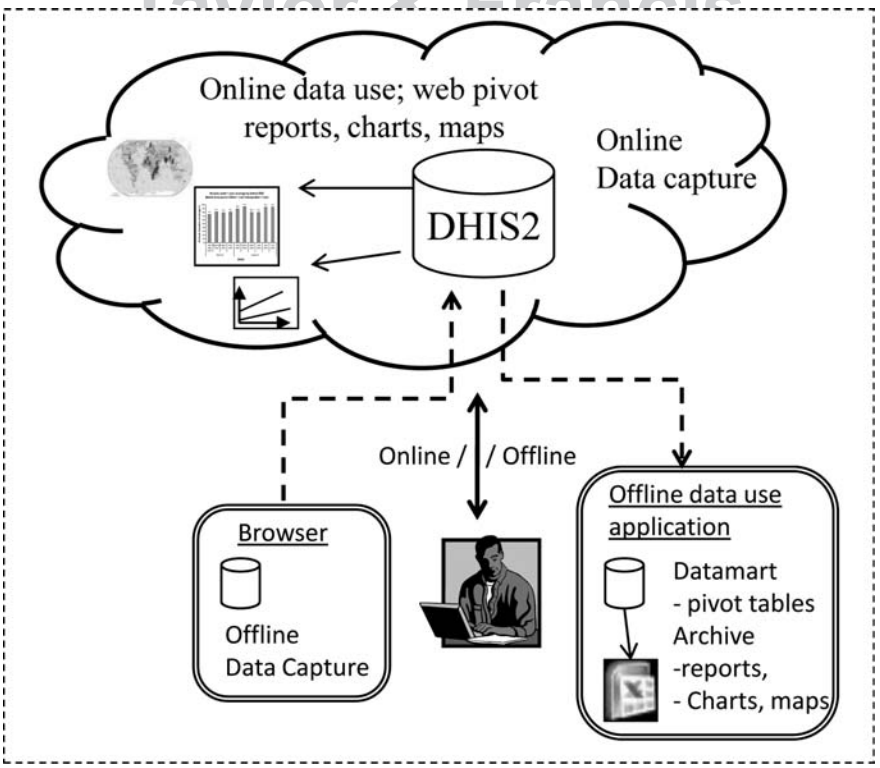

Figure 10.2 Semi-online DHIS 2 design and implementation in Kenya

new web-based module for mobile telephones is being introduced. Also the Participatory Design process in South Africa was characterised by ongoing participatory prototyping of new features on the system while in production, but it is now much easier for users and developers at multiple locations to interact when the system is implemented on one server to which all participants can connect.

Participatory Design in architectures

Discussions on how multiple systems should speak to each other and the standards of data exchange are important topics with which global (e.g. HMN and WHO) and national actors are currently engaged. The HMN and WHO have 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 interconnected systems, the nature and methods of Participatory Design also need to be redefined. This is illustrated through an ongoing HISP initiative in the state of Himachal Pradesh in northern India to develop an integrated health information architecture (IHIA) comprising the following five distinct HISs:

1 District and state data warehouse based on DHIS 2: DHIS 2 as a data warehouse is already in place for routine data from sub-district-level facilities. The initiative in process is to include more types of data representing different health programmes.
2 Mobile telephone reporting from sub-centre level: currently the sub-centres report their data monthly from multiple paper forms into the DHIS 2. Given the harsh winters, which isolate many parts of the state, the project will use the mobile telephone to report data directly to the data warehouse.
3 Name-based tracking of pregnancies and immunisation using the DHIS 2 Tracker: to enable name-based tracking of pregnant women over the life cycle of the services of antenatal, perinatal and postnatal care, and also all newborns over their period of immunisations, HISP has developed the DHIS 2 Tracker as a module in the DHIS 2. In addition to allowing for a name-based monitoring of cases, this data will be aggregated and exported using the SDMX.HD standard to the DHIS 2 to enable facility reports on various parameters such as numbers of ANC visits and numbers of immunisation. Over time, the name-based data would also be transmitted through a mobile phone application, thus enabling integration between the mobile, DHIS 2 Tracker and DHIS 2 facility reporting.
4 A comprehensive hospital information system, integrating an electronic medical record system and data warehouse for hospital management. This project is twofold: (a) to develop an electronic medical record system for district hospitals which is easy to adapt for smaller hospitals; and (b) to integrate the aggregate data from the medical record system in DHIS 2 with other data needed for hospital management, such as human resources, finances and infrastructure. This integration will allow the state to monitor key indicators such as:
   - bed occupancy: number of patient days/nights divided by number of beds, typically provided by month; bed nights during a month divided by number of beds times 30;
   - average length of stay: number of patient nights divided by number of discharges, typically by month;
   - death rate: number of deaths divided by number of patients, by age, service and ward;
   - infection rate: hospital infections divided by number of patients, by ward, age and service.

In this example, the data warehouse represents an integrated framework – an 'umbrella' – within which various systems are gradually being plugged in and subsequently scaled up. The

existing HIS and routine paper-based reporting forms the backbone and point of departure. Rather than having an 'individual system'-based system approach, Participatory Design methods could be understood in terms of understanding the levels of cross-cutting information needs, and how information feeds in from the different software applications. For example, field-level nurses' information needs could be categorised into registering, tracking, reporting and analysis of pregnancy cases, which could be met through different systems and devices such as the DHIS 2 tracking mobile for individual cases and the aggregate module for reporting and data analysis, and by using mobiles in the field and desktops in the health centres.

Similarly, in the hospital setting, while doctors would need clinical patient-based information, administrators would require hospital efficiency indicators based on aggregated information. The architecture approach thus helps to provide information of a greater granularity, which also places the onus on the implementing staff to be capable of deeply understanding the nature of decision-making and information requirements, and the supporting systems that provide this. The technological domain necessarily also becomes more complex, given the multiplicity of existing systems that interconnect. Both system architects and implementers need to mediate between the users and software developers. Implementers or facilitators play a crucial role in spanning the boundaries of the different domains in shaping Participatory Design processes.

In summary, a key challenge for Participatory Design-based efforts arises from the paradox of how to address the challenge of the increasing distance of the user from the integrated software solution, which at the same time requires a more comprehensive understanding of the health system, and its communication to the developers.

Participatory Design lessons from HISP and developing countries

Comparing the HISP case with traditional Participatory Design and the early Scandinavian projects, there are some important differences.

Who are the users? And what about empowerment and politics?

While in the early Scandinavian projects Participatory Design was regarded as a tool for workers to strengthen their position in relation to management, Participatory Design in HISP is targeting users at all levels of the health systems, workers and management alike. Furthermore, HISP would always try to use Participatory Design as a 'best practice' strategy to achieve consensus and good design to the benefit of the common good (Kyng 2010). When engaging in Participatory Design in contexts characterised by diversity of users at multiple levels, as also discussed in Chapters 8 and 9, consensus and good design for all are obvious objectives, though not always possible to achieve. In the case of HISP, Participatory Design to develop better health for marginalised communities in developing countries is a highly political process. However, the nature of politics in which HISP is involved is significantly different from that in the earlier Participatory Design tradition. First, the context and relationship to technology is very different. While the democratic ideals of the Participatory Design tradition were developed in a context where workers were threatened by modern technology and feared for their jobs, communities and health services in developing countries are in an opposite situation: they are threatened by being ignored by new technologies and thereby being left out of development processes. As Castells (1996) has argued, such exclusion from the 'network society' of marginalised communities will only lead to their continued and more systematic marginalisation.

Second, HIS initiatives need to necessarily support the strengthening of the delivery and quality of public health services in developing countries. Participatory Design approaches thus

need to reach out to identifying and serving the marginalised communities with respect to their health needs – 'setting the last first' (Chambers 1997) – and more strongly including the community in Participatory Design efforts. These objectives are by nature political, and not necessarily in line with the interests of health workers, managers or the political class. An improved HIS will as a principle represent transparency by providing information on how the health services are performing, thereby disclosing poor performance, mismanagement and corruption. Some officials from the health system may stand exposed. Strengthening such a focus implies that the community must necessarily be regarded as users of the information and become active participants in the Participatory Design strategy (Braa 1996; and see Chapter 8 of this volume for a general presentation of community-based Participatory Design). Only by creating a sense of community ownership to the HIS will it be possible to ensure democratic control and community participation in the running of the health services, which is the stated goal in the WHO Primary Health Approach and the policies of most countries.

The HISP experience helps to provide multiple perspectives on empowerment, which Participatory Design supports. There is first the process of empowering the users in the health services. Participatory Design has helped, as in South Africa, to foster decentralisation and empowerment of local users in terms of control, access and use of their own information. Users who previously had limited and delayed access to their own data could, with the new system, access their data on their desktops shortly after having submitted their reports. Further, this data would be organised in Excel pivot tables that enabled drill down using a variety of views and calculated indicators. More than a decade since the principles behind such empowerment were established and practised in South Africa, HISP is trying to offer the same support in the new technological paradigms offered by the web and cloud infrastructure. Technical solutions have been provided and are being constantly improved through the Participatory Design process, first, as in Kenya, to enable the data going from the community 'up to the cloud', for example by enabling offline data entry through the implementation of HTML5, and second, enabling the needed data to come 'down to the local laptop' so that local control is strengthened – faster and more 'real time' than before. In addition to the user at community level, management at county, province and national levels is also strengthened, and will for the first time have online access to all data in respective administrative areas, which can be used to direct action to areas that most need it. Third, this health information is the primary source for empowering communities, as it is the key information source on the performance of the health services at community level to support decentralised governance. This was the explicit agenda in South Africa, and today we have some (although limited) examples such as those from the Sierra Leone, where the chiefdoms are comparing their health data, and from Kerala, India, where the health information reports were also sent to the Gram Panchayat (the village-level political entity) for monitoring the health of their community, for instance as related to births, deaths and maternal deaths.

Cyclic and evolutionary Participatory Design in HISP

Participatory Design in HISP is targeting both the DHIS software application and the wider HIS, representing four different but interconnected cyclic development processes.

1 Developing the software – Participatory Design and development of the DHIS software application have involved rapid and exploratory cyclic prototyping in cooperation with users, representing a practical way both to get the requirements right and to develop the software accordingly. 'Right' in the early changing environment of South Africa, as well as later in other countries, meant to develop 'generic solutions' that could be adapted to the

ever-changing context of health sector reform, leading to a flexible meta-data structure. At present, 'right' represents integrated information from different programmes and data sources.

2 Developing the information system – the participatory and cyclic development of essential data and indicator sets is used in the DHIS application as a prototyping tool. This helped to get the generic data models right – or building the LEGO bricks – while also using the DHIS as a Participatory Design tool for prototyping to get the wider information system right, such as the datasets and the hierarchy of standards – the LEGO bricks were used to build the system.
3 Developing the information for action cycle – this represents the cyclical approach to turning the data collected into indicators which further need to be converted into action to make improvements in the health services. Such an approach will follow the planning cycle of the various health programmes and local procedures. For example, in Kenya, every province will have a quarterly assessment and planning workshops where key performance indicators are used. Using information for action will by definition help to break the earlier existing cycle of data not being used because it was of poor quality, and because it was not used it remained of poor quality.
4 Developing the action research cycle – the action research cycle enables the development of the other cycles: building the software, the information system and also that of information for action. Through collaborative action between the health system and HISP, this cycle involves identifying required interventions and their implementation and evaluation, based on the next round of iterations to be made in the cycle and thereby generating a constantly changing environment.

In this way, these four interconnected cycles provide the substance and content of Participatory Design processes within HISP. Each of these cycles involve multiple and specific techniques in use, such as agile prototyping (for development of software), workshops and stakeholder meetings (for developing the information system), carrying out database development, data analysis and capacity-building efforts with real data (for building the information for action cycle), and research and education for the action research cycle. These different Participatory Design interventions take place at multiple levels, from the national offices to province/states and districts, and also the health facilities and community levels. Further, these interventions take place over time, representing cycles which encompass the above cycles in varying rhythms and emphasis at different points of time.

In understanding the nature of these cycles more broadly, Chambers's (1997) distinction between the 'things' and 'people' paradigms related to participation in a development context is relevant. While the things paradigm emphasises neo-Newtonian principles of a technology and top-down focus, the people paradigm represents principles of adaptive pluralism which focus on participation and a more decentralised approach. On reflection, we could say that while the South African work was more people-based, the later efforts around DHIS 2 tend to reflect more of a technology paradigm. However, as Chambers (2011) himself reflects, this distinction is rather binary and tends to reflect the primacy of the people paradigm over things. He sees this distinction as inadequate, especially as there are increasing crossovers between the two domains. The same can also be argued for the HISP efforts: for example, with DHIS 2 increasingly taking on features of messaging and social networking, it becomes more grounded in the paradigm of people, while on the other hand, as facility-level users access the cloud through mobile phones, people are becoming more grounded in technology. The challenge for HISP in the future would be to maintain a coherent balance between these two domains while being firmly grounded in the problems on hand. This is discussed in the section that follows relating to threats and opportunities.

Threats and opportunities, and concluding remarks

The case of Kenya illustrates the potentially improved opportunities for Participatory Design in Africa using the cloud-based infrastructure. Users across the country can engage in instant participation, use new features as soon as they are implemented and feed back, request new features and 'chat' using the online messaging system in DHIS 2. Compared with the case of South Africa, where new builds would have to be distributed physically on CDs and installed in each computer, the cloud infrastructure represents a tremendous improvement in the conditions for Participatory Design.

With the cloud-based infrastructure, however, comes also the threat of outsourcing software-based services from Africa to industrialised countries by providing end-to-end services. A typical example is a project by Pfizer and Vodafone in the Gambia, where Pfizer wants to monitor stock and distribution of malaria drugs in the dispensaries and Vodafone is providing the entire infrastructure – SIM cards if needed (users have their own telephones), mobile network, air-time, data management in their servers in the cloud and provision of the data to the users. DHIS 2 is running as the national HIS in the country and is including similar data, leading to duplication of both data and efforts. We have argued the need for an integrated architecture approach and suggested feeding the data reported by the Vodafone mobiles into the DHIS, i.e. the national HIS. We have also argued the need for pooling the limited resources available for HIS in the Gambia. These efforts towards integration have been in vain, since Vodafone has argued that such integration efforts could only be included 'if there is a place for them in the value chain'.

It is our general view that business models that are locating value chains derived from Africa outside Africa are of no use for Africa. But more specifically, we argue that the outsourcing of what may be labelled the 'information technology learning and innovation chain' from Africa to the West, as illustrated by the example of Vodafone and Pfizer, may even be more harmful. A key challenge, then, facing Participatory Design is how to develop country and regional capacity to be able to counter this trend, and at the same time leverage opportunities for their local good.

Open source – empowering the South

Participatory Design as a pragmatic approach in the hands of Western companies based on cloud computing in Africa is not what we would like to see happening. This would be to drain rather than to build human resources and institutional capacity. A counter strategy would be to revitalise elements of the political agenda which aims at empowering developing countries and institutions to master new technologies and take control over their information resources.

It is our strong belief that open source software is an important element in this strategy. The philosophical underpinnings of the DHIS project are based on the fact that for any developing country to develop its own HIS system from scratch, with levels of functionality equivalent to DHIS 2, would be a huge undertaking far beyond such countries' own resources. Therefore, since the development of software to support the HIS is so complex and such a huge task and since the requirements in many countries are quite similar, it makes a lot more sense to collaborate as a big virtual team in a South–South–North network than to work in isolation.

The entire web-based stack of technologies making up the DHIS 2 technology environment, from Java frameworks to GIS, are free and open source – and they are at the cutting edge of technological development. While companies such as IBM are using FOSS for competitive advantage, the DHIS 2 project has proven that these technologies are as useful for Participatory Design projects, in particular for Participatory Design projects operating in collaborative networks. Looking back at the early Scandinavian Participatory Design project, we may conclude that HISP has been lucky with timing its technological development. For example, HISP was

inspired by the early Scandinavian UTOPIA project, with which it shares many approaches of participatory development of useful tools and empowerment through capacity building. The important difference is, however, that while UTOPIA was made redundant by the introduction of new commercial desktop publishing technologies, HISP is currently being 'lifted up' by current technology development.

Concluding remarks

The HISP Participatory Design experience – both historical and looking forward – is a rich and complex endeavour. It involves a diversity and multiplicity of contexts, technologies, levels, techniques and interventions. Across these multiple dimensions, it is likely that while success is obtained in some facets, less than optimal results are seen in others. The time dimension is fundamental as everything is constantly changing, redefining the relationships between technology, politics and user and health systems needs, which we have argued are the driving forces behind the design, implementation and success – or otherwise – of Participatory Design efforts.

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