

# Participatory Health Information Systems Development in Cuba – the Challenge of Addressing Multiple Levels in a Centralized Setting

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## ABSTRACT

This paper will address issues of user participation in a large centralistic organization. It is based on one year experience of developing a computerized health information system within the Cuban health services. Relevant literature suggests that participative methods may be less feasible in centralistic environments. This paper confirms this by describing how participation in Cuba is restricted by political and organizational constraints. There is however documented that participatory approaches may be very rewarding where such constraints are overcome. Experiences from a broad range of health units and organizational levels in the Cuban project show a trend of weakening centralistic control with regard to hierarchical level and geographic distance, and thus more autonomous organizational units and participating individuals at lower level farther from Havana. The research reported is carried out within a framework of a larger network of similar health information projects being carried out in Africa and Asia, and the case of Cuba is being compared with experience from these countries.

## 1. INTRODUCTION

Locally based and focused health information systems (HIS) alongside local participation and commitment in their development and running are seen as key issues in the delivery and management of health services in developing countries [15][2][21]. However, current HISs tend to be of poor quality due to poor systems and procedures for information handling, lack of local use of information, poor feedback and the fragmentation of the reporting into numerous sub-systems controlled by specific health programs.

Non-working of HIS in developing countries arises from the organizational and social issues being inadequately addressed in implementation.

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For example, Littlejohn et al. [16] related the failure of HIS in Limpopo province in South Africa to the lack of user involvement, and Lippeveld et al. [15] describe HIS reform as complex organizational interventions, needing to be accompanied with change in existing information culture.

In this article we present the experience from one year of action research and participatory design within the health information systems in Cuba. While being a poor country in terms of economic development, the health and educational sectors in Cuba are far more developed than most developing countries.

Compared to other developing countries the health information and health data reporting systems in Cuba, which are paper based up to the provincial level, are well working according to their expected functionality, which is to provide the centre with quality statistical data. However, since the intention and focus of the systems are to collect, collate and report large amounts of data upwards in 78 sub-systems, analysis and usage of information at local level tend to be neglected. In 2002 the authors became involved with the Statistical department of the Ministry of Health of Cuba and started a pilot project to develop a locally based health information systems in 13 different locations including health centers, hospitals, municipalities, provinces and the central level in Havana. Unfortunately, the global political climate during the building up to the war in Iraq made the Cuban government to put most projects including foreign partners, including this one, on hold (2003). Nevertheless, one year of intensive project-work at local level in Cuba form the basis for this article.

The initiation of the project was based on Cuban interest in the Health Information Systems Program (HISP), which started in South Africa after the fall of apartheid in 1994 and where one of the authors have been engaged since then. Starting in South Africa HISP has been engaged in developing decentralized HISs following participatory approaches in a number of countries such as e.g. Mozambique, India, Tanzania and Malawi, all networked with the initiative in South Africa ([3], see [www.HISP.org](http://www.HISP.org), [www.HISPindia.org](http://www.HISPindia.org)). It has proven to be more difficult to apply participatory approaches and a local focus in the centralized and politically controlled organizational setting in Cuba, with poor tradition for local improvisation, than in the other countries in the HISP-network.

The international experience from the HISP network has revealed a number of particular problems and challenges in following participatory approaches in the health sector in developing countries [3]: While the health sector is characterized by fragmentation between different health programs and services and the existence of multiple levels with different needs and agendas, there is at the same time a requirement to follow national standards and a certain level of uniformity within the National health system, controlled by the National Department of health. The consequence is that multiple rather diverse participants need to be involved when applying a participatory approach. Another important issue is that decentralized approaches - as opposed to centralized ones, and given the authorities' requirement to be all-inclusive - (obviously, but often overlooked) need to involve large numbers of basic organizational units (health facilities, health districts), raising the issue of scale.

The participatory design tradition has to some extent so far emphasized intervention in singular units, one or a few work places, and on a smaller scale than what has been identified as needed in the health sector in developing countries. A key lesson from Scandinavian work life action research amounts to a shift of focus "from single organizations and work places...to networks" (of organizations and workplaces) ([7] p. 209). In order to become sustainable, interventions in singular units need to spread to other units and a momentum of learning and implementation needs to be created. As will be shown in the case from Cuba, the key challenge (and conflict) was to extend the scope of the interventions to include whole administrative areas and a larger geographical "scope", not only a few health centers or municipalities, so as to become relevant for the various levels of the health services. Managers of a municipality, a province or a country see no needs for an information system which includes only sub sets of their area of responsibility, and they will consequently not fight for or become "champions" of such systems. When the international political tension increased towards the end of 2002, the issue of "coverage" became very political of precisely that reason, but interpreted in an inverse way. Since full coverage of data from e.g. a province would be very useful for managers and politicians "horizontally" across various vertical command lines at provincial level, such a transparency would make it difficult to keep the system and the project as an "insignificant" pilot. The project with its foreign participants who were getting full insight into the primary symbol of Cuban development; the health system, would have had to be defended in a difficult political situation. To stop the project in 2003 therefore turned out to be the preferred solution.

The remainder of the paper includes a section (2) which seeks to give background on our approaches to participatory design and HIS in developing countries, then section 3 describes the case of Cuba, section 4 presents the discussion, and finally in section 5, the Cuban experience is summarized by comparing it with lessons from other countries.

## **2. PARTICIPATORY DESIGN, HEALTH INFORMATION SYSTEMS AND HISP**

The action research and participatory approaches followed in the research in Cuba and in HISP more generally draws on the Scandinavian work life tradition where the first projects aimed at empowering workers and their participating unions. The problem

these Scandinavian projects faced, which is evident also in the later heritage of the participative design tradition, was to move beyond prototypes and models. The key issue that remained unresolved was exactly how to make action sustainable, i.e. how to turn a prototype into a routinely used system. According to [7] sustainability of action research will rely upon the ability to spread the action to new places in a network of action and learning. This may be of particular importance in the health sector in developing countries where it will be crucial to extend the scope beyond one or a few pilot sites so as to cover entire administrative areas and ultimately the entire country. Only in that way will the system become relevant to managers at different levels within that area, which again is a prerequisite for obtaining the necessary support.

One might argue that the "de-politicization" of participatory design is a consequence of the limitation of the scope, as power relations in organizational hierarchies are not being challenged. During the last 7-8 years important elements of the Scandinavian collective systems approach has resurfaced as a strong political "design movement" in South Africa through the Health Information Systems Program (HISP) [1] [3]. Born out of the anti-apartheid movement and combined with Scandinavian systems design influence, a participatory systems design project established in three pilot districts gradually spread out to cover the entire country and is today the official health information system in South Africa. Its relative success in South Africa led to the export of the software and the ideas on health management to countries like Mozambique, India, Malawi, Mongolia and now Cuba. The participation of Norwegian researchers in this international programme has been strong, and the HISP-participation in the bilateral collaboration with the Cuban Ministry of Public Health has been based at the University of Oslo.

The health information systems (HIS) targeted by the action in Cuba and by HISP in other countries are the routine health information systems which all countries have established to collect, collate and report data on most activities and patient-health services encounters within the health sector. These systems are usually highly fragmented into 10-50 different systems - mostly linked to specific vertical health programs such as tuberculosis, vaccination, HIV/ AIDS and different types of services such as hospitals and preventative care. These systems tend to be centralized with little local use of information for action, and the fragmentation between different health programs and services leads to overlaps, gaps and lack of standard definitions for data elements and indicators. This is compounded by the wide-spread use of technology or software that is not suitable for the purpose - a typical example being the use of Epi Info or Spreadsheets not only for survey data (appropriate) but also for routine data (not appropriate) - resulting in further fragmentation of available data and information. The tendency is for managers and health workers to provide data upwards (often referred to as "stargazing"), with mainly negative feedback (e.g. when data flow stops) to subordinate levels. As a result of all these factors, health information systems are in general not meeting the basic information needs of health services management at various levels [15]. Furthermore, development of more sophisticated health information systems have proven to be difficult both in developed and developing countries, and a large number of failures are reported [12][15]. The complexity of health

care delivery; fragmented organizational setting; poor local involvement and buy-in; the fact that IT-professionals rather than health professionals drive the development, leading to a technical rather than a health-need based focus; all these factors have usually combined and resulted in spectacular and very costly failures.

The need for applying participatory approaches and thus to create “ownership” when developing health information systems is generally acknowledged in the public health community as exemplified by the very influential RHINO (Routine Health Information Network) 2002 workshop:

“The restructuring of routine health information systems should involve all key stakeholders in the design process. Experience suggests that systems that are designed by a team of “information experts” without adequate involvement of key stakeholders usually fail to reflect the needs and practical reality of service providers and managers, and does not encourage the ownership of systems.” [18 p.3]

The need to address multiple levels is equally acknowledged:

“The healthcare information system structure should permit generation of the necessary information for rational decision making at each level of the health system, each of these levels has specific functions that require specific decisions to be made.” [15 p.3]

The need in the health sector to involve multiple levels and to scale up to cover large areas will involve multiple communities of practice and many organizational units or workplaces. This poses a challenge to the “traditional” participatory design techniques which are emphasizing intense interaction with a restricted number of users. This problem of scale cannot in this case be reduced to fictional users, ‘personas’, as suggested by Grudin and Pruitt [10] when addressing a parallel problem of scale in addressing millions of people in a consumer market, since in health care, political commitment and buy-in are required. In South Africa this problem was addressed by an informal ‘activist’ oriented prototyping strategy. Prototyping is often quite formal and structured, with well-established user groups, channels of communication and conflict resolution (e.g. [5]). Within the complex political and institutional framework in which HISP has been operating, formal user groups would easily have become battlegrounds due to the current large-scale transformation of South Africa’s administrative structure.

“The methodology used is thus more informal and to a significant degree based on improvisation, whereby any interested or innovative user, regardless of her place in the hierarchy, had full access to the development team (a meritocratic approach). ... Access is not regulated in any way, but the development team normally has to guide users to a significant degree in understanding their own requests and how they can be implemented in practice. Such guided user participation is obviously time-consuming and only possible with a limited number of users.” [3]

The free open source database application software being developed in South Africa (DHIS –District Health Information Software) is implemented in MS Office (Access) and is the basis for the prototyping in Cuba as well as in the other countries in the HISP network. The key advantage of the software as a

prototyping tool is that it is flexible and can be quickly changed and adapted to typical health information systems needs based on aggregated data and the text strings of the user interface may be translated to any language and MS/Unicode supported alphabet.

### 3. THE CASE OF CUBA

#### 3.1 Cuba and its Health System

Cuba is one of the few remaining socialist states in the world, and the only one on the western hemisphere. After the collapse of the Soviet Union, its far biggest trading partner and subsidizer, the country entered the “special period” of rapid decline in income and living standards. The infrastructure suffers from a lack of maintenance, and commodities such as medications, oil, computers, and paper is hard, and expensive, to get. But contrary to many other developing countries, Cuba enjoys a relative richness. Education up to university level is free, as is health care. The levels of crime and violence remain at a very low level, and each citizen is guaranteed a certain amount of food through the rationing system.

Cuba is world famous for its magnificent achievements in the health sector, especially considering its limited resources. Today’s health system is built from scratch after Castro took over, and is proudly presented as a glorifying example of how successful the revolution is. Cuba is the country in all the Americas with the highest percentage of health expenditure covered by taxes and social security contribution, close to 90 % [20]. The health system is thus the primary symbol of Cuba’s political achievements and it is therefore not surprising that “foreign” involvement in the development of the health information systems (i.e. the authors) causes political concerns in a time of increased international tension.

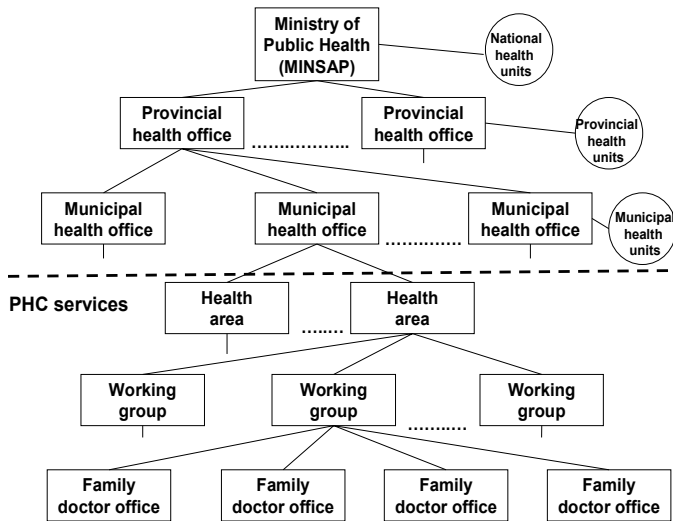
Figure 1 shows the hierarchy of the Cuban health system. The central level is the Ministerio de Salud Pública (MINSAP), the Ministry of Public Health, which is located in Havana. Cuba is divided into 14 provinces, and the average provincial population is about 600 000 people. The provinces have from 6 to 15 municipalities, each with an administrative health unit responsible for municipal health services. The municipalities are further divided into health areas, which each have a polyclinic that provides primary health care (PHC) services to the population in the area. The lowest level of the health system is the Consultorio Médico de Familia, a basic primary health care unit called family doctor office that serves a given population, often a neighborhood. Every family doctor office has a doctor and one or two nurses. They are serving a population of 500-1000 people, an extremely low number of people per doctor. The family doctor offices are grouped by a working group, which consists of minimum 20 family doctor offices, sometimes more than 30, and has a group of specialists doctors that are shared by the offices in that group. A health area can have about 1-8 working groups and each group in the health area reports to the local polyclinic.

The overall hierarchical structure described above is further divided vertically into 22 parallel structures, each with their independent line of command managed by a national director. Altogether, the Cuban health system is a complex and fragmented system.

Soviet models have influenced the forming the Cuban health system, with a strong focus on statistics as a means of controlling

mortality and morbidity, efficiency and progress. Cuba has a large health statistics department within the health system that is responsible for all health information. The project was conducted within this department and the national director was our main contact within the Cuban health system.

The amount of health data that is collected and the number of health statisticians employed in the Cuban health system make the Cuban health statistics department one of the largest of its kind in the world. Cuba has a well-defined information system for data collection and reporting. Basic computerized reporting systems are provided at the provincial and national levels, however below these levels there are few computerized health units. The statistics department is an independent hierarchical structure in parallel to the main health hierarchy with health statistics offices at every level from the national level in Havana to polyclinics (staffed by 3-7 people) and health units at the bottom of the hierarchy. The flow of information follows this structure within the statistical department. The overall task of the health statisticians at every level is to make sure that the required data is reported at the



**Figure 1. The health hierarchy with administrative levels and units. Typically, a polyclinic is responsible for one health area.**

required frequency to the statistical unit at the level above. From a health statistics office at the polyclinic, at the municipal health office, or at the provincial health office the dominant information flow is going vertically upwards to the next level and not horizontally to the neighboring offices and local health management.

## 3.2 The Cuban HISP Project

### 3.2.1 Project Overview

In October 2001 a Cuban delegation visited the University of Oslo and was introduced to the HISP initiative. The Cuban interest in the initiative resulted in a visit to Oslo by the Cuban national director of health statistics in March 2002 where he participated in a HISP workshop. His increasing interest in HISP

and its software (DHIS) resulted in a Cuban-Norwegian collaboration project with the following objectives:

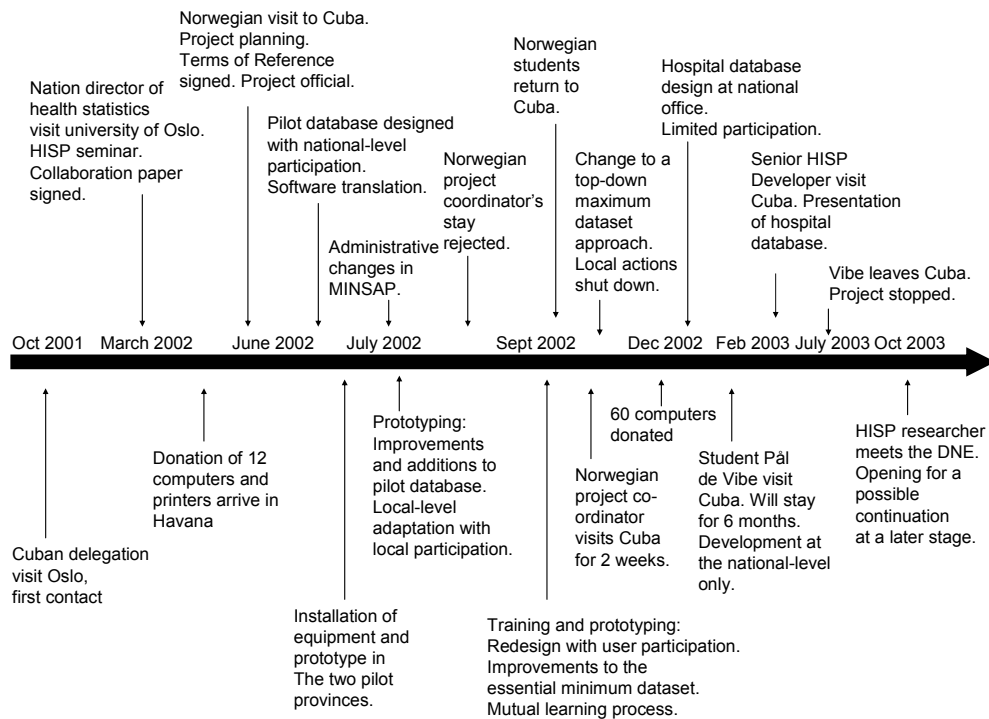
- 1) develop of a database system to strengthen the national health information system at all levels focusing on local analysis and local use of information, and
- 2) provide a sufficient learning process at all levels to facilitate a sustainable Cuban system.

The systems development work conducted in Cuba took place May 2002 - June 2003, and Figure 2 shows the main project activities in a chronological order. The project was established in Havana in May 2002 with much support and optimism at the national office (the DNE) of the health statistics department. The national director at the DNE had full support from the Minister of Public Health and hence the project had a strong political go.

Two pilot provinces, Matanzas and Sancti Spiritus were selected and six municipal offices, two polyclinics and one municipal hospital were chosen as pilot sites within these two provinces. These local sites represented only a partly coverage in the two provinces, and the DNE were very reluctant to go for full provincial coverage and did not want to involve all municipalities within any of the two provinces.

To meet the objective of developing an HIS to support local health management, an approach that focused on designing a locally adapted system in the local context was initiated. The prototyping tool DHIS facilitates development of computerized routine health information systems, and this tool formed the basis of the Cuban systems development project. The pilot database was designed in June 2002 in cooperation with the central level in Havana based on a national perspective of local work processes, and later, this pilot was continuously improved and redesigned during the development at the local levels. The fact that there was already a functional pilot system when the local adaptation process started facilitated the use of the prototype as a tool to communicate with the local workers. Another positive feature was the ability to quickly implement and test out new design ideas supported by the flexible software (DHIS). In this way an important requirement in cooperative prototyping was facilitated; to bring the current skills of the users in contact with the new technological possibilities [6]. In some of the places we experienced that this equality between the two collaborating parts resulted in local commitment and enthusiasm towards the new system, and important step towards local ownership and sustainability [9] [14] [18]. However, in other places the level of cooperation was restricted to passive participation and resembled traditional design where the systems developers are dominating the process of identifying user requirements [6].

In July 2002 there was a drastic political change in the MINSAP, and the Health Minister together with most of his vice-ministers and national directors were sacked and replaced. It was said that this radical change process and similar incidents from other ministries were reactions to the politically tense situation in Cuba due to U.S. threats on the Cuban government. New visions and strategies on how to improve the health system were developed in the new administration, and part of this new strategy was to



**Figure 2. Chronological overview of project actions.**

reduce foreign investments and collaborations. Our main contact, the national director of health statistics was among the few national directors who survived this change process and he managed to keep the project going throughout this turbulent time. However, after this change process we experienced a complete lack of political support. The project's scope and priorities were gradually decreased with restrictions on the extension on pilot sites and on who could be involved. Especially, the restrictions on the involvement of the Norwegian coordinator and Cuban personnel outside the health statistics department limited the project's progress.

In November 2002, after three months of local development actions, the DNE management stopped all activities in the two provinces and demanded a new approach with focus solely on the national level. Much efforts invested by the local levels were neglected by the central decision-makers, and many potentially good development processes were stopped. The DNE management explained that their need to change the development approach was based on a lack of control of local project activities. The DNE did not agree on the need for local participation and to spend so much time out in the two provinces, as this context sensitive approach was completely new to them. They argued that a top-down approach with development solely at the national office had always been a success in Cuba, and that the project should follow this method. There is no tradition for involving local levels in decision-making, and the DNE did not agree that local involvement in the development would lead to a better system. This citation from the DNE management illustrates their view of local-level participatory processes:

“The local health managers do not know what good information is and they do not know what data that is important to them”

This shift of approach must also be seen in light of the changes in the ministry and subsequent uncertainty and unpredictability in the politics. Later work in 2002 and in 2003 took only place at the national health statistics office in Havana, with no interdepartmental participation. From March 2003 the DNE faded out the project and by June 2003 the project was officially shut down. The work conducted out in the provinces in 2002 was never reinitiated and the national database developed at the DNE was never implemented out in the field. We have not got any clear explanations from the Cubans for shutting down the project, but have heard that it was not the right time, or bad timing as the DNE administration put it.

### 3.2.2 System Design

The design process has been quite turbulent with rapidly changing requirements and scarce resources. The Cuban health system consists of many hierarchical levels; each of them with its own needs and priorities. To cater for these different needs a multileveled participatory approach was followed applying participatory prototyping at all levels in the hierarchy. This resulted in four more or less compatible databases being developed meeting the needs of the different levels of the health system. Two databases were developed to cater local needs, one for the municipal health administration and one for the polyclinics. These two databases were in addition tailored and modified to each health unit or municipal health office. A third database was developed at the provincial level to obtain full provincial coverage at an early stage in the development project

when few municipalities were equipped with computers. As the political situation changed and the focus shifted to the central level, the last database was developed to replace an existing national reporting system for hospital patient flow that was running on old software with little flexibility. A lack of resources complicated the development. Petrol for cars, and thus efficient transport, proved hard, expensive and time-consuming to get. Paper was in constant shortage, as were computers and related equipment. The US embargo had also direct effect, in addition to the overall lack of products, in restricting the software that could be used. Microsoft licenses could not be brought from Norway, and even free updates and freeware on U.S. Internet sites like Sun Microsystems' website and download.com could not be downloaded to a Cuban IP-address.

Thanks to a flexible database tool and a flexible design approach these changes were manageable, and in the end a compatible set of locally adapted database structures aligned with the political decisions as well as the scarcity in resources, were developed. The participatory approach yielded information about the local processes, which could not have been obtained in any other way [19]. These locally tailored database solutions could not have been developed from a distance, say in a computer lab in Norway or even at the national level in Havana. A traditional design approach with an early requirements phase and clearly separated development phases would not have been flexible enough to take both the need for local learning and the rapidly changing requirements into account.

### 3.2.3 *Participation in the Sub-Cases*

A more detailed look at the 13 different sub-cases and the participation at each place reveal that there are quite different experiences amongst the pilot sites. Figure 3 below gives an overview of participation in the pilot sites presented in a hierarchical way and with distances (hours by car) to the national office, the DNE in Havana. We have classified the level of participation as poor, ok, or good. This was done in a subjective way, based on our opinion and experiences from working at each site. However, actively pursuing participation over several months, we feel the level of participation in this project is portrayed accurately in the figure.

There are three main user groups of interest regarding participatory development of a national HIS, namely health statisticians, IT staff, and health management. The statisticians are the daily users collecting and processing data and it was within the health statistics department the project was based. IT-skilled staff at the national level here means the Ministry of Health's own ICT department, and at lower levels often network administrators or even local students with knowledge of computers. This group was important regarding training, maintenance and sustainability of the new system. The last user group consists of the local management of each health unit and the health administrations at national, provincial and municipal level. These managers are the users of health information and the group that would benefit the most from an improved computerized HIS. To achieve participation with IT staff or local management in the Cuban health system interdepartmental communication and collaboration is necessary. This horizontal collaboration was hard to achieve when we found ourselves locked inside the statistics department in a vertically fragmented health structure. Our best participatory

experiences are from the pilot places where we managed to get participation from all three user groups, and especially where the local management was actively involved in the development process.

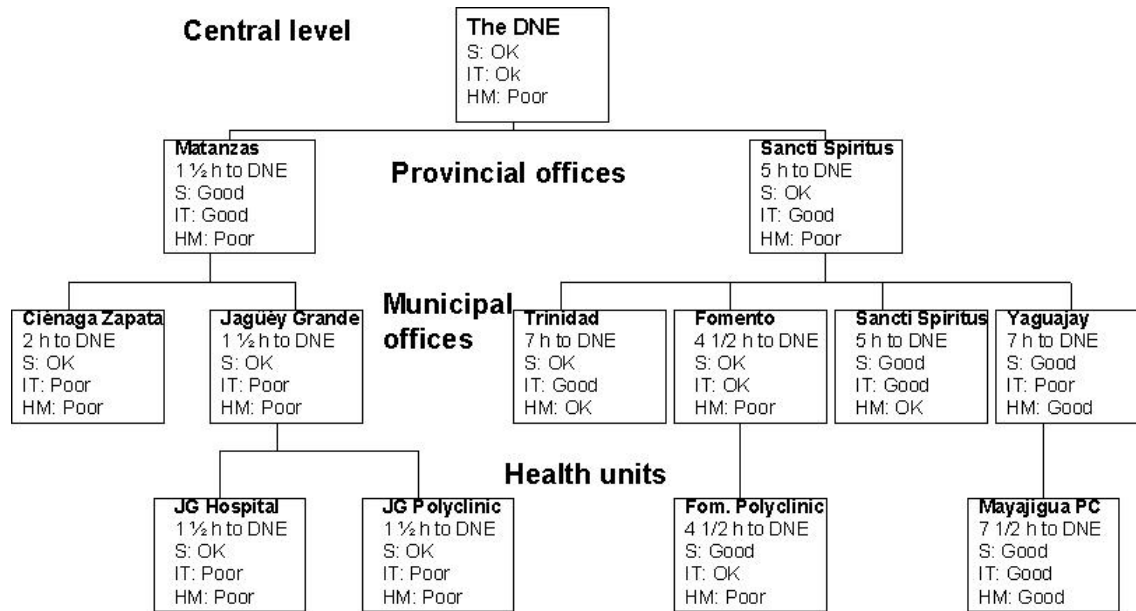
By categorizing these differences from the 13 pilot sites we can see that there was better participation at the lower levels than the higher levels, and also better participation in more rural isolated places than in places with easy access from the capital. Poor transportation and infrastructure create decentralized units where people have to take decisions themselves. The current oil crisis in Cuba has further strengthened the isolation of rural villages far away from Havana. Our general experience is that participative approaches in these remote and isolated nodes tend to be very fruitful [19]. The two pilot provinces are quite different in terms of access from the capital; while Matanzas can be reached in less than an hour, Sancti Spiritus is about 6 hours away, and given the constant struggle for combustion a DNE-visit to the provincial office in Matanzas is much more likely than a visit to Sancti Spiritus. During the project the national director of the DNE visited the municipal office of Jagüey Grande in Matanzas three times, while Yaguajay, a rural municipality in Sancti Spiritus, not even got a visit from their provincial office.

The Mayajigua polyclinic in the municipality of Yaguajay is a good example of a pilot site where we experienced a broad participatory process. In this rural polyclinic the local management took part in profound discussions on local use of information and they took part in planning further actions and improvements of the system together with a very IT-skilled statistician and other staff. Here the statistician seemed much more concerned about the local health situation and more closely linked with the local management than in other places involved. The chief statistician had much experience with computers, and a computer was already in place from a UNICEF-project. All standardized reports and forms had been computerized into Excel worksheets, and the polyclinic as a whole seemed more autonomous in many aspects. By own initiative this statistical office invited management to presentations, workshops and training. The very rural and remote location of this polyclinic, located an half hour drive from the already very remote Municipal centre Yaguajay, another pilot site where the management became very involved, appears to be a significant reason why the participatory approach at least for some time was successful here.

In the large city-municipality Sancti Spiritus the local manager also became very involved, but more by chance. He had 8 health areas, each with a polyclinic in his Municipality, and was very specific when identifying his information needs; the database application needed to provide him with flexible ways of comparing the performance and health status of the 8 health areas in his area by giving him easy access to indicators and data from these areas. The current system is based on aggregating data to total Municipal figures and is not useful for local analysis and management, or it is very cumbersome to get the needed information. Furthermore, he wanted computers (i.e. the database) installed in four large polyclinics which had a large number of family doctor offices of the similar reason; look into and compare performance of these offices.

Trinidad is another town where the management immediately saw the advantage of using the database application to get access to

disaggregated data for comparison across units in their administrative area.



**Figure 3. The hierarchical structure of the pilot sites, distance to Havana and to what extent health management (HM), statisticians (S) and IT-personnel or -skilled people were participating (IT). PC: polyclinic, Fom: Fomento, JG: Jagüey Grande**

These positive experiences align with the more active variants of participation, as the cooperative design approach. The local health managers who we in some way were able to involve expressed considerable interest in the project and the possibility to be able to access and analyze data from all the units in their managerial areas. The Cuban health system is very reporting and data intensive and managers have a very clear understanding of the advantages of computers, databases and spreadsheets in accessing and analyzing larger amounts of data as compared to the current paper based system where “access” is at best complicated. Furthermore, they seem to have clearly defined information needs. There is consequently considerable potential for involving managers in a committed and active participative process [8]. Unfortunately, political problems have made such involvement next to impossible and all initiatives as e.g. those reported above have been stopped by the central level.

The municipality of Jagüey Grande, which is on the highway just outside Havana, is the pilot site where the most time and computer resources have been invested. In this village we had three pilot sites; a local hospital, a polyclinic, and the municipal office. Despite extensive efforts, there was limited participation from local health management, and compared to the four pilot municipalities in the Sancti Spiritus province it was much harder to achieve interdepartmental cooperation here. The proximity of the polyclinic, hospital, and municipal office made it possible with the limited resources to have workshops for all three offices together, and one such was held over three days at the end of 2002. Management was invited to participate, or at least see the reports and graphics the statisticians had produced, but they did not show up to avoid interfering with a project that belonged to another department. The visits of the national director of the DNE were, to them, a message that the project belonged to statistics and clearly not a municipal project. As a result, in Jagüey Grande, the project was “locked inside” the health statistics department. In

the previously mentioned Mayajigua polyclinic the local management did not feel this close involvement by the national level and saw the project more as a chance to improve local health services than accomplishing demands of the central level. Local ownership and commitment are crucial to establish a participatory process and these two pilot sites where completely different on this important issue.

At central and provincial levels participation from managers was generally very poor. At these offices we worked solely within the offices of the health statistics department and had limited contact with other health departments. At the national level there is a group called CEDISAP that specializes in health software. Furthermore there are departments that are dedicated to primary health care and preventive services. Involving such personnel would have given the development a vital push forward, but this was impossible to achieve due to a strictly fragmented command structure.

The level of participation in the different places was also dependent on the human resources, and some of the variations seen in Figure 3 are due to differences in skills and understanding of the tasks. However, in most places good participation and cooperation resulted from local interest and commitment, as in the municipal offices in Trinidad, Sancti Spiritus, Yaguajay and Fomento where they allocated skilled IT personnel from other offices or the community to assist.

## 4. DISCUSSION

### 4.1 Contextual Constraints to Participation in the Cuban Health System

Based on our experiences we will discuss the contextual constraints to a participatory development approach in the Cuban health system under the following three headings:

1. Problems with following a multi-user participatory approach in a fragmented health structure
2. Participation problems due to lack of central political will to local participation
3. Local participation and expression of own and different opinions not facilitated

#### *4.1.1 Problems with Following a Multi-User Participatory Approach in a Fragmented Health Structure*

A national routine HIS involves many kinds of users with different needs, and to develop a well functioning national system we focused on involving all users in the design process. Statisticians, health managers, and ICT personnel were particularly important user groups.

The Cuban health system is a fragmented structure with several micro-powers in the hand of national directors. Each national director has its own vertical hierarchical structure and line of command and there seems to be little interdepartmental collaboration. Our working domain has been within the health statistics department, a department administered by the DNE director. We struggled to meet the desired broad selection of participants as the DNE administration has been very clear in its strategy to only involve personnel from its own line of command, the health statisticians. Instead of being able to freely select participators based on the needs of the development process, this selection was limited and controlled by power relations within the health system [6][11], which in many ways hampered the cooperative design process.

One would think that a health statistician is a perfect participator in developing a health information system, but in Cuba health statistics has a special role that made our lock-in in the statistics department even more critical. Cuba's centrally planned economy has many similarities with the planned economy model of the former Soviet Union, and as in the Soviet Union, the statistics offices play an important role in providing the statistical material needed to monitor whether the plans are fulfilled or not. In such a system, the information systems focus on monitoring and measuring fulfillment of centrally defined plans at the central levels, rather than on local use for improved quality of services. The present Cuban health information system is defined to support the quantitative needs of the planned economy, and its main purpose is to receive as much data as possible at the national level. As a result the health statistics department and its information systems are not targeted at providing information to the local health management. The statistics offices we visited saw their job more to serve their top level than the local management structures. As a consequence, the local statisticians, despite being well educated and skilled in their work, had little interest and knowledge about data analysis or information use. With some exceptions, the involvement of statisticians did not provide the broad cooperative design process needed to develop a sustainable national HIS targeted at local use of information. To achieve such a broad participation, local health workers and managers as well as local ICT personnel would have to be part of the development process as well.

#### *4.1.2 Participation Problems Due to Lack of Central Political Will to Local Participation*

As we have explained earlier, a focus on the local level and an involvement of local stakeholders were not prioritized by the national level. In addition, the DNE had no interest in involving other sections of the health system at any level, so there was little political support to let the local health management participate in the design process. In a centralized context with little local autonomy, central political support is of utmost importance in order to get anything done at the local level. Without clear orders from the level above there is not much hope to get a successful local participatory process. In the authoritarian health system control is extremely important, and to the DNE management this means controlling all actions in their own line of command. By empowering local workers down the hierarchy the power balance within health statistics would be altered and represent a power change the DNE management would resist [13] [17]. Even though the DNE management realizes that improved data processing and use of health information at the local levels would lead to a better system also for the national level, the need for central control limits to what extent they allow empowerment of the local levels. In the vertically fragmented health system with little interdepartmental collaboration the statistics department has almost a monopoly on health information. Increased horizontal information sharing among departments at local levels, which is what the new HIS was targeted at, would mean a weakened political position to the national office of health statistics given the political power inherent in information control. By making full datasets easily available, transparent, and shared through a common database and tools for data processing and analysis through the DHIS (including spreadsheets) at the provincial and municipal levels, managers from other health departments and politicians would have had full access to information and would no longer have had to rely on the DNE at central level, who would subsequently lose power over the information. This potential scenario was realized by DNE and the first restriction put on the project was not to allow the collection of full data sets (i.e. including all sub-units) at provincial level. The second restriction put on the project was to not be allowed to interact with other line management or provincial management at all. Eventually this political situation made the DNE to move towards a centralized top-down development approach focusing solely on the needs of the central levels. From November 2002 the activities in the local sites were stopped and the focus shifted to computerization of the reporting system at central level which meant to strengthen the present vertical reporting structures and central monitoring functions. These are political objectives that did not align with a local-level participatory approach.

The reason why the local activities were stopped was not central objections to developing good local information systems, rather it was fear that reports on uncontrolled and even foreign activities at local levels would be reported up to central level through other vertical health structures and through the political line that caused the concern. The minister of health and most of his directors had just been sacked and taking into account the tense international situation, it was definitely not a viable option for any manager to allow foreign action researchers to run free at the local levels of the health system!

### 4.1.3 Local Participation and Expression of Own and Different Opinions Not Facilitated

The strong hierarchical structure of the Cuban health system has affected the participatory approach. Participation and cooperation have been successfully applied within HISP in countries like South Africa, Mozambique and India. India also have a strong centralized and hierarchical bureaucracy, but provided some central support, there are no restrictions on horizontal interaction and interchange of conflicting political meanings. Cuba is different in that it is strongly centralized and politically controlled, and criticism and questioning of orders or of the system are seldom heard in public. This closed environment is a difficult context for raising competing and different opinions, and thus a difficult setting for applying a participatory process. At least we can say that the possibility to express own and different opinions is not found in the same way as in the other HISP countries where much more open debate is facilitated. However, there might be other ways or channels of criticism and expression of competing views in the Cuban culture that are different from our understanding of it. The participatory methods we have used assume the “South African way” of expressing opinions, and may have neglected a “Cuban way”, which is obviously more indirect, “secret” and slow and based on informal networks, or the available vertical political structures.

## 4.2 Analyzing the Results of the Multileveled Participatory Approach

Above, in section 3.2.3, we looked in more detail at the results of the participation in the different sub-cases and tried to generalize some tendencies from our multileveled approach. Participation tended to be more fruitful at the lower levels than at the higher levels and also better in more rural isolated places than in places with easy access from the capital.

We have pointed out the importance of a broad participation with involvement of different user groups, and our struggle to obtain participation outside health statistics. However, this struggle has varied at the different hierarchical levels, and it seemed as the centralized mechanisms geared at strengthening the vertical command lines had less impact on the lower levels than at the higher. We have experienced that the degree of participation with local health management, and to some extent the local IT staff was closely related to the degree of interdepartmental collaboration and integration of the human resources found at each place. A tendency we have seen while working at the different levels and in many different places, is that the more rural or local-level the statistics office is the higher is the degree of integration with the rest of the health departments at the local health office. The DNE in Havana does not encourage the local health statistics offices to collaborate with other departments, and it prefers as little interdepartmental cooperation as possible. This fragmentation is more visible at the central and provincial levels than at municipal and health unit levels. One reason is that the local health offices are much smaller than the ones at the higher levels, and thus the health statistics offices are situated much closer to the other offices. At the national level the health statistics office has its own building, while at a polyclinic all departments have offices in the same hall. Comparing offices at the same hierarchical level we have also experienced a tendency towards more interdepartmental collaboration at the rural and

isolated offices than at the ones within easy access from Havana. This tendency towards more local autonomy in rural places might exclusively be a result of the physical isolation and thus a need for a stronger local management, but based on our experiences, we suggest that this is also related to the distance from the power and centralized control mechanisms found in the capital Havana.

Heeks et al [12] are outlining a number of unfavorable contexts for participatory approaches including centralized, authoritarian and hierarchical organizations where senior staff is unlikely to be willing to share power and involve the lower ranks. This could have been a description of the Cuban health system and the problems encountered when trying to apply participatory approaches there. However, the process in Cuba has revealed that when applying a multileveled approach in a certain scale a great variety of results, ranging from successes to failures may occur. Building on [12] we suggest a model for understanding multileveled participation in a centralized and hierarchical context focusing on aspects of user participation caused by mechanisms of the centralized and hierarchical structure rather than human skills or technical aspects of the infrastructures. This separation is of course difficult to make as all contextual aspects play a role.

Variables influencing the strength of centralized mechanisms:

Hierarchical distance to the power centre

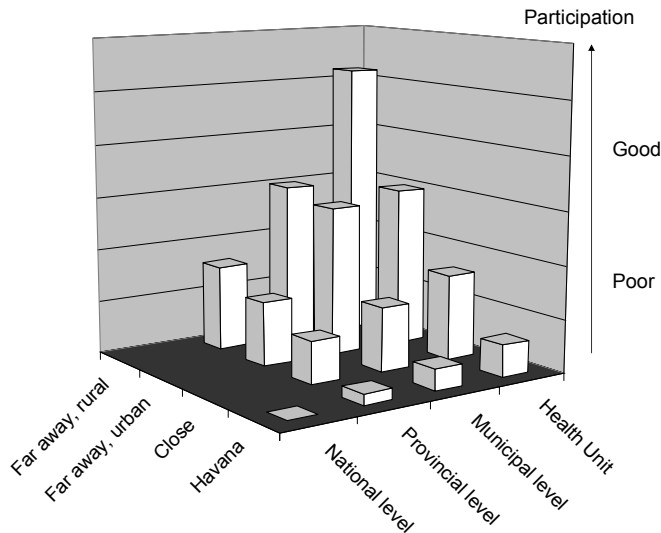
Physical distance to the power centre

**Table 1. Requirements and constraints to participation**

<b>Important properties of a good participatory process in HIS development:</b>	<b>Mechanisms of a centralized, hierarchical context that are constraints to participation:</b>
Access to meet the right users.	A fragmented hierarchical structure, several command lines, many departments, and little interdepartmental collaboration.
Involving a variety of stakeholders.	A strict political system with focus on monitoring, control, and punishment of dissidents. Not a culture for rational skepticism or questioning decision-making.
Confident users, some local autonomy, local will and possibility to participate, and interdepartmental collaboration.	Centralized decision-making, nationally defined ISs for central use, and institutionalized local health workers.
Users with self-interest and commitment.	No emphasis on local decision-making and local empowerment.

We present a model (Figure 4) that shows how the success of the participatory process measured by the properties given in the table above, will vary due to a variation in the strength of the constraining mechanisms of a centralized context presented when moving down the hierarchical system or physically away from the

geographical power centre. The values in the figure are not exact, but are used to illustrate the different levels of participation.



**Figure 4. Variation in participation in the pilot sites based on hierarchical and physical distance to the DNE in Havana.**

## 5. A SUMMARY – CUBA IN A WIDER CONTEXT

Compared with other countries where similar processes have been initiated, Cuba stands out as a contrast. HISP-efforts have been implemented to a greater or lesser degree in South Africa, Mozambique, Mongolia, India, Malawi, Ethiopia and Tanzania. Cuba is in many ways a special developing country; the political system is very strict, it is very poor, but education and health services are well developed and free. In terms of technical infrastructure, Cuba is comparable with poor countries as Mozambique and Malawi. A problem in Mozambique has been to achieve geographical coverage of the project, of the simple reason that not all districts have electricity. In terms of education and health infrastructures, Cuba is well developed and in many ways better of than e.g. India and South Africa. For example: while in Cuba a team composed by at least a doctor and a nurse is responsible for serving a population of 5-800, in India one trained health worker, not even a nurse, is serving a population that is ten times bigger. In terms of distribution of poverty and wealth, the other countries are much more diverse than Cuba.

The participation in Cuba has been very narrowly confined inside the health statistics department of political reasons, and local level involvement has been difficult to achieve due to a centralistic tradition of control. India has a bureaucratic centralistic health system comparable with Cuba, but local level participation as well as interdepartmental participation has been made possible due to higher level political support [4].

In South Africa the participation at all levels was made possible by aligning a range of actors around common goals of improving health care in deprived communities, and in many ways as a continuation of the anti-apartheid movement. Contrary to the

situation in Cuba, the political activity (and freedom) and engagement in South Africa have provided good condition for a participatory approach. One lesson from South Africa is that participatory design approaches aiming at giving a voice to the lower levels of the hierarchy applied on a larger scale and on multiple levels invariably turn into highly political processes. Obviously, such processes need political support in order to become sustainable. In Cuba, the centralized organizational and political setting has, contrary to the case in South Africa, made it very difficult to mobilize support that is contradicting the official political structures, thus confirming that centralized organizations provide serious obstacles to participatory approaches (e.g. [13]).

The environment for change in South Africa has also been far better than in Cuba, with a total restructuring of the health services taking place after the end of Apartheid. The knowledge and willingness to implement larger projects are present in South Africa, the by far most successful economy in Africa which is to a considerable extent based on larger industrial and agricultural projects.

The situation in Mozambique is different. The HISP project there has been of a smaller scale and only three pilot provinces have been involved over a longer period of time [4]. However, also there the participatory processes involved several levels and different health programs and sectors. The major problems facing the participatory approaches have most often been linked to a central reluctance and inability to implement action. Committed involvement has been achieved through trial and errors in the fields, which again have been presented and discussed at higher level workshops and consensus on the way forward has been reached several times. However, the way from consensus on a plan of action to actually implementing the planned action has proven problematic in Mozambique. This may partly be explained in the poorly functioning and poorly skilled Mozambican bureaucracy and civil structures, inherited from Portugal which at that time was a “third world country”. Another explanation is that in

Mozambique and other African countries, personal and other informal networks are regarded as more important in maintaining and securing your future than the formal work relationships. To maintain status quo and not involve in uncertain change processes may therefore be regarded as the safest strategy since changes may result in disrupted personal networks. Yet another explanation more specifically to the situation in Mozambique relates to the rapid changes there over the last two generations; 20 years of freedom struggle, resulting in a Soviet style economy and another 10 years of civil war, which again is replaced by peace and a rather radical market based capitalism, have caused public servants to adapt a “wait and see what will come next” attitude which is severely hampering implementation and action. Nevertheless, contrary to the situation in Cuba, the conditions for participation are good, people are willing and they are definitely allowed to. Problems are rather related to the implementation of design decisions coming out of the participation.

Conditions for participation differ across the HISP countries; in India top political support was needed and obtained through political negotiation in an open society. In Cuba, top level support was to some extent present, but only through the statistical line management. However, in Cuba support from the political structure is needed in order to carry out local level participation.

A problem in Cuba is that such support is not easily negotiated openly. In Mozambique, it is very easy to get a variety of health workers, managers, health programs and levels involved in small scale and less committed participatory projects. But, as explained, “serious” implementation is however harder to come by, and will rely upon decisions at the very top level, where there is considerable reluctance towards giving absolute go-aheads. In Cuba, on the other hand, when top level decisions are taken, they will be executed, at least to such an extent that all involved will know what they should do. The relatively federal structure in South Africa is different from the other countries in that the provinces and even lower represent the relevant level of decision making in our case. This made it possible to test things out in pilot sites, and then go for full scale implementation in first a region, then a province and then two provinces, before the national level got involved and subsequently facilitated similar processes in all provinces. South Africa thus stands out as different from Cuba in most respects. However, a certain top-level support is needed for development over time also here, but there is ample room for improvisation during an initial period.

The development of “long-term” national teams has been important in South Africa, Mozambique and India. Also in Cuba there were attempts to create such a national team with the overall responsibility for the project. However, this was not successful as there were not enough resources allocated and it was not prioritized by DNE, i.e. lack of political support. There are several small nodes of skilled groups, but due to lack of a national nucleus they are not communicating.

**Table 2. Comparative summary on participation**

<b>Cuban context:</b>	<b>Related findings from other HISP countries:</b>
<p>Hard to include different stakeholders due to fragmented hierarchical structure and centralized command lines.</p> <p>The volatile political situation also influences this, with understandable skepticism to full access for foreign researchers, and fear of reprisals that lead to less rigorous participation from local staff.</p>	<p>Highly political process after apartheid in South Africa ensured participation of a wide range of actors.</p> <p>Also centralized in India, but participation has been facilitated with top support.</p> <p>Easier to negotiate top support than in Cuba</p> <p>Easy access to relevant actors in Mozambique for small scale projects.</p>
<p>Strong control from top level also ensures that decisions from the top lead to action “down the line”</p>	<p>More federal and decentralized decision making in South Africa. Possible to prototype and develop in one province at a time.</p> <p>Mozambique lacks the civil structures to transform fruitful participation to action, if decisions on such are taken at top level.</p>

Summing up the activities in Cuba as compared to similar activities in Mozambique, South Africa and India, it is obvious that the centralized political control combined with a volatile political situation internationally leading to problems both for participation at local level and across line management at each level (horizontally), represents severe problems, specific for Cuba. It is hard to foresee whether there will be any new collaborative efforts between HISP and Cuba in the future, but given a less tense international situation and a more stable political climate in Cuba concerning foreign relations, the possibility is of course there. However, as a true participatory approach has proven difficult to achieve in Cuba, the systems development approach in a future project would have to be slightly different. To the HISP initiative this research project has given useful experiences from a Latin-American context, as well as a Spanish version of the software; a foundation for other potential Latin-American HISP projects.

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