Participatory Design for Social Development: A South African Case Study on Community-Based Health Information Systems

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ABSTRACT

In this paper, the role of participation within the domains of information system (IS) research and social development is analyzed. Specifically, we examine how the process of IS development, and the IS itself, can reflect and shape the status of social development. Traditionally, participatory design (PD) research in IS has focused on business contexts in the Western world, with minimal application to developing country settings, especially in the context of social development. This paper seeks to contribute to developing these understandings and bases its analysis on a case study of a community-based health IS in South Africa.

The case study involved the design and development of a community-based child health IS in a rural area of South Africa. Nationally, the formal district health IS in South Africa includes data only on those people who access health services through the health facilities. The premise behind developing a community-based child health IS was to include all the people living in that district in the district health IS.

Analysis of the case study reveals three ways in which traditional PD needs reconceptualization. First, it is not only the users of the IS who should participate, but also those individuals who are affected by the IS, even when those individuals have no direct interaction with the system itself. Second, whereas there is some recognition in PD literature of the need for the participation of people at different levels vertically distributed within an organization, there has been little recognition of the value of involving actors outside the organization or sector. Third, the capacity of the users and those impacted by the system needs to be developed to ensure effective participation in the IS design and development processes. These three approaches to PD in IS, whose purpose is to contribute to social development, are essential components of a participatory strategy. © 2007 Wiley Periodicals, Inc.

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1. INTRODUCTION

Primary health care (PHC) is a crucial element of national health care delivery, especially in developing countries where the majority of the population living in rural areas rely on governmental systems of health care. The PHC structure is also responsible for providing the community with various outreach facilities, for example, implementing immunization programs and tracking the progress of tuberculosis (TB) patients. These various PHC-related programs require routine reporting of health services information and also nonroutine data arising from, for example, epidemics that require immediate action and surveys, such as on human immunodeficiency virus (HIV) prevalence among pregnant women. Field-level health care workers spend a significant amount of their time collecting, recording, storing, or transmitting various forms of data.

The potential of information and communication technologies (ICTs) to support both the routine and nonroutine data reporting systems is increasingly being recognized by governments in developing countries, and various initiatives ranging from name-based record systems to the computerization of district health information systems (ISs) are being implemented in different contexts (Bodvala, 2002). Despite the tremendous potential that ICTs provide to support health care management, stories abound of technology that failed to live up to the promised potential (Heeks, 1999). On their own, ICTs are not sufficient to make changes, and many factors contribute to this nonfulfillment of potential. The PHC system is an organizationally complex one, composed of multiple levels of hierarchy and various vertical health programs (for example, malaria and TB). Factors such as history, geography, culture, infrastructure, inadequate skill levels, and pressures of everyday work further heighten the complexity. In various developing countries, the prevailing culture of information and communication, whether supported by ICT or not, typically reflects the practice of reporting data upward to satisfy the needs of the bureaucracy, rather than supporting action at the local level of the community, where information is often needed most (Mosse & Byrne, 2005).

These conditions of complexity in the health system make the task of design, development, and use of IS a very challenging one. An important step in trying to address this complexity is to enhance participatory processes of various stakeholders in the design, development, and use of IS. System design represents a social process of negotiation among people’s different needs, expectations, and worldviews, so as to develop a shared understanding of their own and each other’s interests, perceptions, and roles. It is of course a highly political exercise that addresses issues of equity, power, information sharing, and social transformation. The negotiation can in itself potentially be empowering and form an integral part of the system design and development process.

In the 1970s it was argued by developing agencies, such as the United Nations Development Program, that participatory processes in community-based programs could contribute to improved social development. The main aim of participatory processes in development programs is to increase the involvement of marginalized people in decision making in order to improve the relevance and sustainability of programs. Furthermore, health status influences what people can positively achieve and hence their social development. “Expansion of health care, education, social security, etc., contributes directly to the quality of life and to its flourishing” (Sen, 1999, p. 144). Additionally, participatory processes in the design process can improve the effectiveness and sustainability of that IS. This paper takes the argument further and argues that if participatory design (PD) in IS is to contribute to social
development, then participation, as compared to the way it has been traditionally viewed in IS research, needs to be reconceptualized.

IS initiatives are increasingly being designed and implemented to support social development programs. Thus, it becomes crucial to understand how the traditional PD approaches should be expanded to take into account the social development motivation. Accordingly, the rest of the paper is structured in the following way: First we explore the recent debates on the role of participation in the domains of social development and also in IS. We also try to gain a better understanding of the linkages among IS, PD, and social development. Against this backdrop we briefly describe a case study in which participation was a fundamental component of developing a child health community-based IS. We then explore the contribution this case study makes to the reconceptualization of participation in IS design.

2. PARTICIPATION

2.1 Participation and Social Development

Participatory development is justified in terms of sustainability, relevance, and empowerment (Cooke & Kothari, 2002, p. 5). The main aim of participatory processes in social development is to involve economically and socially marginalized or excluded people meaningfully in the decisions that affect their lives (Guijt, 1998, p. 1). The issue of community participation has been dealt with comprehensively by international agencies such as the World Bank and UNICEF and other development organizations in development projects (not necessarily IS related) employing techniques such as rapid rural appraisal (RRA), participatory rural appraisal (PRA), and more recently participatory learning for action (PLA). As Cooke and Kothari note (2002, p. 5):

Participatory development is conventionally represented as emerging out of the recognition of the shortcomings of top-down development approaches. The ineffectiveness of externally imposed and expert-oriented forms of research and planning became increasingly evident in the 1980s, when major donors and development organizations began to adopt participatory research and planning methods.

More recently the success of methodologies such as PRA and RRA in addressing the complex social-historical-cultural conditions that surround social development has been questioned and various criticisms have been expressed by researchers in the field of development studies (McGee, 2002). Participation, especially in the context of community, is intricately linked to questions of democracy, power, and asymmetries that historically exist within communities. The popular participatory approaches and methodologies were initially criticized for their technical limitations, and it was realized that there was a need to reexamine these approaches to ensure that the techniques used facilitate more equitable participation rather than perpetuating the status quo (Cooke & Kothari, 2002, p. 5). More recently in community development programs, there has been considerable debate around the theoretical, political and conceptual limitations of participation, such as the view of communities as homogeneous (Guijt & Shah, 2001) or the adoption of a simplistic view of power (Kothari, 2002) and insufficient focus on the structural determinants of well-being (Cleaver, 2002; Francis, 2002). In contrast to development studies, the research on PD in IS does not reflect a similar level of maturity or the inclusion of social science concepts. We now briefly discuss some of these issues with regard to PD research in IS.
2.2 Participation and IS

Over the years, research on IS design has emphasized the important role of user participation in the design of effective IS. This body of research has been important to help refocus the previously dominant technical orientation of systems developers, stemming from a primarily computer science tradition, to include and actively recognize the needs, aspirations, and expertise of users. The rationale behind this refocus is twofold. On one level there is the recognition that it is ethically and morally right that workers should be involved in the development of systems that will affect their working lives. On another level there is the recognition that ongoing failures of traditional technical approaches can potentially be overcome through the use of PD-based approaches (Fitzgerald, Russo, & Stolterman, 2002, p. 52). Mumford aptly summarizes this view of participation: “Participation is viewed pragmatically and ideologically—something that helps efficiency, satisfaction and progress, but which is also morally right” (Mumford, 1984, p. 103).

PD research in IS originated in the mid-1970s in studies carried out primarily in Scandinavia and the United Kingdom, and later in the United States. Asaro summarizes the European participatory approaches in IS as having two strands. The first strand is the collective resource approach adopted in Scandinavia, with an emphasis on union empowerment. The second strand is the sociotechnical approach in Britain, focusing on autonomy in work group organizations through power sharing, joint responsibility, and multiple leadership (Asaro, 2000). In the United States there was a more limited and later adoption of the PD approach, reflecting the very different sociopolitical conditions, especially between Scandinavia and the United States. PD was primarily adopted in the United States to support different prototyping and business process reengineering (BPR) endeavors by creating more efficient and effective organizational and business practices (Puri, 2003, pp. 37–38). In contrast, the Scandinavian PD approach emphasizes the concerns of politics, distribution of power in the workplace, and the ways imbalances can be corrected through the participation of the workers.

As such, PD, including its role in addressing issues of power, has been a topic of keen debate in the IS literature. However, much of the research and many debates have been confined to western contexts, with only limited and peripheral contact with developing country settings. Although some evidence of the attempts to extend IS research to developing country domains has recently become discernible in the mainstream IS literature (for example, Puri, 2003), the issue of PD in these settings has not been given specific research attention.

Increasingly there have been debates on the role of ICTs in development, with the main concern being how ICTs can improve social development (Sahay & Avergou, 2002). One example is the special issue in *MIS Quarterly* (2007) that specifically focuses on the role of ICT for development. The development context is fundamentally quite different from the typical business contexts of the Western world where PD research originated. This difference in context requires research focused on illuminating the interlinkages among PD, social development, and IS development.

2.3 PD in IS and Social Development

As discussed, participation can improve social development through the inclusion of the voices of the excluded, who are affected by the development programs. IS initiatives designed to support social development are also dependent on effective participatory
processes. However, few cases in IS or development studies literature have discussed issues around participation from both the viewpoint of IS and the development context. Participatory IS design can be used to create awareness of the social situation and to mobilize the commitment and action of government and society to address this situation. There are increasing attempts to use participatory IS design for social development purposes. The Scandinavian PD history arises from such a tradition, although within a different context of the trade union movement. Korpela and colleagues have explored the use of activity theory in IS research as an emancipatory method based on collaboration in the domain of health care within disadvantaged settings (Korpela et al., 1998). The authors have argued that the adoption of a developmental stand not only contributes to a better understanding of the IS within an organization, but also helps in developing an IS that functions better.

Madon and Sahay (2002) give the example of the nongovernmental organization (NGO) Jana Sahayog, based in Bangalore, whose mandate is to improve the information environment of slum dwellers in the city. Recognizing that much critical information is gleaned from informal sources, such as from slum dwellers themselves, Jana Sahayog tries to identify and enhance traditional communication skills in the slums. For example, slum dwellers are encouraged to produce audiocassettes and videotapes describing their problems and requirements. Audiocassettes help address the issue of illiteracy, which is very prevalent among slum dwellers. Puri also describes the use of community-based approaches to participation in development projects involving the use of ICTs, Geographical Information Systems, (GIS) in this case, to address challenges of land degradation. Similarly, there are various ongoing attempts to develop e-government applications aimed at the community, as well as the recognition of the need to facilitate participatory approaches involving community-based IS (Puri, 2003).

The stance adopted in this paper is that both the participatory process of designing and the participatory use of the data from the IS contribute to social development. Additionally, as Brown (1991) contends, the development of an IS is a meaningful indicator of social development, reflective of the texture and democratization of the IS and information flows:

My thesis is that the expansion and consolidation of the information system provides a more meaningful, and altogether less subjective, indicator of social development than either normative change or progressive empowerment, and that evaluation of social development should proceed by the elaboration of techniques to monitor information flows and not by attempts to ascertain either value shifts or direct changes in political relationships. I suggest that when one judges any sort of social development activity . . . a major criterion employed, explicitly or implicitly, to evaluate effectiveness is the texture of the information system, and that the democratisation of information flows is an important measure of health of any community-based initiatives. (Brown, 1991, p. 262)

ISs are not just about the end product, but also about the process by which they come into being and are redefined over time. Participation by both designers and users is obligatory in the process of designing and using any IS. A social developmental approach stresses the importance of process as a goal in itself. For example, the way in which we collect data must embrace developmental principles. In the context of health, which is the focus of this paper, information on health can be used to explain, more generally, the developmental context of a society. Sen (1999, p. 44) makes the case for a strong relationship between public expenditure on health care and poverty and argues for an informational basis for this
connection. For example, if social benefits are to assist in the alleviation of poverty, then there is a need to have information on the criteria for the selection of those who should (or should not) receive these benefits (Sen, 1999).

As important as the information that is included is that which is excluded. The process of participation shapes which information or people are included or excluded, and that in turn significantly shapes the developmental outcomes. What is included depends on who participated, why and how, in the design of the IS. The following case study analyzes the role of participation in the development of a child health CBIS in South Africa. The IS in turn shapes how effectively social development objectives of improving the state of child health may or may not be met. The analysis of this case provides us with insights into the ways the role of participation can potentially be reconceptualized in the context of IS projects for social development purposes.

3. CASE STUDY: BACKGROUND AND RESEARCH APPROACH

3.1 Background

After 1994 the South African government gave top priority to using the PHC approach in the delivery of health services, emphasizing the need to serve the community, as well as recognizing the importance of community participation in the delivery of those services. In 1997, the National Department of Health adopted a new strategy regarding the care of children under the age of 5 years. This strategy, under the label of integrated management of childhood illnesses (IMCI), has the overall aim of reducing mortality and morbidity due to common diseases, and thus improving the life and welfare of children under the age of 5 years in South Africa. The UThukela District Child Survival Project (TDCSP) was selected by the National Department of Health as one of three learning sites for the development of a community component of child health in 1999. The design of the community-based child health IS was part of this larger child health project. The community-based child health IS was implemented in OKhahlamba, which is one of five municipalities in the UThukela District of KwaZulu-Natal on the eastern coast of South Africa. The population of OKhahlamba Municipality is mainly rural, poor and relatively underresourced.

TDCSP was an NGO that initially operated in the OKhahlamba Municipality from 1995 to 1999 and expanded to the rest of the district from 1999 to 2003. Through a partnership with the community and Department of Health, TDCSP’s mission, during its 8 years of operation, was to create a well-being context (a context of emphasis on wellness) through child health, maternal health, and human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) interventions that were codesigned and implemented in a holistic, integrated, and sustainable manner. In developing a community-based IS, TDCSP relied heavily on its strategies of participation and capacity development.

Nationally, the formal district health IS in South Africa can be described as a facility-based IS focusing on the clinics and hospitals, and not on the community. Consequently only those who access health services through these facilities are included in the system. With the increasing impact of HIV/AIDS in recent years, children have increasingly become a more vulnerable and further marginalized group often not able to access health services. Consequently an increasing number of children are denied their right to good health and are excluded from the health IS. Policy and resource decisions made by the
district, based on the current health facility information, reinforce the exclusion of these already marginalized children.

The premise behind developing a community-based child health IS is that vulnerability of children can be tackled by using two interconnected strategies. The first is through increasing the awareness and visibility of the situation of children, and the second through mobilizing the commitment and action of government and society to address this situation. These strategies can be supported by designing an IS for action—an IS that can be used to advocate and influence decisions and policies on the rights of these children. These strategies to address the exclusion of children from the district health IS were adopted in one municipality in a rural area of South Africa.

The research strategy adopted in developing this community-based child health IS was characterized by three key features: interpretive research, longitudinal design, and action research. Each of these features is now described.

### 3.2 Research Approach

#### 3.2.1 Interpretive Research.
Interpretive studies attempt to understand phenomena by exploring the meanings people assign to them and the context in which people act (Lee, 1994; Myers, 1994; Walsham, 1995). An interpretive approach to IS design is based on the assumption that data are socially constructed and value-laden. Data collected within an IS are only transformed into information, and then knowledge, through the interpretation and meaning people assign to them. Access to information and the social meanings ascribed to it influences knowledge and actions. These very actions influence the use and interpretation of the IS and consequently influence the development and refining of the IS. Community-based IS development requires an understanding of people and the social and cultural contexts in which they live. In our case it was important for us to understand what social meanings community members ascribe to the vulnerability of children, and how these meanings could be translated to indicators that could be effectively monitored by the IS.

#### 3.2.2 Longitudinal Design.
Longitudinal case studies have been used by many IS researchers (Walsham, 1995, 2001; Avgerou, 2002) to explore organizational contexts and consequences of IS change. Fundamental to adopting a longitudinal approach in this case study was the desire to operate within existing structures and institutions and to build on activities already in place. Furthermore, to ensure real participation there was a need for capacity development at various levels, which could not take place within a project-related time frame imposed by outsiders. Time was also needed to understand the context and to build a trusting and caring relationship among members. The first element of developing the community-based child health IS commenced with the participatory situational assessment in November 1999 and with a monitoring and evaluation workshop early the following year. Previous situational assessments, surveys, and evaluations contributed to the understanding of the context in which the IS was to be designed. The process of specifically developing and designing the community-based child health IS commenced in 2002 and the implementation of the revised IS in the first half of 2003. An evaluation of the district health IS, of which the community-based child health IS was a component, took place in November 2003.

The main milestones and events in the design of the child health CBIS are summarized in Table 1.
TABLE 1. Major Milestones and Activities in UThukela District Child Survival Project

<table>
<thead>
<tr>
<th>Year</th>
<th>Milestone</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>First interventions of the Child Survival Project in OKhahlamba, including health IS</td>
</tr>
<tr>
<td>1999</td>
<td>Expansion of project’s activities to the rest of the district; site chosen for piloting of community child health intervention; participatory situational analysis and assessment conducted</td>
</tr>
<tr>
<td>2000</td>
<td>Monitoring and evaluation workshop conducted</td>
</tr>
<tr>
<td>2001</td>
<td>Midterm evaluation, including evaluation of HIS</td>
</tr>
<tr>
<td>2002</td>
<td>Beginning of field work on child health community-based IS</td>
</tr>
<tr>
<td>2003</td>
<td>Community-based IS-implemented in June; end-of-project evaluation, including evaluation of health IS; end of Child Survival Project activities and support in UThukela District</td>
</tr>
</tbody>
</table>

3.2.3 Action Research Framework. The aim of action research approaches is not just to study and describe an existing situation, but to change it through specific interventions. The particular action research approach in this case study was informed by Elden and Levin’s (1991, p. 131) action research model. The cyclical approach to implementing, analyzing, and evaluating the changes in the IS involved both the researchers and participants and is indicated in Figure 1.
The action research model presented here serves as an analytical tool of the process that took place in the case study, but each stage or phase was not linearly conducted, nor was each step distinct. Often aspects of the project were dealt with simultaneously with elements from another stage. For example, evaluation and reflection were continuous activities and fed into revisions of whom to include in the process. Social processes do not have any clearly defined end points, and the end of an action research project is necessarily arbitrary (Checkland, 1991, p. 401). The project still needed an exit strategy and agreement on the time frame of operation. This action research process can be summarized with four categories: establishment of research processes and boundaries, such as the exit strategy; problem diagnosis; action intervention; and reflective learning (Lau, 1997). Each of the phases is now discussed.

4. ACTION RESEARCH PROCESS AND OUTPUT

4.1 Establishment of Processes and Boundaries of the Community-Based IS Research

The main activity in this stage of action research was the determination of the overall boundaries and framework of the research. Agreement was reached by the insiders and the outsiders in terms of the objectives of the research, roles and responsibilities, resources needed, and principles of operation. The entry and exit of the researcher and the dissemination of the learning gained in the research were also agreed upon (Baskerville and Wood-Harper, 1996, p. 238).

One of the authors was involved with TDCSP from 1997 until the project ended in 2003. The author was approached by TDCSP in 2001 to facilitate the development of the community-based IS, an aspect of the community child health intervention that had not been developed at that time. In general, the author’s role at the community level in the development of a community-based child health IS, and in support of TDCSP, included various activities, such as facilitation of meetings and report writing, training on research collection and analysis, evaluation and field work in data collection, and participation with the team during many dissemination sessions.

The first step, after agreement was reached on the need for the research, was the establishment of a working group to conduct the research. Participants in the working group were selected on the basis of the positions they held within the district, the networks they were currently part of, the skills and expertise they possessed, as well as their willingness to participate. The team mainly comprised representatives from TDCSP, the Department of Health, community health workers and facilitators, and community development officers and community field facilitators. Over different periods, university staff, community leaders and representatives, the Department of Education, and international and local NGOs were also involved. The roles and responsibilities of all parties were not only agreed to and documented for clarification purposes, but for prevention of confusion or misunderstanding at a later date. Although many participants had experience in monitoring and evaluation and had been involved, albeit to a lesser extent, with the community component of child health interventions, brief discussions were held with all team members on the current status of child health and related information in the district. These discussions were considered necessary in order to establish a common starting point. All working group members were trained in research methodology and data analysis.
Some of the challenges at this stage were the result of trying to fit the additional work into the already busy schedules of the research group. However, the group agreed that the research was also important for them in their everyday work, and agreement was reached with their supervisors to allow for the additional work to be included in their work schedules. Meetings were to be held on the same day as other routine meetings in order to maximize participation.

4.2 Problem Diagnosis

The child health intervention within TDCSP, along with the district health management team, adopted a future-focused approach to planning for child health. The implications of this approach for IS design and development were that children’s health would be measured in a holistic way and that there would be a shift toward expressing children’s health status in respect to the attainment of a vision. This approach reflects what needs to be done to achieve the vision and thus ideally stimulates action. When TDCSP commenced, the community child health intervention, agreement on the vision, and objectives of the intervention had been agreed upon through PLA sessions with community participants (comprising men, women, youth, councilors, traditional leaders and Community Health Committee members) in two different wards in different subdistricts. The vision was as follows: To achieve the optimal health, growth, development and well-being of children within the family and community in the UThukela Health District.

The TDCSP conducted a participatory situational analysis and assessment at the commencement of the community child health intervention in 1999. This involved a demographic overview of the district, a review of the health services in the pilot area, and a summary of the health information gained from the facility-based health IS and the community health workers. The main people responsible for child health (the duty bearers) and other key people in the community (the role players) were identified1 on the basis of the participatory situational analysis and assessment.

An example of the participatory methodology employed was the process of the identification of the main role players and duty bearers, which is illustrated in Figure 2. The photograph is of a flip chart sheet of paper with circles of varying sizes drawn on it by the participants in the workshop. Participants were asked to represent the child as a circle at the center of the picture and the rest of the duty bearers and role players in circles of differing distances from the child. The closer the circle is to the child, the more important is that role player or duty bearer. If action were necessary to improve the care of the children of the community it was felt that these people would need to be involved in the design of an IS. The following groups of people were identified through this exercise and therefore participated in the research: children, community health workers, clinic health committees, traditional leaders and healers, councilors, social workers, early childhood practitioners, mothers (including teenagers), fathers, grandmothers, and TDCSP staff.

The participatory situational assessment further explored and described the community infrastructure in the district and reported on the results of focus group discussions (FGDs).

1A duty bearer is a person who is legally obliged to fulfill certain rights, a claim holder or rights holder is the subject who is entitled to the right, and a role player is a person who is engaged, whether obliged to or not, in the process of realizing that right.
and PLA sessions on child health and care-seeking practices. From the research, a glossary of local terms for childhood illnesses was developed (Gibson, Kerry, & Kerry, 1999). Gaps in the information about child health were investigated at a later stage, through FGDs, critical incidence analysis, and further PLA sessions (Gibson, Kerry, Mchunu, Khumalo, & Kerry, 2000).

Subsequently, a workshop was held in Bergville in February 2000 to explore the existing district health IS in relation to the monitoring and evaluation of the vision for child health. Participants included mothers, fathers, Community Health Committee members, local and district government representatives, university staff, international and national NGOs, and TDCSP staff. One of the interesting aspects of this workshop was a discussion on the vision that had been previously determined. Agreement on the objectives for the attainment of this vision were necessary if we were to design an IS that could assist with the monitoring of the vision. It became evident that very few participants who attended this workshop could understand the “codetermined” objectives that had been previously agreed upon at another community meeting. The objectives were translated into simple English and then into isiZulu. It became apparent that the original objectives did not represent the views of this particular group of workshop participants.
Once agreement had been reached on the objectives, workshop participants were asked to arrange themselves into groups and to discuss the following question: *If we are achieving these objectives, what can we SEE, HEAR, and how can we MEASURE what is happening?* Although it was noted that very few of the indicators present at that time in the district health IS had been identified by the community or had been developed with community participation, some of the indicators that emerged from this exercise were similar, for example, the percentage of children immunized and breastfed. Other indicators were not so clearly measurable, such as abuse at the household level, which participants said could be measured through being able to “see and hear” less abuse. This workshop and a review of the district health IS in November 2001 provided the impetus to explore the “see and hear” aspects of a community-based child health IS.

The next stage was to discover the underlying meanings of community members in terms of the vision surrounding the attainment of “holistic health and well-being” for their children. In this respect, a total of 10 interviews, 15 FGDs, and one meeting took place between July and September 2002 in order to understand the community’s information needs, who should participate in the design and use of the IS, and the format in which the information should be communicated. The duty bearers and role players who were identified in the situational assessment were included in the various groups of research participants. Because of the small number of children involved in previous discussions, an additional FGD with children was conducted in May 2003. Different community members expressed views that helped facilitate a greater understanding of the meanings of the terms *well-being* and *at risk* for a child. Another helpful aspect was the analysis of the factors and practices that contribute to these situations, how the situations can be identified and measured, what action can be taken, and by whom it should be taken.

Local people acted as facilitators during the discussions and interviews, for example community health workers, community field facilitators, and orphan group “mothers” who had an understanding of the local norms and values. In the initial stages, because of differences in status and roles within the community, groups comprising, for example, mothers, children, councilors and facilitation staff met separately to discuss what they wanted for children. These meetings were conducted in the local language and held near the homes or workplaces of the individuals. At a later stage, representatives from the various groups met jointly to share the findings arising from the research and to discuss the way forward.

One important element arising out of these discussions was the need to move beyond measuring child health status in terms of physical being, to taking a more holistic approach and to including the context in which the child is living. It was seen as important to monitor the context in which a child is living (the process of moving toward well-being or risk) as well as the actual state of well-being and being at risk (end product). Focusing only on the end product may cause intervention on behalf of the child to occur too late. The aforementioned factors affecting the conditions for well-being and being at-risk were not viewed as isolated, but interwoven in a socially, politically, and culturally complex situation.

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2 Although children had been identified as participants in the field work, it was assumed that children would be part of the FGD conducted with the youth groups and teenage mothers in the area. However, the FGD with the youth groups did not take place and few children between the ages of 7 and 15 had participated in any of the other FGDs.
Initial meetings helped to determine a local term for indicators, which was izinkomba. In terms of measuring at-risk and well-being, the discussions explored broad areas of measurement rather than developing precise formulations of indicators. This was because community members felt that they were not looking for a value to be placed on childhood vulnerability or risk, but rather that there was the need to track changes in this status, and to identify the necessary actions to be taken when a child was falling into risk or danger.

From the FGDs and interviews, various izinkomba for well-being and at-risk were suggested and subsequently grouped into common areas or themes. Working sessions with representatives from the district health management team, the project, and community members, as well as discussions with the community health workers and facilitators, helped to refine the izinkomba. The photograph in Figure 3 shows part of the process of grouping the izinkomba into themes. All of the responses from the field work were written on orange pieces of paper. These pieces of paper were placed in one vertical column on a large piece of cloth. The responses (izinkomba) were refined as indicators (green paper), and then papers of other colors were used to identify how the data would be collected (blue), who would collect the data (pink), and how often data would be collected (yellow). Each piece of paper was placed after much discussion in the respective column on the cloth.

3The cloth was used in many exercises and was a large piece of parachute material that had been sprayed with mounting glue beforehand. This meant that the cards could be placed on the cloth and moved around to different places on the cloth with ease as the discussion progressed—it was like a large portable “sticky” board.
The data collection and analysis processes were iterative, evolving, and connected in a cyclical manner. The participatory modes of analysis, such as interviews, discussions, feedback from presentations and writings, as well as insights from theoretical work and other empirical work, contributed to the data collected and made further analysis and interpretation possible.

Once there was a clear picture of what the community wanted to measure and what was currently available and in what format, a discussion was arranged on what community-based data collection tools were required. From these discussions, the use of a household observation form was piloted as an approach to measure these types of izinkomba. Participants felt strongly that the assessment should be used by the community health worker as an empowering communication tool rather than as a means of inspection.

The capacity of the role players and duty bearers to act if they received the necessary information or knowledge was then addressed. An important requirement was to ensure access to the data and its flow to people who could take action. These discussions led to recommendations on changes in the information flows, as well as routine district data formats.

Overall the research identified that while some data for at-risk and well-being were being collected, there was no feedback to the people responsible for taking action at the household level. Some suggestions made were the need to include in the district health IS indicators of the context that shapes the status of children and the enhancement of forums for reflection and analysis of the data.

4.3 Action Intervention

The system implemented has built upon the traditions and culture in practice and therefore is primarily a paper-based and orally communicated IS. Using an observation form, the community health worker assesses and registers the risk or well-being of the child at the monthly household visits and discusses the situation with the caregiver present. Advice is given immediately, possible solutions identified, referrals made, and, if necessary, assistance provided in household decisions.

The data gleaned by the individual community health worker is compiled by the community field facilitator and an “Assess, Analysis, and Act” process is followed to discuss the data and to share experiences. This takes place on a monthly basis. The aggregated data (at village level) are presented to the community at quarterly village health days, chaired by the Community Health Committee and organized by the community health workers and facilitators. Parents, mainly mothers and grandmothers; schoolchildren; and district staff attend the meeting. Feedback from the aggregated data is given through song, dance, poetry, role-play, and bar graphs.

The compiled community data (for all villages in the municipality) are sent to the district health information officer, who should include the aggregated municipality data in monthly feedback reports to the health facilities and to the district program staff. Ideally the community-based data submitted to the district information officer should also be shared with other programs at district and higher levels, and should include a feedback loop of analysis and reflective questions for those who submitted the data. Additionally, local government should be involved in the information flows. These two links have not yet been made because of the absence of a district information officer and the volatility of local government structures during the research process.
In summary, four main changes were introduced into the district health IS:

- Participatory determination of indicators that the community needed to be included into the system: The new indicators included information on communication and relationships within the household, deaths within the family, employment, and access to education and social services. These are indicators that can be used to describe the context in which the child grows up and should be largely articulated by and collected within the community.
- Adaptation of the existing community health worker data collection forms to include these indicators.
- Enhancement of different discussion forums for analysis of the data collected to stimulate reflection and use of the community-based data.
- Integration of formats and flows of information in the health IS.

These changes were implemented in the municipality in June 2003 and an agreement was reached later that year to expand the system to the rest of the district.

4.4 Reflective Learning

The evaluation of TDCSP, which included an evaluation of all the interventions and hence also the district health IS, was conducted in November 2003. Given that the community-based IS had only recently been implemented, it was really too early to judge its impact on broader health system outputs, such as child health. Therefore, in terms of evaluating the aims of the research—to be able to use the IS to describe the situation of children and to act upon the information generated to improve the condition of children—it was too early to say whether or not this would happen. Benefits identified in the evaluation were largely process-oriented. These included the reduction in the number of data collection tools (from five forms to two) and the subsequent decrease in time spent on collating the data; the training of 75 community health workers and the involvement of those workers in the design process; and the development of a culture of communities’ monitoring themselves and the status of their children. More broadly, the community-based IS research helped to emphasize the importance of information at the community level within a district health IS, making it clearer where information should flow on the basis of who can take action and highlighting the importance of feedback of information to the community-level partners in child health (UThukela District Child Survival Project, 2004).

However, reflection goes beyond an end of project evaluation and occurred throughout the action research process. Participation was a fundamental principle of all TDCSP activities from the outset. However, during the process of participation in the IS design process, reflection occurred on the tools used, approaches adopted, and who participated (or did not). Other reflective processes mentioned earlier include the following:

- Developing a future-focused vision
- Reflecting on the existing IS and recognizing lack of data on children and lack of community-determined indicators
- Exploring the measurement of the context and state of child for inclusion in a health IS
<table>
<thead>
<tr>
<th>Stage of research</th>
<th>Key actions</th>
<th>Participatory approaches</th>
</tr>
</thead>
<tbody>
<tr>
<td>Process</td>
<td>Identification of the need to develop a community-based information system (IS)</td>
<td>Monitoring and evaluation workshop held; situation analysis conducted</td>
</tr>
<tr>
<td></td>
<td>Agreement reached on terms of reference for research team</td>
<td>Group discussion among members of team at different stages of the process</td>
</tr>
<tr>
<td></td>
<td>Determination of a vision for child health</td>
<td>Participatory tools, such as participatory learning for action, used in community meetings</td>
</tr>
<tr>
<td></td>
<td>Conducting of a situation analysis and research to address gaps</td>
<td>Participatory tools, such as mapping, critical incidence analysis, Venn diagrams, and gaps analysis, used</td>
</tr>
<tr>
<td></td>
<td>Exploring of meanings of child health (well-being and at-risk)</td>
<td>Training of researchers on data collection and analysis</td>
</tr>
<tr>
<td>Output</td>
<td>(Re)designing of the information flows</td>
<td>Culturally appropriate formats of communication at community level</td>
</tr>
<tr>
<td></td>
<td>Facilitation of reflective practices</td>
<td>Largely oral and paper-based (some data from community entered into computerized IS at district level)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>One-to-one discussions at household level</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Song, dance, role playing, and charts used in the village health days</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“Assess, Analysis, and Act” at community health worker meetings</td>
</tr>
</tbody>
</table>

- Undertaking participatory and iterative analysis of data and meanings of health
- Enhancing forums for reflective practice in the IS

Throughout the process, reports were written and circulated among the researchers, community members, TDCSP, donors, academics, researchers, and various levels and individuals within the Department of Health. A number of papers that highlight the practical and theoretical aspects learned from this project have been written and presented in different forums.

The participatory approaches used throughout this case study are summarized in Table 2.

5. DISCUSSION: RECONCEPTUALIZING PARTICIPATION IN PD IN IS

In this case study, the meaning of participation in PD was reconceptualized in at least three different ways:
• Going beyond end user participation
• Adopting a multilevel and multisectoral approach
• Enhancing reflective practices and the capacity to participate

Each of these issues illustrates a departure from conventional ideas about participation in PD. These departures principally involve the recognition of different strategies and approaches to PD to ensure the required diversity of participation and participants.

5.1 Going Beyond End Users

The conventional focus in PD is on the participation of the end users, and little attention is paid to those people who will be affected through the delivery of the services by these end users. For IS to be used as a tool for social development the scope of the term users in IS needs to be expanded to include all those affected by its implementation. Korpela and colleagues argue for the inclusion of the community served by the health facility in IS development, along with the computer professionals and health providers (Korpela et al., 1998). However, those affected by the IS should not be viewed as one homogeneous group, a point that also has to be faced in development studies projects. As Puri notes in his work on GIS implementation for land management in India, a common error in community development projects is to view communities as a homogeneous whole, devoid of differences that occur at all levels of society (Puri, 2003, pp. 32, 33).

Despite the stated intentions of social inclusion, it has become clear that many participatory development initiatives do not deal well with the complexity of community differences, including age, economic, religious, caste, ethnic and, in particular, gender. Looking back, it is apparent that “community” has often been viewed naively, or in practice dealt with, as a harmonious and internally equitable collective. (Guijt & Shah, 2001, p. 1)

In participatory approaches, there is often the wrong assumption of a static picture: differences are simplified in terms of insider and outsider; normative assumptions are made that presuppose that participation moves from coercion to autonomy, and the closer participation is to autonomy the better. All of these typologies ignore the diversity of participation that can take place within each of the levels or groups (Guijt & Shah, 2001, p. 10). When related to community development programs, the argument for participation is based on a more intuitive and ethical viewpoint, rather than on empirical grounds. The internal dynamics and differences are inadequately understood.

This mythical notion of community cohesion continues to permeate much participatory work, hiding a bias that favours the opinions and priorities of those with more power and the ability to voice themselves publicly. (Guijt & Shah, 2001, p. 1)

In the case study presented, the role players identified as responsible for children’s well-being were involved in the design and development of the community-based IS. The involvement of the community in the determination of indicators allowed different perspectives on the measurement of child health to be included in the IS. The indicators chosen were not all quantifiable. This is quite different from the predominant focus on quantitative indicators in health IS design. Chambers also challenges the pursuit of excessive accuracy of data when approximations are good enough. He notes, “What often matter are
judgements of trends and of relative amounts, and insights into causality” (Chambers, 1997, p. 42). He urges that people aim for “approximate precision” and accept “optimal ignorance,” or knowing only what they need to know. As such the diversity and differentiation of the community contributed to the design of the IS. As seen in the case study, it is important to monitor the context in which a child grows up if action is to take place before a child ends up in at-risk situations. People outside the community do not have access to this information. Community links with the health facility IS are essential in order to make decisions concerning the situation of children.

5.2 Adopting a Multilevel and Multisectoral Approach

Conventional PD approaches have explored IS design in one organization and in some cases even between different hierarchical levels within that organization, but have rarely analyzed the use of PD in different organizations or in community settings. There are very few examples of the participatory designing of IS outside the work context in published literature (Byrne, 2004; Kanungo, 2004; Korpela, Mursu, & Soriyan, 2002). Participation and participatory processes within a community setting stand in sharp contrast to the conventional organization settings of unionized Scandinavian companies in the 1970s described in much of the literature on PD in IS.

For example, the identified role players who affect the development of a child in this case study represented both multisectoral (health, education, welfare, and local government) and multilevel (household, community, and district) groups. An IS that would then support these key players and take their interests and concerns into account would necessitate a multilevel and multisectoral approach and address the different levels of interdependencies.

Since a variety of groups, organisations, and influential individuals comprise the community, an attempt to bring about community change must take this complexity and divergent interests into account. Network development provides a means of thinking about linking various parties to bring about system development. (Braa, Monteiro, & Sahay, 2004, p. 292)

Indicators for holistic child health covered areas concerned with education, infrastructure, social welfare, and employment. It was important not to duplicate existing systems, but to build upon what was already present, a concept emphasized through the metaphor of cultivation, where we shape and influence, recognizing the agency of what is being cultivated, rather than try to control the process. The product are unified, sociotechnical networks, which evolve in small steps and help us acknowledge the complexity, the dynamics, and the emergent character of the change process (Aanestad, 2002).

Linkages between the existing district health IS and the data held by the local municipality and other departments are still needed if a comprehensive district health IS is to be achieved. A process is needed to align the various actors in terms of the vision for child health to be attained and to obtain clarity on their role and responsibilities in the attainment of that vision. In this process, the local problem(s) need to be addressed, but there are many other levels that need to be developed or interlinked to the local network (Braa et al., 2004). Multilevel and multisectoral meetings were easier to organize at a community level than at the district levels, largely because of the multiple roles community members play, and which are not organized according to vertical health interventions. At the district level, because of different reporting and supervisory systems, approaching health practically from
a multisectoral position was more difficult, because of the vertical organizational structures in which the actors operate. Therefore, the linkages among community, health facility, and the different spheres of government still need to be enhanced in this case study.

5.3 Development of the Capacity to Participate

In PD, capacity to participate is usually assumed, but there is often the need to develop this capacity. An initial position that can be taken entails the opening up of spaces for dialogue and the establishment of communication loops among the different levels. On the basis of the research conducted it was discovered that in this district, the care of a child on a day-to-day basis is primarily the responsibility of the mother of the child, but in terms of traditional beliefs the well-being of the child is, in effect, the responsibility of the family. The father of the child and the paternal grandmother exert a considerable influence on what care-seeking practices are adopted. Thus household visits by the community health worker included discussions with all the main decision makers and thus information flows extended to all family members. Developing forums for discussion at different levels within the IS can help to improve dialogue among the various responsible parties and can offer an opportunity for genuine reflection on the meaning of the data collected.

For actors to participate in dialogue it is necessary to recognize the structural conditions that are required for such a dialogue to take place, and any impediments to achieving it. Issues that are often neglected in the literature on IS design are how the information is to be used and what are the capacities or capabilities to use this information once it has been collected.

Responsible adults must be in charge of their own well-being; it is for them to decide how to use their capabilities. But the capabilities that a person does actually have (and not merely theoretically enjoys) depend on the nature of social arrangements, which can be crucial for individual freedoms. And there the state and the society cannot escape responsibility. (Sen, 1999, p. 288)

In our case study, we explored capacities to act on the basis of the information that the participants wanted included in the community-based IS. Crucial to this case study, in terms of having the capacity to act, was access to information. Community members viewed becoming part of the current data flow and developing a community-level information flow as fundamental to their capacity to act.

Many researchers in the domain of social development (Cleaver, 2002; Francis, 2002) criticize participatory approaches for ignoring the structures in place on the grounds that they leave social development vulnerable to power exploitation. Capacity development is required to overcome the constraints identified in the research process. This goes beyond the skill enhancement issues addressed by Ehn (Ehn, 1993) to issues of responsibility, knowledge, and access to resources (Jonsson, 2003). Arrangements were made to enable people to participate in the design process through using the local language, holding meetings near where they lived or worked, having a facilitator they trusted and, moreover, having training on data collection methods and analysis, as well as orientation on child health issues. Furthermore, traditional forms of communication, such as song, dance, poetry, and drama, are all used in the revised information flows.

Table 3 summarizes the main points of departure from conventional approaches to PD, what was achieved in this case study, and what are the challenges still to be faced.
TABLE 3. Rethinking Participation and Challenges to Be Addressed

<table>
<thead>
<tr>
<th>Point of departure</th>
<th>Achievements</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community involvement</td>
<td>Community-based information system implemented in one municipality Agreement reached to expand to the rest of the district</td>
<td>Issues of scalability of community-based information system (IS) to be addressed</td>
</tr>
<tr>
<td>Multilevel and multisector approach</td>
<td>Codetermined vision Good participation of Department of Health and community members</td>
<td>Need to have other sectors, besides health, involved at district level Improvement in information flow and feedback between community structures and district needed</td>
</tr>
<tr>
<td>Capacity to participate</td>
<td>Participatory involvement in changes in IS: community-determined indicators; tool design, information flows, and communication forums Community members trained in research methodology, data collection, and analysis; reflective forums enhanced</td>
<td>Traditional positions of hierarchy and social inequality still inhibitory to participation in mixed forums</td>
</tr>
</tbody>
</table>

6. CONCLUSION

The case study presented in this paper shows that the meaning of participation in PD needs to be more clearly defined and rearticulated in the context of contemporary IS research. Since IS research is increasingly concerned with understanding the role of ICTs in alleviating developmental constraints, the contexts of social development and IS need to be integrated. Given that PD is contextual, practical examples of how and why participation took place are needed. The analysis of participation, in this case study, indicated the need to move away from the workplace to the community served by the PHC services, from a vertical health system to a more multilayered and multisectoral approach, and from skill enhancement in system design to capacity development, which facilitates participation and addresses the challenges faced within systems and structures of health and related sectors. More examples of participatory approaches in community settings in developing countries still need to be documented.

This paper is an attempt to help fill this gap in the conventional PD literature—the practical nature of participation in developing countries. Much of the research and debate on PD in IS has been confined to Western contexts, with only limited and peripheral contact with developing country and community settings. Three key aspects of PD in developing countries emerge from this case study, namely, different strategies of participation, scaling of participation, and contextual specificity.

The appropriateness of participatory approaches in developing countries has been debated in IS literature on two levels. On one level it has been suggested that the traditional cultures of developing countries are hostile to PD. “There is little evidence, for example, that the idea of deciding on feasible information systems changes through an effort to reach consensus can be effective in many developing countries” (Avgerou & Land, 1992, Information Technology for Development DOI: 10.1002/itdj)
This quote carries the assumption that developing countries have more rigid bureaucratic organizational structures than do the so-called developed countries. On the other hand, there are claims that participatory approaches to action research, outside the IS field, were more common in the Southern Hemisphere than the Northern Hemisphere. Brown (1993) notes that traditionally action research in the North attempts to improve organizational performance and generate social science theory. In the South, a more participatory approach that attempts to raise levels of consciousness, address basic social problems, and deal with empowerment is adopted.

Furthermore, in many African countries decisions that affect the community at large are traditionally made collectively. Community meetings are called and the case for and against the issue is made. Through traditional structures, community members can air their opinions and concerns. This is in keeping with the spirit of *ubuntu* or collective personhood and collective morality (Mbigi, 1997, p. 2) that is a fundamental concept in most African societies. Principles of continuous consultation and consensus, the use of ceremonies to express meaning, and the need for spiritual and individual reflection are all principles on which the concept of *ubuntu* is based and were used in our IS design process.

The mass democratic movements for independence in India and South Africa were built fundamentally on participatory premises, clearly illustrating that the assumption that developing countries do not have a tradition of participation is incorrect. What this reveals is not that participatory approaches to IS design are not possible in developing countries but given that the context is different, the strategies and approaches to allow, sustain, and scale participation will necessarily be different.

One example of PD of IS in a developing country context is the work by Braa and associates, who use the concept of networks of action to address issues of sustainability and scalability. They emphasis that “local action research interventions need to be conceptualized and approached as but one element in a larger network of action in order to ensure sustainability” (Braa et al., 2004, p. 337). Scaling (spreading) of the intervention is a prerequisite for sustainable action research. The scaling is less about increasing size than facilitating the necessary learning processes that enable the process to continue and develop (Braa et al., 2004, p. 341). A multilevel approach in the case study presented here was adopted as a strategy to address the creation of such a network, but its achievement remains a considerable challenge.

An analysis of three case studies implementing health IS in three different developing countries (Mozambique, India, and the case study presented in this research) reveals that the politics of design, the nature of participation in IS design, and the methods, tools and techniques for carrying out design projects are shaped by the diversity of the socioeconomic, cultural, and political situations prevailing in each of these settings. Although common strategies, such as capacity development, that cut across the three case studies could be found, it is the importance of the contextual nature of PD that emerges most strongly (Puri, Byrne, Nhampossa, & Quraishi, 2004).

For PD in developing country contexts to be successful, the design should be built on points of potential, challenges, and opportunity. For example, in this case study, the foundation consisted of the principle of *ubuntu*, the tradition of collective decision making, and the celebratory nature of communication. There is no single algorithmic best practice regarding PD in IS that is applicable to all situations (Puri et al., 2004).

The experiences outlined here have implications beyond community-based child health IS development and developing country contexts. These specific implications can be extended to new PD contexts. For example, there is a need to expand the term *users* to include...
those affected by the IS, and therefore the scope of PD must be broadened to include the environment outside an organizational context. The contextual nature of participation is another example. Participation in collective decision making and hence in IS design is not something that is confined to Western societies. In all situations IS designers and practitioners need to explore the challenges and opportunities in their particular context, and not confine themselves to the conventional views of PD.

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REFERENCES


Sahay, S., & Avgerou, C. (2002). Introducing the special issue on information and communication technologies in developing countries. The Information Society, 18, 73–76.


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