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eHealth Case Study No.5

Participatory Design of a Community-Based Child Health Information System in South Africa

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Application

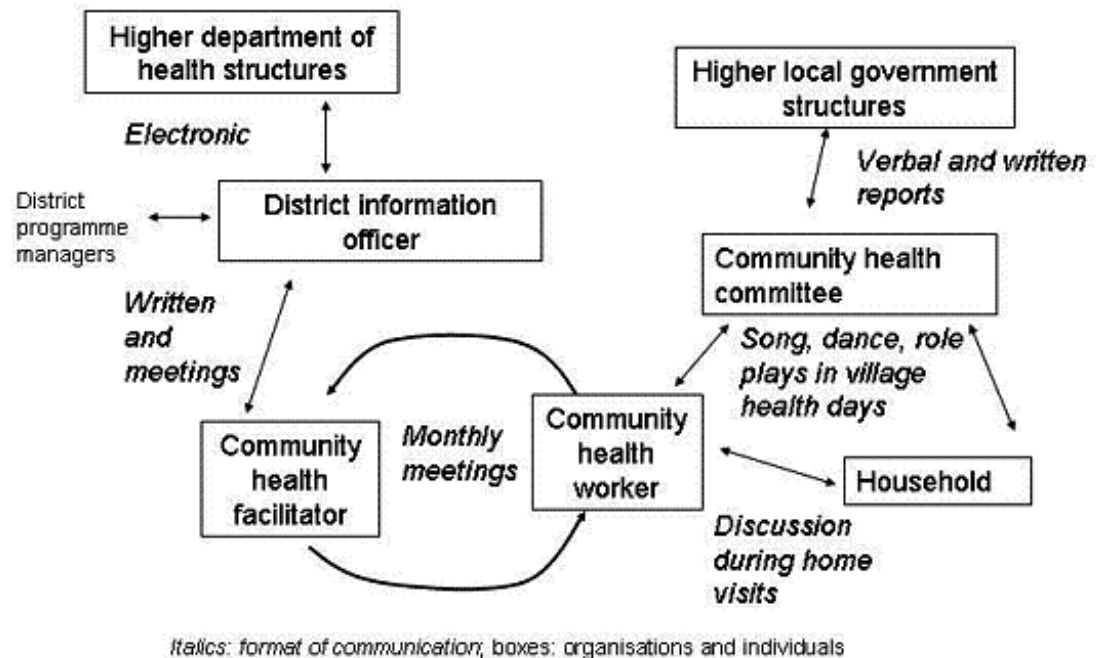
uThukela District on South Africa's eastern coast is home to the uThukela District Child Survival Project (TDCSP), which was initiated in 1995. The Project works in collaboration with local communities and the Department of Health to create a context in which optimal health and well-being are achieved and sustained. As part of a child health project started in 1999, a community-based child health information system was planned, beginning in Okhahlamba municipality (one of five municipalities in the district).

Application Description

Work on the community-based information system (CBIS) began in 2000 with a participatory situational assessment and a monitoring and evaluation workshop. Surveys and evaluations contributed to the understanding of the context in which the information system was to be designed. The process of specifically developing and designing the CBIS commenced in May 2001 and was finalised in December 2002. Implementation of the revised information system commenced in the first half of 2003 and an initial evaluation of the system took place in November 2003.

The CBIS is primarily a paper- and oral-based system. Community data is collected through the community health workers' (CHW's) monthly visits to households, and is fed back to the community through village health days. The aggregated data is compiled by the community health facilitator and is sent to the district health information officer who includes the data for each municipality in her monthly feedback reports to the health facilities and district programme staff. At district level the data is entered into a computerised system. The data is also sent electronically to the province for further transmission to national level. This process is illustrated below:

Revised information flows and communication loops



Four main changes have been made in the district health information system because of the development of the CBIS. The first was the determination of the indicators the community needed to be included into the system. This meant that indicators which described the context as well as the physical condition of the child were needed, e.g. love, clean environment, good growth. The second major change was the adaptation of the existing community health worker data collection forms to include these indicators. Thirdly, to stimulate reflection and use of the community-based data, different forums for analysis were enhanced: monthly CHW meetings include individual reflection as well as group reflection on the data, and village health days involve a process of assessment, analysis and action based on the data presented to them through song, dance, poetry and histograms. The last change has been in the information flows. Households receive feedback immediately from the CHW during her visits, communities receive information feedback at the village health days, and health facility staff receive information feedback through the district information officer.

Role of ICT

Only at the higher levels of this health system is ICT involved. A national standardised software program, based around Microsoft Access and Excel, is used at the district and higher levels of the system. The focus of this case lies more on the collection and use of the data that forms the foundation for this e-health system.

Application Drivers/Purpose

The rationale underlying the CBIS project is that vulnerability of children can be tackled on two interconnected levels. The first is through the creation of awareness of the situation of children and the second is through the commitment and action of government and society to address this situation. The first can be supported by designing an information system for action - an information system that can be used

for advocating and influencing decisions and policies for the rights of these children. The existing district health information system in South Africa is a district health facility information system (based on clinics and hospitals). Policy and resource decisions made by the district, based on the current health facility information system, reinforce the exclusion of communities and their children. By integrating this CBIS with the existing health facility information system, a more comprehensive district health information system on children was to be achieved.

Stakeholders

From a participatory situational analysis and assessment the main people responsible for the delivery of services (the duty bearers) and other key people in the community (key role players) were identified. If action needed to be taken 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. Thus the following groups of people participated in the project: community health workers, clinic health committees, traditional leaders, councilors, social workers, early childhood practitioners, mothers (including teenagers), fathers, grandmothers, Department of Health staff, and TDCSP staff.

Health and the Poor

Okhahlamba municipality - where the community-based child health information system was implemented - is rural and comprises predominantly poor Africans (90%) who live mainly in tribal areas (80%) but also on adjoining freehold land (10%) and on white-owned farms (10%). Project impacts are therefore intended to benefit the poor in a fairly direct sense by helping community members improve their decision-making about the health of children. More generally, the CBIS has been designed to help caregivers and other members of this poor community to:

- manage childhood illnesses better and better attain a state of well-being for their children;
- learn from their, and other people's, experiences;
- make informed decisions; and
- claim their and their children's rights by holding duty bearers accountable.

Impact: Costs and Benefits

The costs involved were mainly time and human resource. The design of this CBIS that supported the care of the excluded children in the community included a total of 10 interviews, 18 focused group discussions, and one meeting. Participatory methods were employed in order to understand the context (powers, traditions and customs, socio-economic conditions) in which community members live.

Identifiable benefits to date have largely been process-oriented: in other words, improving the processes by which the health information system operates. They include:

- Reducing the number of data collection tools from five forms to two: an observation form for each household visit and a monthly summary form.
- Training of 75 community health workers, and involvement of those workers in the design process.
- Development of a culture of needing information with the CHWs, especially around growth monitoring and promotion.
- Reducing the amount of time required for data collation in monthly CHW meetings from three hours to one hour.

More broadly, the CBIS project has helped to emphasise the importance of information at community level within a district health information system, making it clearer where information should flow based on who can take action, and highlighting

the importance of feedback of information to the community-level partners in child health.

As a result of these benefits, agreement has been reached to expand the system to the rest of uThukela district.

Given that the CBIS has only recently been implemented at the time of writing, it is too early to judge its impact on broader health system outputs, such as child health. However, the overall child health project within which the CBIS resides has been shown to have a positive impact on child health as measured through improved immunisation rates, improved knowledge and care-seeking behaviour, and improved breastfeeding rates.

Evaluation: Failure or Success?

As noted above, it is too early to evaluate the CBIS. However, within the November 2003 evaluation, the TDCSP manager summarised the impact to date in the following way: "This process has shifted thinking within the project from the idea of the monitoring of community interventions to the empowering approach of communities monitoring themselves and the status of their children. . The work shows potential but is still in its infancy."

Enablers/Critical Success Factors

1. **Prior foundation** . One reason behind the success of the CBIS was the foundation of pre-existing work on health systems. The existing district health information system had been developed in the first phase of activities of the project and provided a platform from which that information system could be expanded to include the community. During earlier work, the TDCSP had also established a partnership with the community and the Department of Health that was an important foundation for the CBIS project.
2. **Being part of a larger whole** . Having the CBIS as part of a larger community and district health intervention meant that easy access to the community and a forum for allowing feedback of information to the community for reflection and evaluation were already in place. Further, the outcome of the project could easily be fed into planned interventions, such as training on child health for the community health committees. Making health information systems interventions an integrated part of a larger health project is thus one key to success.

Constraints/Challenges

1. **Shifting responsibilities** . The community health workers moved from being employed by TDCSP to being employed by the government's Department of Health, though still remaining accountable to the community health committees. With this change, the scope of the work the CHWs were doing widened considerably - from a specific focus on households with at-risk children of under five years to a very broad community development focus. This shifted the amount of time that they spent with the households with children and decreased motivation for data collection on children.
2. **Vacant positions** . The position of district information officer was vacant for the duration of the CBIS participatory development. It was therefore difficult to embed the culture of the CBIS into the district health information system during this period (though since the appointment of an officer, there has been agreement to expand the process to the rest of the district).
3. **Non-overlapping data sets** . The areas within which the community health workers operate is not coterminous with the catchment areas used by the Department of Health. This has made it difficult to include community-based information in higher-level information systems.

Recommendations

1. **Provide a voice for communities** . eHealth and other health information systems need to include a community-based information systems component based on the needs and values of the community. This ensures that community voices are heard within the health system, and that decisions made further up the health system can be based on a complete picture.
2. **Adopt a participatory approach** . A CBIS is mainly about communities being empowered to manage and monitor their own health interventions and the impact of these interventions on their community. This implies the need for community members to participate in the process of designing health information systems. Their capacity to participate and the creation of an enabling environment to participate needs to be developed as part of that process.
3. **Adopt a flexible approach** . The complexity of the social context requires an adaptable and flexible approach to the design and development of e-health and other health information systems that involve communities. It is a time- and resource-consuming process. The availability of these resources within the given context affects the process, rate and order of progression. Adjustments to dates and venues of meetings or to data collection procedures will depend on factors such as the weather, harvesting and finding time within a busy community life to conduct discussions. The process will need to take into account all these factors.

Further Information

Contact author.

Case Details

Case Editor : Richard Heeks.

Author Data Sources/Role : Project Implementation Role.

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