PARTICIPATORY DEVELOPMENT OF A MINIMUM DATASET FOR THE KAYELITSHA DISTRICT

B Mash, M Mahomed

Background. Traditional ‘data-led’ information systems have created excessive amounts of poor-quality and poorly utilised data. The Health Information Systems Pilot Project (HISPP), a Western Cape project that started in 1996, initiated a process in one of its three pilot sites to model an alternative approach to developing a district health information system.

Objective. To develop a minimum dataset for Kayelitsha as part of an action-led district health and management information system in a participatory ‘bottom-up’ process.

Method. The HISPP, in conjunction with health workers in the proposed Kayelitsha district, developed a minimum dataset through a process of defining local goals, targets and indicators. This dataset was integrated with data requirements at regional and provincial levels.

Results. A minimum dataset was produced that defined all the data needed according to the frequency of reporting and the level at which it was required.

Conclusion. The HISPP has demonstrated an alternative model for defining health information needs at district level. This participatory process has enabled health workers to appraise their own information needs critically and has encouraged local use of information for planning and action.


References


Accepted 26 Mar 2000.

In observing health information systems in developing countries it has been noted that ‘... the road to health leads through information, but the exact path to follow must be defined by local people’.1

Health information is essential in terms of achieving good health status and local involvement is crucial to a successful health information system. The problems with health information systems at the primary care level in South Africa are excessive data collection, rigid centralisation, poor-quality data, poor use of data, poor feedback and fragmented flow.2 Braa et al. argue that: 'The process towards a health and
management information system must be driven from within, by local management and community structures and it must be based on locally felt needs. The focus must be on processes which occur at a local level – a “bottom-up” approach rather than “top-down” development. Motivation, commitment and the creation of a sense of ownership of the health and management information system by all interested parties are of vital importance. This is only achievable through a participatory process which engages local health management, health workers and the community in participation with higher level policy makers and planners.

In other words, local involvement and a participatory approach are essential in health information systems development. This approach has been advocated in South Africa in the form of a nine-step process that includes the setting up of local health committees and the decentralisation of decision-making power to the local level. The conventional ‘data-led’ approach to reforming health information systems assumes that all data are inherently useful and that the accumulation of data is beneficial in itself. Sandiford et al. disagree with this notion and propose an ‘action-led’ approach that ‘... attempts in the first instance to relate information needs to interventions or potential interventions with a focus on how the information generated will influence decisions and the significance of these decisions for the health of the target populations’.

Their view suggests a selective approach regarding which data should be collected, with the main selection criterion being that data will assist with and lead to decision-making. Given that South Africa has a history of ‘data-led’ information systems, which are not successful, how do we practise a different ‘action-led’ approach?

The approach of defining goals, targets and indicators enforces the link between data collection and management decision-making and can help with developing an action-led health information system. This approach can be used as the method of developing a local minimum data set within a process of developing a district health information system. The rational guidelines for district health information systems produced by the Department of Health have spelt out three methods of defining information needs, namely by brainstorming, by information audit and by defining goals, targets and indicators. The third method is recommended although it has been pointed out that it is more time-consuming. The Scandinavian tradition of participatory development reinforces the view that a participatory approach is essential in information systems development.

The Health Information Systems Pilot Project (HISPP) was established in 1996 with the aim of developing an action-led, district-based health and management information system (DH&MIS) in the Western Cape. The HISPP has worked initially in three proposed districts, namely Khayelitsha, Mitchell’s Plain and Blaauwberg. Within these proposed districts the HISPP has developed an information system utilising a participatory ‘bottom-up’ process involving health workers from both the government and non-government sectors. The purpose of this article is to document how the health workers in Khayelitsha decided on their own minimum data requirements for the DH&MIS. A review of the literature did not reveal any similarly described process and it was therefore felt that the publication of this article would provide a useful model for other districts and provinces.

Khayelitsha has a predominantly Xhosa-speaking population estimated at 350,000 people, and forms one of the proposed districts within the Cape Town metropole. It is situated approximately 30 km from the city centre and is mainly an informal settlement of poor socio-economic status. The community is characterised by high unemployment, poverty, illiteracy and poor health indicators. The infant mortality rate is estimated at 38/1,000 live births and the incidence of tuberculosis as 883/100,000 population. The area is served by a complex network of health services including the City of Tygerberg Municipality (COTM), Community Health Services Organisation (Provincial Administration of the Western Cape (PAWC)), Groote Schuur and Karl Bremer Hospitals, and many other non-governmental organisations (NGOs). Within the government sector there are 3 community health centres (PAWC), 7 clinics (COTM) and 2 midwife-obstetric units (PAWC). The district health authority is not yet established, although a District Health Services Co-ordinating Team is active as an interim structure and services continue to be delivered in a fragmented way by a variety of organisations.

**PROCESS OF DEFINING THE MINIMUM DATASET**

The minimum dataset as described here refers to a clearly defined set of variables for which data will be collected and which would be the minimum required for the effective management of health services. It is different from the traditional description of a minimum dataset which is based on the patient record in that it will include data on target populations, socio-economic variables, infrastructure and environmental health. The process of defining the minimum dataset required the co-operation of a number of structures within the district, as shown in Fig. 1. The District Health Services Co-ordinating Team was a formal structure set up by the PAWC to help facilitate the transition to a district health system. The team of 7 people included local level management from all the government health services in the proposed district. Although the group had a mandate to co-ordinate interim district activities, it was not meeting on a regular basis. The team was supportive of the HISPP process and several members participated in the other structures described in Fig. 1. Although this team had the most authority it did not contribute significantly to the content of the dataset as it was not functioning well.
The District Health Services Forum was an informal structure set up by the District Health Services Co-ordinating Team to include NGOs in the process of transition to a health district. It also allowed government health workers, particularly nurses, from the various facilities to have a direct voice in the transition process. The NGO sector in Khayelitsha was strong in the areas of reproductive health, mental health, disability and community health worker projects, and representatives from these organisations attended regularly. Although attendance at the forum was voluntary, the 40 - 50 members committed themselves to 8 working groups that met separately to discuss issues related to the topics listed in Fig. 1. The working groups each chose a facilitator and met in between the forum meetings to work on various tasks that included the HISPP process. The forum had the least authority of all the structures but was the most inclusive and contributed significantly to the content of the dataset. The working groups varied in size and level of commitment, with the reproductive health and disability groups being the most active.

The HISPP project established a local co-ordinating committee with representatives from each working group of the District Health Services Forum, the District Health Services Coordinating Team and health workers from the different health facilities. The HISPP also advertised and employed a site facilitator to drive and co-ordinate the process. The HISPP process was planned, facilitated and the report edited and collated by the HISPP site committee. This process enabled people to assess the quality of existing information; the main problems identified with the existing information system are listed in Table I. These findings, confirmed by previous studies, stimulated the health workers to consider how the information system could be improved.

Following the completion of the annual report, the next step was for health workers in the district to define the content of the new DH&MIS. A detailed description of this process constitutes the focus of the rest of this paper. Simultaneously with the HISPP process, the PAWC was also
defining its data requirements at regional and provincial level. This process concentrated on defining the data that health centres and clinics should report on a routine monthly basis. The routine monthly report (RMR) was developed alongside the HISPP process, with each initiative influencing and informing the other.

Each of the working groups participated in a workshop to define the minimum data required in its area of interest. The working groups reviewed the information currently available in the annual report for 1996 and then defined planning tools in the form of goals, targets and indicators. Goals, targets and indicators set at the provincial or national level were also discussed and incorporated or modified as appropriate. The 'goals, targets and indicators' approach is spelt out in a training manual by Campbell et al. A goal was defined as a broad policy objective that stated in general terms the direction in which people wanted to move. One goal was set for each working group, and from this a number of operational targets or specific objectives were developed. The quality of these targets was assessed using the Smart format as shown in Table II.

For each of these targets an indicator was defined that could be used to measure progress in achieving the target. An indicator usually consisted of two items of data, a numerator and a denominator, from which a calculation could be made. The indicator therefore defined the data that needed to be collected and the content of the minimum dataset. The method and frequency of data collection was discussed for each indicator; for example whether it should be collected annually by survey or daily as part of the clinic routine.

The data from the RMR, as suggested by the regional and provincial structures, was presented to staff at each health facility. The staff were asked to assess the items by considering three criteria, namely whether it was 'essential to know', 'nice to know' or 'dangerous to know'. 'Essential to know' was defined as data that should be used for planning, action or decision making by health workers at district level. 'Nice to know' was defined as data collected 'for a rainy day', in case someone asked for it, or on the off-chance that it might be useful. 'Dangerous to know' was defined as data that were usually stored away, never analysed or looked at and that only added to the time spent by busy staff in collecting it. The viewpoints of the local staff were collated by the HISPP and feedback was given to the PAWC at provincial workshops where the content of the RMR was debated.

The dataset was also presented for discussion to the NGO sector within the district and to managers at regional and provincial levels. Once agreement was reached on data requirements at regional and provincial levels, the level at which the data were required could be finalised, namely facility, district, municipal local council, regional, provincial or national level.

**RESULTS**

The content of the minimum dataset is too bulky to present here completely, but examples of the goals, targets and indicators from two of the working groups are shown in Tables III and IV.

The reports from each working group were then collated into a minimum dataset that listed the data requirements according to the frequency of reporting. The headings in the minimum dataset and examples are shown in Table V. The minimum dataset is too lengthy to describe in full in this article, but is available from the authors.

**DISCUSSION**

It has been argued strongly that the participation of health workers in defining their own information needs would establish and promote a culture of information. Primary care providers in South Africa do not usually value data and have the expectation of feedback of information that is for 'other people'. It is hoped that 'bottom-up' initiatives such as HISPP will model a process of defining a reduced amount of practically useful data and of changing negative attitudes towards health information. In Khayelitsha, this process has led to a greater interest in collecting and collating useful and accurate data and an expectation of feedback of information that will enhance local planning and decision making. The action-led approach to defining the dataset has enabled people to set clear goals and targets for the health services and in many areas, such as the HIV/AIDS programme, has stimulated activity towards achieving these targets as well as creating indicators to monitor...
### Table III. Goal and selected targets and indicators for child health and nutrition

<table>
<thead>
<tr>
<th>Targets</th>
<th>Numerator data</th>
<th>Denominator data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduce the infant and under 5-year mortality rate by 30% and reduce disparities between population groups</td>
<td>Deaths in children under 1 year and 5 years</td>
<td>No. of live births and population &lt; 5 years</td>
</tr>
<tr>
<td>Reduce mortality from diarrhoea, measles, and ARI in children by 50%, 70% and 30% respectively</td>
<td>No. of deaths from gastro-enteritis, ARI and measles</td>
<td>Deaths among children under 1 year and 5 years or population under 1 year and 5 years</td>
</tr>
<tr>
<td>Increase immunisation coverage among children up to 1 year to at least 80%</td>
<td>No. of children with completed immunisations under the age of 1 year</td>
<td>No. of live births</td>
</tr>
<tr>
<td>Reduce the prevalence of children underweight for age among children &lt; 6 years of age</td>
<td>No. of children &lt; 6 years who are &lt; 3rd percentile</td>
<td>Population &lt; 6 years</td>
</tr>
<tr>
<td>Reduce the prevalence of severe malnutrition among children &lt; 6 years to 1%</td>
<td>No. of children &lt; 6 years who are &lt; 60% EWA</td>
<td>Population &lt; 6 years</td>
</tr>
<tr>
<td>Increase the rate of first contact between infants &lt; 6 weeks and health services</td>
<td>No. of children examined for the first time up to and including 6 weeks of age</td>
<td>No. of live births</td>
</tr>
<tr>
<td>Assess the relative workload of children &lt; 6 years</td>
<td>Total attendance of children &lt; 6 years</td>
<td>Total attendance all ages</td>
</tr>
<tr>
<td>Monitor the incidence of acute diarrhoea in children &lt; 6 years</td>
<td>No. of cases of diarrhoea among children &lt; 6 years</td>
<td>Population &lt; 6 years</td>
</tr>
<tr>
<td>Monitor the incidence of acute chest infection in children &lt; 6 years</td>
<td>No. of cases of acute chest infection among children &lt; 6 years</td>
<td>Population &lt; 6 years</td>
</tr>
</tbody>
</table>

ARI = acute respiratory infection; EWA = expected weight for age.

### Table IV. Goals, targets and indicators for people with disability

<table>
<thead>
<tr>
<th>Targets</th>
<th>Numerator data</th>
<th>Denominator data</th>
</tr>
</thead>
<tbody>
<tr>
<td>To ensure that 50% of people with disability have the appropriate assistive device within 3 months</td>
<td>No. of assistive devices issued to people with disability</td>
<td>No. of assistive devices required by people with disability</td>
</tr>
<tr>
<td>To ensure that care is provided at home for people with limited mobility and who are unable to reach health services, i.e. people with stroke, spinal cord injury</td>
<td>No. of home visits done</td>
<td>No. of patients requiring home visits</td>
</tr>
<tr>
<td>To monitor referral rate</td>
<td>No. of referrals to secondary/tertiary institutions</td>
<td>No. of patients seen for rehabilitation</td>
</tr>
<tr>
<td>25% of adults registered as disabled to have received micro-enterprise training by June 1999</td>
<td>No. of adults with disability on facility register who had micro-enterprise training</td>
<td>No. of adults on facility register who require micro-enterprise training</td>
</tr>
<tr>
<td>20% of adults with disability who underwent micro-enterprise training to be generating their own income by end of 1999</td>
<td>No. of adults with disability on register who underwent micro-enterprise training and who are generating their own income 1 year later</td>
<td>No. of adults with disability on register who attended micro-enterprise training during previous 12 months</td>
</tr>
<tr>
<td>To monitor socio-economic status of PWD</td>
<td>No. of PWD who are generating their own income</td>
<td>No. of PWD on register</td>
</tr>
<tr>
<td>To ensure equal participation of PWD in decision-making processes concerning disability services in Khayelitsha</td>
<td>No. of PWD attending the disability working group</td>
<td>Total attendance at the working group</td>
</tr>
<tr>
<td>To ensure available and accessible transport for PWD by the year 2000</td>
<td>No. of PWD on register who have access to transport</td>
<td>No. of PWD on register</td>
</tr>
</tbody>
</table>
Table V. Structure of minimum dataset

<table>
<thead>
<tr>
<th>Type of data</th>
<th>Variable</th>
<th>Source</th>
<th>Frequency of reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td>Population</td>
<td>Census</td>
<td>Every 5 - 10 years</td>
</tr>
<tr>
<td></td>
<td>Mortality</td>
<td>Local authority</td>
<td>Annual</td>
</tr>
<tr>
<td></td>
<td>Notifiable diseases</td>
<td>Notification system to local authority</td>
<td>6-monthly</td>
</tr>
<tr>
<td></td>
<td>Health Service data</td>
<td>Schools health services</td>
<td>Annual</td>
</tr>
<tr>
<td></td>
<td>Health Service data</td>
<td>Health Facility TB Register</td>
<td>Quarterly</td>
</tr>
<tr>
<td></td>
<td>Surveys</td>
<td>Department of Health</td>
<td>Annual</td>
</tr>
<tr>
<td></td>
<td>Environmental health</td>
<td>Environmental health officer surveys</td>
<td>Annual</td>
</tr>
</tbody>
</table>

This progress. Ultimately it is hoped that the availability of information linked to clear goals and targets will empower local management to make more rational decisions.

There is a qualitative difference in the type of data collected in the new dataset with more data focused on assessing health status and the development of health services and less emphasis on data to monitor workload and for supervision of staff. The content of the final dataset has also been a process of negotiation between different levels of the health service. In some areas, such as that of rehabilitation, the local process has clarified and informed players at regional and provincial levels, whereas in other areas the needs of higher levels has led to modifications in the local dataset. The final product has been an integration of information needs from the facility to the national level, with some information collected only for that facility and other information flowing all the way to national level.

The process has also had problems and limitations. At the start of the HISPP it was anticipated that district health authorities would be created formally during the research project and that this would allow implementation of the dataset in more concrete terms. This has not materialised. The initial interest in the transition process to health districts was harnessed by HISPP, but when the district failed to materialise the interim structures collapsed as people's energy and attention were diverted elsewhere. The District Health Services Forum and Co-ordinating Team had ceased to function by the beginning of 1998. The absence of district managers has impeded the implementation and use of the health information system as it is designed for decision making at this level. In addition, the existing management culture is more reactive in its responses to problems and conflicts than it is proactive in planning and setting goals, for which health information would be useful. There is therefore a need not only to create district-level management, but also to ensure that this management has the capacity for proactive decision making and planning. The development of the health information system should be linked to that of district-level management to ensure effective implementation. The lack of district-level management to participate in defining the dataset has also resulted in a lack of indicators for financial and administrative purposes.

The defining of a minimum district dataset is only one component of an effective health information system. Other elements would include effective data collection tools, efficient flow of information, collation of data, validation of data, and analysis and feedback of information. The previous information system was characterised by fragmentation, with data flowing to a variety of unrelated offices and reporting of diverse information between organisations. The new dataset promotes uniformity between organisations in terms of the data collected and allows collation of the data in an integrated manner at a central district information office. This will facilitate feedback of information with comparable data for different facilities within the district and the development of a single computerised database to handle all the data collection. The acceptability of the dataset may be limited by the rapid turnover of staff, especially doctors, who despite the participatory process may still feel it has been imposed on them or may misunderstand the underlying rationale as they were not present during the initial
Rapid assessment of cataract surgical coverage in rural Zululand

A P Rotchford, G J Johnson

Objective. Cataract surgical coverage (CSC) is a useful indicator of the degree of success of a cataract intervention programme. However, because previously described methods are time-consuming and labour-intensive, they are rarely performed. This study describes a simple and inexpensive assessment of CSC based on screening of pensioners at pension delivery sites in a rural district.

Design. Random cluster-based cross-sectional survey.

Setting. State pension distribution sites in Hlabisa, a rural district in KwaZulu-Natal, South Africa.

Subjects. 562 old-age pensioners.

Method. Subjects found to be blind (visual acuity < 3/60) and those reporting a history of eye surgery were examined using a torch and direct ophthalmoscope by an ophthalmologist.

Outcome measures. Cases of blindness due to operable cataract and post- cataract surgical subjects were identified.

Results. CSC was found to be 38.5% (95% confidence interval 29.1 - 47.9%). Blindness prevalence was 10.3%, with 69.0% due to cataract.

Accepted 27 Sep 1999

Objective. Cataract surgical coverage (CSC) is a useful indicator of the degree of success of a cataract intervention programme. However, because previously described methods are time-consuming and labour-intensive, they are rarely performed. This study describes a simple and inexpensive assessment of CSC based on screening of pensioners at pension delivery sites in a rural district.

Design. Random cluster-based cross-sectional survey.

Setting. State pension distribution sites in Hlabisa, a rural district in KwaZulu-Natal, South Africa.

Subjects. 562 old-age pensioners.

Method. Subjects found to be blind (visual acuity < 3/60) and those reporting a history of eye surgery were examined using a torch and direct ophthalmoscope by an ophthalmologist.

Outcome measures. Cases of blindness due to operable cataract and post- cataract surgical subjects were identified.

Results. CSC was found to be 38.5% (95% confidence interval 29.1 - 47.9%). Blindness prevalence was 10.3%, with 69.0% due to cataract.

Accepted 27 Sep 1999

Rapid assessment of cataract surgical coverage in rural Zululand

A P Rotchford, G J Johnson

Objective. Cataract surgical coverage (CSC) is a useful indicator of the degree of success of a cataract intervention programme. However, because previously described methods are time-consuming and labour-intensive, they are rarely performed. This study describes a simple and inexpensive assessment of CSC based on screening of pensioners at pension delivery sites in a rural district.

Design. Random cluster-based cross-sectional survey.

Setting. State pension distribution sites in Hlabisa, a rural district in KwaZulu-Natal, South Africa.

Subjects. 562 old-age pensioners.

Method. Subjects found to be blind (visual acuity < 3/60) and those reporting a history of eye surgery were examined using a torch and direct ophthalmoscope by an ophthalmologist.

Outcome measures. Cases of blindness due to operable cataract and post- cataract surgical subjects were identified.

Results. CSC was found to be 38.5% (95% confidence interval 29.1 - 47.9%). Blindness prevalence was 10.3%, with 69.0% due to cataract.

Accepted 27 Sep 1999

References


Accepted 27 Sep 1999

October 2000, Vol. 90, No. 10 SAMJ