

# PARTICIPATORY DEVELOPMENT OF A MINIMUM DATASET FOR THE KHAYELITSHA DISTRICT

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*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 Khayelitsha 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 Khayelitsha 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.

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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'.<sup>1</sup>

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.<sup>2</sup> Braa *et al.*<sup>2</sup> argue that: 'The process towards a health and

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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.<sup>3,5</sup> 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.<sup>4,6</sup> Sandiford *et al.*<sup>6</sup> 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.<sup>7</sup> 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.<sup>8</sup> The national guidelines for district health information systems produced by the Department of Health<sup>9</sup> 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.<sup>10</sup>

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 as 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 acting 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.

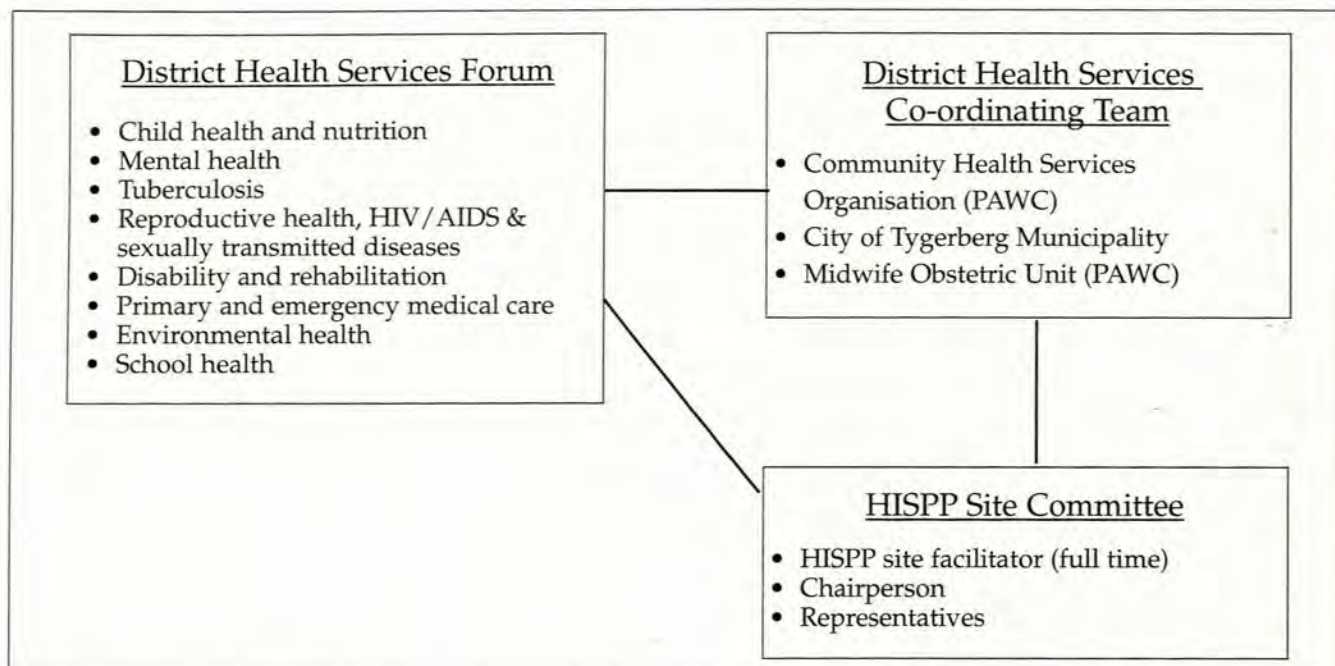


Fig. 1. Structures enabling participation of health workers.

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 Co-ordinating 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 committee and site facilitator played an important role in planning, facilitating, monitoring and documenting the process.

A Community Health and Welfare Forum was also in existence in Khayelitsha and reported to the Khayelitsha Development Forum. The Community Health and Welfare Forum was composed of representatives of local health

committees and attempts were made to involve them in the process. These attempts were largely unsuccessful owing to lack of common ground, the effort already required to co-ordinate the health services and the constantly changing membership of the Community Forum. The lack of common ground between the HISPP process and the Community Forum was characterised by different agendas. The HISPP wanted to focus on health information needs, whereas the Community Forum wanted to deal with broader issues relating to the transition of health services that were not part of the HISPP process. Several members of the Community Forum contributed to the process through their work with local NGOs.

The HISPP began the process of developing a health information system by asking health workers within the district to write an annual report for 1996 using the information that was currently available.<sup>11</sup> Each of the working groups was asked to contribute a report related to their area of interest, and the co-ordinating team was asked to write an overview on the district, health facilities and staff. The 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,<sup>2</sup> 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



**Table I. Problems with the existing health information system**

Data not routinely analysed by or reported back to those who collect them
Data flows to a variety of offices outside the district and are fragmented
A large amount of unnecessary data are collected and not analysed
Some important data are not collected
Data are inaccurate or missing
Data are difficult to interpret as useful information

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.<sup>12</sup> The 'Goals, targets and indicators' approach is spelt out in a training manual by Campbell *et al.*<sup>7</sup> 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.

**Table II. SMART targets**

Attributes of targets	Definition
Specific	Says what has to be achieved in clear and concrete terms
Measurable	Is able to be quantified or easily measured
Appropriate	Fits into local needs, capacities and culture
Realistic	Can be reached with available resources
Time-bound	To be achieved by a certain time

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.<sup>13</sup>

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.<sup>2,6,8</sup> Primary care providers in South Africa do not usually value data and have the perception that it is for 'other people'.<sup>3</sup> 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.<sup>3</sup> 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

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

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

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

Goal: To improve the quality of life of all persons with disability (PWD) in Khayelitsha		
Targets	Numerator data	Denominator data
To ensure that 50% of people with disability have the appropriate assistive device within 3 months	No. of assistive devices issued to people with disability	No. of assistive devices required by people with disability
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	No. of home visits done	No. of patients requiring home visits
To monitor referral rate	No. of referrals to secondary/tertiary institutions	No. of patients seen for rehabilitation
25% of adults registered as disabled to have received micro-enterprise training by June 1999	No. of adults with disability on facility register who had micro-enterprise training	No. of adults on facility register who require micro-enterprise training
20% of adults with disability who underwent micro-enterprise training to be generating their own income by end of 1999	No. of adults with disability on register who underwent micro-enterprise training and who are generating their own income 1 year later	No. of adults with disability on register who attended micro-enterprise training during previous 12 months
To monitor socio-economic status of PWD	No. of PWD who are generating their own income	No. of PWD on register
To ensure equal participation of PWD in decision-making processes concerning disability services in Khayelitsha	No. of PWD attending the disability working group	Total attendance at the working group
To ensure available and accessible transport for PWD by the year 2000	No. of PWD on register who have access to transport	No. of PWD on register



Table V. Structure of minimum dataset

Type of data	Variable	Source	Frequency of reporting
Demographic	Population	Census	Every 5 - 10 years with annual estimation
Mortality	Number of causes of death of children < 1 year	Local authority	Annual
Notifiable diseases	Acute flaccid paralysis	Notification system to local authority	6-monthly
Health Service data	Number of schools with lifeskills training programmes	Schools health services	Annual
Health Service data	Number of smear-positive pulmonary TB patients cured	Health Facility TB Register	Quarterly
Surveys	Prevalence of HIV among antenatal attendees	Department of Health	Annual
Environmental health	Number of households with access to adequate sanitation	Environmental health officer surveys	Annual

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

development. In addition, the lack of an actual health district may lead to parallel data flow, with each organisation insisting on its own individual channels in addition to the integrated HISPP approach. Another limitation of the dataset reflects the theory-practice gap whereby the dataset as defined in theory must be modified in the light of experience through implementation and reflection on its actual use in decision making.

The process of defining the dataset took at least 10 months and is a reflection of the time needed to achieve effective participation and the problem of co-ordinating inputs from a variety of fragmented organisations. This may limit the replicability of this exercise. However, should formal districts be established, this will simplify the number of stakeholders to be consulted and speed up the process.

## CONCLUSION

The minimum dataset was implemented on 1 July 1998. The HISPP has developed a minimum dataset in a participatory 'bottom-up' approach that demonstrates an alternative model for defining health information needs at district level. This participatory process has enabled health workers to appraise critically their own information needs. Following the implementation of the new minimum dataset in the Khayelitsha district, it remains to be seen if the information will lead to improved decision making and planning by local management. The successful implementation of the dataset depends on the establishment of health districts, the development of management capacity and the presence of all components of a functioning health information system.

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