

## Precious Modiba, Lucy Gilson and Helen Schneider

Centre for Health Policy  
University of Witwatersrand



*This chapter presents data from in-depth interviews conducted with 13 people who are HIV positive in Gauteng Province and compared with data obtained from focus groups of public health sector users in other parts of the country. The interviews with HIV positive users sought to establish pathways of health service utilisation and the factors influencing these. The first entry point into the health system of people living with HIV is the hospital, and in Gauteng Province this often involves tertiary or quaternary hospitals. Primary Health Care services are often bypassed in favour of specialist academic clinics and hospitals. Utilisation patterns are influenced by a number of factors. The response of individuals to their HIV positive status is a key factor – for example, in the process of coming to terms with their status, HIV positive people may seek repeated tests in the hope that they were previously incorrect. Although not universal amongst all HIV positive users, several experienced being tested without consent, broken confidentiality with test results being revealed to others, poor pre and post test counselling, and failure of providers to inform users about test results. Those HIV positive users who were satisfied with their initial experience of care, hinted that the quality post-test counselling was a key factor. Good counselling enabled them to come to terms with their diagnosis and to overcome denial. Care was seen as positive when it was experienced as being of good technical quality, and was accompanied by a positive provider attitude, courtesy and confidentiality. By and large positive perceptions were linked to dedicated HIV clinics rather than general clinics. Common negative experiences of care in general clinics were victimisation of HIV positive users, callous treatment from health providers, poor confidentiality, overcrowding, long waiting times, limited hours of service and shortage of drugs. HIV positive users explained the providers' behaviour as lack of appropriate training, poor personal attitudes, and provider hopelessness and helplessness in dealing with HIV/AIDS. Issues common to both data sets included the high value of and trust placed in a service that provides a positive experience; poor provider attitudes linked to poor confidentiality; the importance of provider links with and knowledge of their community as enabling them to be sensitive to users and their circumstances; and the need for uninterrupted access to appropriate essential drugs. Both sets of users indicated their concerns about using public hospitals although they were not asked explicitly about their experiences at this level.*



## Introduction

The interaction between service users and health services is critical to the overall performance of the health system. Levels of user satisfaction, patterns of utilisation, patient compliance and even health outcomes are all influenced by the nature of this interaction. So gathering and listening to the voices of service users is a critical input into efforts to strengthen health service provision.



This chapter presents two sets of service users voices. The first and main set is drawn from a wider study of HIV/AIDS services provided at the primary level in Gauteng Province. In February and March 2001, fourteen HIV positive service users, recruited from NGOs and AIDS support groups, were interviewed individually about their experiences of accessing and using public health facilities. Details of these respondents are provided in Box 1. The second set of voices is drawn from 24 focus group discussions conducted in 1998/99 as part of a wider study that investigated the costs and quality of 19 public and private primary care facilities across four provinces. In this chapter only issues about public services that were raised in these discussions are identified (see Palmer<sup>1</sup> for views on private services). Summary details of the focus groups are provided in Box 2. Interviews were conducted at a place away from the health facilities. HIV positive respondents were identified through NGO networks; focus group participants were recruited from within the communities served by the clinics of focus on the basis of their age, gender and broad socio-economic status.



### **Box 1: Interviews with HIV/AIDS service users\***

- ◆ 14 respondents: 6 male and 8 female
- ◆ Average age 35 years
- ◆ 11 never married
- ◆ On average two children per person
- ◆ 13 had achieved high school education
- ◆ On average each had known about their HIV status for 3.4 years, but this ranged from 6 months to 6 years across the whole group.

\*Study of primary care HIV/AIDS services funded by the Health Systems Trust

### **Box 2: Focus group discussions with primary care service users\*\***

- ◆ 12 groups: 8-12 people per group
- ◆ People recruited in the streets - inclusion criteria were age category, gender (female), not having health insurance and willingness to be interviewed.

\*\*Study entitled: 'New purchaser/provider relationships in primary health care: the desirability of contracts between health authorities and private providers' funded by DFID



The nature of the interviews or discussions was quite informal, based on a guiding list of questions rather than a structured questionnaire. The intention of the interviews was to allow users to describe their own experiences of



accessing and using health services, reflecting on both positive and negative experiences. Interviews with HIV positive service users focused on their experiences of being HIV positive as well as their experiences of using publicly provided HIV/AIDS services. The focus group discussions, in contrast, were focused on primary care more generally and included some consideration of the availability of mechanisms for interaction between communities and health facilities. In both cases, the discussions also raised some issues about public hospital care.

The chapter is structured around the themes, identified by the main sets of experiences raised by the service users themselves.

### Utilisation of health services by HIV/AIDS users

The following table identifies the pathways through the public health system followed by nine of the fourteen HIV/AIDS service users (from whom complete data were available) from the time of their diagnosis to the time of interview.

As the table shows, most (six) service users used hospitals (largely tertiary or quaternary) as their first entry point into the health care system, and four had subsequently visited two more, different hospitals. Three of these four people had been admitted to specialised hospitals for treatment of Tuberculosis (TB) and mental illness. At the time of data collection, six users were attending public primary care clinics, the remainder were well and not in need of treatment. Only two users had been to private doctors during their treatment pathways, and one had attended a traditional healer. Overall, these respondents had, since diagnosis, used a minimum of two and a maximum of eight different service providers in their search for care and assistance.

Half (7) of the service users themselves initiated the action that led to their HIV positive diagnosis. A school pupil, for example, had presented him/herself for an HIV test after participating in a peer counselling programme. The rest, however, decided to have a test because of their own concerns about their health and slow process of recovery from other illnesses. As one respondent who had been admitted to a TB hospital explained:

*“I stayed there for sometime and I realised that I was not getting better. They were not telling me what was wrong with me, but I knew I had TB and I did not know what else I was sick from. So I requested people who came to the hospital to teach us about AIDS, that they should arrange an HIV test for me. I wanted to know where I stand in terms of my health. So they agreed, then I signed with the social worker, the doctor and the doctor’s assistant that they should take my blood for testing. So the doctor took my blood and he told me to wait for the results.”*

**Table 1: Utilisation of health services from time of diagnosis to interview**

User	Facility 1	Facility 2	Facility 3	Facility 4	Facility 5	Facility 6	Facility 7	Facility 8	Year of diagnosis
1	Hospital 1	Clinic	Traditional healer						1996
2	Hospital 1	Hospital 2	TB hospital	Clinic 1	Clinic 2	TB clinic	Clinic 3		2000
3	Hospital 1	TB hospital	Hospital 1	Hospice	TB clinic	PHC clinic			1998
4	Private doctor 1	Private doctor 2	Hospital 1	Private doctor 3	NGO clinic	Hospital 1	Clinic1	Hospice	1995
5	Clinic 1	Different private doctors*	Clinic 2 and hospice*						2000
6	Hospital 1	Psychiatric hospital	Hospital 1	Hospice/ clinic*					1995
7	Hospital 1	HIV clinic							1995
8	Clinic 1	Clinic 2	HIV clinic						1998
9	Hospital 1	Hospital 2							1997

\* Services used concurrently

Among the other seven respondents, four had effectively been persuaded to have an HIV test by medical professionals – for example, whilst attending antenatal care. One person had even been asked to decide whether or not to have a test in the presence of other patients. Two respondents stated that they had neither been asked nor given consent for a test to be conducted, nor had anyone else in their family given consent. As one explained:



*“I collapsed at work when I heard that my wife and I were to separate. When I collapsed I was not sick and there was nothing wrong with me. I think it was issues of stress and that’s when they took my blood for testing before, without getting consent from me. It was when I regained consciousness that I was told I was HIV positive.”*



While twelve of the fourteen interviewees had been asked for their consent before HIV testing, eight maintained that they had not received pre-test counselling.

*“They just asked me if I knew about AIDS. Then I said not exactly, because that is what everybody talks about. Then they asked me why I wanted to do an HIV test. I gave them the reason. They did not do any counselling.”*



Those who had been counselled generally indicated that they were given information on HIV and the meanings of the negative and the positive status.



## Factors influencing Utilisation of Health Services

### Personal responses to HIV positive status

One of the key factors underlying utilisation of health services was clearly the respondents' own responses to their HIV positive diagnosis. Three respondents indicated, for example, that they had presented themselves several times for HIV testing. As one explained:



*"I went for another test because I believed that sometimes it happens that things might change. So when I went to get my results, I found out that my status hadn't changed."*

The service user who had visited most providers since the time of the initial diagnosis also indicated that she had been tested seven times for HIV and had used various health facilities to confirm her HIV status. Such behaviours are presumably linked to the individuals' own, understandable denial, of the diagnosis.



For some people, the initial HIV positive diagnosis was clearly a very difficult thing with which to come to terms. Two people talked about losing their will to live and even contemplating committing suicide after they were diagnosed HIV positive:



*"I felt that I was dead already, because I told myself that OK, it was the end of the world. I will no longer live like a human being. Those are the things that were happening to me at the time."*

Another said that he became very angry towards women because he understood that his wife had infected him. A fourth said that she used to get drunk as a means of ignoring and forgetting the diagnosis.



Others were more accepting of their situation and themselves. Some responded to their diagnosis by getting involved in activities that could empower themselves and the wider HIV positive community.



*"I extended my hand to TAC and the AIDS Consortium and NAPWA. Since then I never looked back. I have known many people who some I still meet even today."*

All respondents had disclosed their status to their families. For one the shock of being diagnosed HIV positive had only been made worse by his/her family's responses.

*"My aunt used to say, there is AIDS. If it happens that someone in this house goes to the hospital or clinic to do an HIV test and that person is positive she will kick him or her out of the house. She chased me away after she found out."*

However, all service users interviewed belonged to a support group. Such groups were seen, at a minimum, as a way of preventing boredom. More





positively, they were also seen as important because they provided material support such as clothes and food, as well as emotional support that helps people to cope.

*“The group helps and we share ways of coping, how to be confident about yourself, we talk about various ways the HIV virus is contracted so that people could know how to cope with this disease.”*



Support groups had even provided some service users with a base from which to conduct HIV/AIDS education activities in the wider community. Those who had become activists often seemed able to draw on wider networks of support than others:

*“I get support from my family, friends, and neighbours, the PWAs support group, schools, teachers, churches. Yes I have strong support and a lot of support. There is a shop owner who is providing me with groceries every month. Sometimes if I need sort of cash, she gives me. Then I do whatever I need to do, I appreciate. Then there is a doctor she is assisting during test, even to the extent that if I need medication she can buy it for me.”*



#### Initial experiences of care

A second important factor underlying service users’ utilisation of health services is their initial experience of care. In addition to whether they are consulted about the first test, three key issues of concern to users are:

- ◆ Whether they are told their test results
- ◆ The confidentiality with which their test results are treated
- ◆ The nature of the counselling they receive at the time of their test.



Several interviewees indicated that they were not told the result of their HIV test when returning to the facility to collect it. Consequently, they had gone on to visit several facilities in order to get a final diagnosis.

Three of the respondents clearly felt undermined by the behaviour of the health professionals they met at the time of their first test. One of those tested without consent, commented:



*“And when I looked around every member of the ward knew about my HIV status. Really it was not good at that time. Even now, you see, when a person knows something about you, you can see his or her reaction from the beginning. Yes, the way they look at you, you see, you know these things and then obviously, he will ask you so many things, you will end up running from people.”*



Finally, the majority of service users had been given post-test counselling. Its importance in enabling people to come to terms with their diagnosis was indicated by those who were satisfied with the counselling they had received. They indicated that the counselling was critical in helping them cope and in

enabling them to overcome denial. One respondent described the importance of his relationship with his post-test counsellor:

*“The counsellor was good, I still had that denial. I could not agree with all the things and it was difficult to be in the position the counsellor was expecting me to be in. It took me three months because the counsellor had patience. She made follow-ups and she encouraged me in many things, she arranged courses for me to attend, like counselling course, basic HIV/AIDS course. So when I did the course my relationship with my counsellor was so good because she encouraged me in many things.”*

However, counselling experiences were more often rather negative. Explaining her dissatisfaction with counselling and the communication around her test, one interviewee said:

*“The doctor called me to his room, and he told me the results, he was with a nursing sister, he did not tell me that I was HIV positive, he told me that I had AIDS and that I was going to die, just like that and then after I was shocked and I did not want to answer him – he told me that there was no cure for AIDS.”*

#### Positive experiences of care

Perceptions of the care received after the initial interaction with the health system continued to influence patterns of health care use. Those who had positive experiences of a particular facility were, therefore, continuing to make use of it because they had been given treatment and care that met their expectations.

*“It is better, I am lucky, because I haven’t got that sick, because I go to the clinics. At least at the clinic where I go for treatment, I can say its better because they have patience for people, they try very hard, they don’t talk without paying attention.”*

As Box 3 indicates, the positive attitudes and approach of providers was seen to be a very important element of well-perceived care. Two people felt that they were treated well because their health providers had received specific HIV/AIDS training. Another valued the courtesy and confidentiality of her current clinic, having been subjected to considerable harassment at the clinic she had previously visited. Some were, finally, happy just to be able to get appropriate medication. Unfortunately, many of the positive accounts related to experiences in dedicated HIV clinics, rather than general clinic services.



### Box 3: Positive experiences of services

*“The doctors there [at the HIV clinic] are, they give support. It is the doctors with HIV training. They know everything. If you’ve got this they will give the right medicine, if you’ve got anything they will give you a right tablet for that.”*

*“She tries by all means to do whatever, because others don’t give you injection they just say I will give you...”*



*“When I first went to see her she tried by all means, for me to get injections, tablets and became alright. So now I am all right. When it is coming to going to these other clinics, even if I have headache, a very bad one I won’t go to them, I will go to this doctor. I saw that she has a lot of patience. Lets say she knows that one needs to understand a sick person. So she tried in the way she knows.”*



*“The [HIV] clinic is right because everybody feels free. Everything is confidential. Doctors treat patients equally. There is no such a thing that you the best and you not the best. Everybody feels free because sometimes they offer lunch to the patients and their treatment is right. They make sure when you leave you are right and satisfied about the treatment.”*

*“I haven’t experienced any problems because when I go there they give tablets.”*




### Negative experiences of care

Although service users reported positive experiences, negative experiences were more commonly identified. Health care providers were often seen to victimise HIV positive people and to treat them callously. Service users reported that they often disclosed their HIV positive status to health providers in order to get appropriate medical treatment but only ended up being blamed. As Box 4 indicates, such attitudes only contribute to the despair some feel on hearing their diagnosis. It was also said that nurses frequently accused people living with AIDS as being: *“always sick”* and patients were often told: *“you will be like this forever... But I asked isn’t there something we could get from the clinics?”* Overall, the perception of service users was that health providers in clinics: *“...don’t care about people. They are not quick in providing treatment no matter how sick a person is.”*





**Box 4: Callous attitudes**


*"I found a certain doctor. He asked me what was wrong and I told him that I was not shocked or had a headache or something, may (be) it was the symptoms because I was HIV positive. He said to me I am going to die a terrible death. I have sinned. I have to pray to God for forgiveness because I was sleeping around. I was very angry because I did not expect that from a doctor, a professional doctor, how can? I am expecting that when I see him I should see life. I mean I am depending on the doctor, not to swear at me. Then I went to the matron. Actually I went to see a certain Sister who is the friend to the sister I usually see when I come to the clinic. The two of them give right treatment. Then I went to her and she said, no its wrong, how about you go to the matron. I knew each and every right of HIV positive people. I thought I could take the story to the newspapers and I will make this doctor's life very miserable right now. Because there is no person who deserves to be HIV positive and there is no person who is suited to be HIV positive. So she said I should speak to the matron first. Then I went to the matron and we then went to that doctor, when we confronted the doctor, he denied. He said he was talking to me as a father and then I said to him as your real daughter I did not expect that from you. How do you expect me to feel when you tell me that I am going to die? I don't want you to tell me that ... even though I am going to die, I want you to tell me that I am going to live."*

Service users also reported poor confidentiality as being part of the negative attitudes of health care workers towards HIV positive patients. Three service users talked explicitly about confidentiality being broken when they visited clinics and hospitals for treatment. One described how nurses gossiped about her because she was HIV positive and felt that their behaviour had been abusive.

*"When you go to the clinic, you will see Sisters nudging at each other talking about you. They speak with their eyes. So that is abusive."*

Another explained how consultations are conducted without privacy:

*"... while the door is open, knowing that it is not okay. Knowing very well that the door should be closed during consultation."*

A third related how, on admittance to hospital, a nurse read her clinical notes and discovering that she was HIV positive, shouted: *"Shoo! You HIV positive AIDS."* in the presence of other people. The same person clearly expressed the need for confidentiality.

*"What if I don't want my status to be known? What if one of my neighbours was admitted at the hospital and was listening?"*

Other problems identified included: overcrowding in clinics, long waiting times, limited hours of service, and, a very common complaint, lack of drugs:



*“Here everyday sometimes they don’t give us tablets, they just tell us that they are finished. They tell us that we should go to the other clinics.”*

Such problems sometimes generated horror stories. For example:

*“I won’t count how many people died at \_\_\_\_\_ hospital. When I was admitted there, I used to see people dying because there is a shortage of tablets.”*



Criticisms of hospital care were particularly strong and included long waiting times, poor facilities (such as clothing) and poor treatment (Box 5).

**Box 5: Negative experience of hospital care**

*“There is a patient who also attends here. He was in ward 16 and he was treated badly and we were even considering suing that Sister. That patient was made to sleep in the bed with a plastic, there were no sheets, he was not even given a blanket to sleep with. He had to bring his own blanket. He was weak and had diarrhoea. His wife came to the hospital everyday to wash and feed him. He could not even walk, he could not get medical treatment because he could not walk. He was not able (to) stand up and fetch the treatment. That Sister did not want other patients to help him, he could not eat, he spent three days without food. His food was put on the trolley, they told him to get up and get the food. He could not walk, not that he did not want, he couldn’t walk. No one had time for him, maybe because he is HIV positive. His wife was helping him. We got a complaint from her. She told us that she found her husband sleeping in a messy bed. She was with their two children and the very same sister said to her you should not touch that child you will infect her. Imagine just because she touched someone who is HIV positive, meaning that you will infect the child with the virus.”*



**Explaining experiences of care**

Training and personal attitudes were the main factors identified by service users as explaining positive health care provider behaviour. Being HIV positive was also seen as supporting better behaviour. An AIDS activist also noted that people living with HIV/AIDS could encourage better attitudes.

*“So we need to teach them and to do so is to involve them. We can do something, mm like changing attitudes, to do this I feel if they can work with somebody who is open, during their spare time, that person can play a bigger role. So if the government can employ someone who is positive in each clinic and every clinic, then this could take us somewhere. For this issue of virus and other issues because we are trained not only for HIV or AIDS.”*





More generally, however, health care providers' behaviour was seen to reflect a sense of helplessness and hopelessness about how to deal with HIV/AIDS (Box 6). Several service users thought that nurses attitudes were because they feared contracting HIV themselves or because they perceived themselves as not being in danger of contracting HIV.



*"They are so ignorant, they say it will never happen to them. Many of the nurses become volunteers in Hospices for HIV/AIDS people, they should know that anybody can be HIV positive. They think because they are nurses it will never happen."*

At the same time, service users recognise that their own behaviour may exacerbate poor attitudes.



*"You find that sometimes we are wrong. Sometimes we need to change our attitude because now we are aware that the nurses are not right and we also have an attitude. We don't treat people right. We don't treat nurses right. Sometimes you find a good nurse and you find that our attitude towards that nurse is not right. That is not right."*

Other less frequently identified factors were the high levels of utilisation and overcrowding in some clinics.

**Box 6: The hopelessness of service providers**



*"Because you see the message is the same, there is no medication [referring to the anti- AIDS drugs]. Even now if you can go to the local clinic more especially.. they will tell you that, hey... there are Sisters I know who tell their clients that even the immune booster won't help you."*



*"Last time when I was admitted at \_\_\_\_\_, I had short breath. So the nurses looked at the doctor and they said we are tired of you, you know that there is no cure for AIDS."*



Nurses usually question HIV positive patients presenting at the clinics for treatment, asking them *"What must we do? There is nothing we can do."*

**Comparing issues raised by both groups of users**

Table 2 compares the key issues raised by the HIV positive service users with those identified by the broader set of primary care users.

In both sets of voices, views and experiences clearly vary. Some people have positive experiences and value the care provided to them. For example, in the second set of voices, one small rural clinic was broadly well perceived by all interviewed:



*"They are very good and friendly. They try everything in their power to help you."*

Similarly, despite the negative attitudes of many staff in a large and busy health centre in an urban area, users clearly appreciated it.

*"So although it is overcrowded, it is right for the community of xx, and the treatment is good as well, even though the nurses harass us sometimes."*



However, poor attitudes were identified as a common problem – and were seen as reflected in poor confidentiality as well as the provision of what is perceived as poor care. Even in the second set of voices it is clear that poor attitudes may reflect health care providers' views of particular groups of patients – not only those who are HIV positive, but also young women attending pregnancy or maternity services, or foreigners.

*"It was in 1997, I was going to have a baby and I had an infection. I will never forget the way that nurse treated me ... Because she was treating me with disrespect, I don't know whether it was because I had an infection so she thought maybe my husband was a womaniser, she was so rude."*



*"The nurses tell everybody who are the people that comes for contraception, so the young girls don't want to come for birth control."*



In this second set of voices, positive provider attitudes were sometimes identified as being a function of the provider's connections with, and knowledge of, their local community – allowing them to have sensitivity to users and their circumstances. In contrast, explanations for negative provider attitudes in the second set of voices not only include workloads but also some hints that primary care providers react defensively to what they perceive as a loss of status in the eyes of the users.

Drug shortages were commonly raised in both sets of interviews. But they were even more strongly identified as a problem among general primary care service users. This problem appears to reflect actual experiences of being denied drugs, as well as user perceptions of the 'weakness' of the drugs provided through the Essential Drugs List.



*"But every time they give you the same stuff ... they give you xx because they can't get stronger pain tablets."*

*"They just give you those cheap tablets and medicine."*



*"When you drink their medicine, it's not like medicine, it's just water. It's weak."*

Finally, although neither set of users were explicitly asked to comment on public hospital services, both sets of voices raised concerns about their treatment at this level. These concerns suggest that the problems experienced





within hospitals are considerable and are felt more acutely than those experienced at primary care level.

*“Like my uncle was once there and I noticed his drip was not working. When I went to the nurse she said if I want to be a nurse I must take the clothes that she is wearing and wear them and go and help my uncle.”*



*“They expect you to wake them up if you are in pain.”*

Perhaps this is not surprising given the greater level of vulnerability likely to be experienced in receiving any form of in-patient care and the greater level of de-personalisation possible within a larger organisation.



**Table 2: Summary of user voices from two surveys**

HIV positive users	General primary care users
<b>(1) Overall views</b>	
Variable across clinics, generally poor view of hospital when mentioned	Variable across primary care clinics Poor attitudes sometimes offset by other positives
	Generally poor for hospitals, but not primary focus of interviews
<b>(2) Positive experiences</b>	
Positive attitudes	Some staff have caring attitudes, willingness to listen: linked to good competence
Positive experiences of post-test counselling	
Adequate drug availability	
	Positive views on competence in some clinics
<b>(3) Negative experiences</b>	
Forced testing	
No pre-counselling	
Problems with post-test counselling	
Poor confidentiality	Problem, but not everywhere; mention of poor confidentiality re HIV status
Negative interactions with staff (victim blaming, responses to disclosure)	Lots on clinics – uncaring attitudes, failure to listen Generally negative attitudes in hospitals reported
Limited service availability (time)	
	Competence of providers seen as limited in some clinics, sometimes also seen as a function of attitudes, sometimes as directly linked to preference for doctors over nurses
	Fairness of hospitals generally seen as poor
Drug availability problems	Big problem: drugs limited and weak
<b>(4) Explanations of providers' negative behaviours</b>	
Workloads/high use	Sometimes raised
Helplessness as response to HIV	
Ignorance/lack of education	
Fearless for themselves	
Users are demanding	Users are demanding raised as an issue
	Defensive responses to criticism reflect feelings of loss of status?
	That care is free sometimes raised as explanation for clinic performance
<b>(5) Explanations of providers' positive behaviour</b>	
Have had appropriate training	
	Local knowledge of staff – know their patients

Note: empty cell in table means issue not raised in interview/discussion

## Conclusions



As can be expected, users want a health service that treats them promptly and with courtesy, listens to and assesses their problems competently and thoroughly, and provides them with appropriate treatment. From the interviews, it is clear that users will try out the different services available to them, until they find the one that best matches these expectations. In places where choices are limited (e.g. rural areas), people may simply carry on going to the same facility until they receive some sort of satisfaction. In the case of people with HIV, the process of coming to terms with being HIV positive may itself involve multiple visits to different facilities. These various patterns of service utilisation may, however, not correspond to the most efficient use of resources - dissatisfaction with a service may lead to increased and less rational forms of utilisation. Thus meeting the needs of users is not only a good in itself, but also has implications for efficiency.

A negative reception and poor attitudes of staff severely undermine people's trust in a service. Many users, especially people with HIV, feel that they are simply not wanted at health facilities and that their privacy and anonymity are at risk. In Gauteng Province, people with HIV have thus naturally migrated to the specialist HIV clinics, where both the human and technical quality of care are perceived to be better. While respect for consent procedures is apparent in Primary Health Care settings, many health workers still do not know how to provide adequate post-test counselling, and often convey the impression that nothing can be done about HIV. If Primary Health Care services are to play a meaningful role in AIDS care and support, there needs to be a re-orientation of the approach to people with HIV. Such an approach would be similar to the management of other chronic diseases: ensuring continuity of care, a comprehensive approach to 'wellness' management, early identification and treatment of opportunistic infections, adequate referral arrangements, both to community support structures and to hospitals, and the provision of palliative care.

Where clinic services are experienced positively users will willingly attend these services. The category of professional (nurse or doctor) appears to matter less than the quality of the attention given to patient needs. The increased presence of trained counsellors (including lay counsellors) and HIV support groups linked to Primary Health Care facilities was seen as very important. This infrastructure could be of value in managing other health problems, such as mental illness and violence against women.

Medicines clearly play a significant role in user perceptions of care. The unavailability of drugs fundamentally devalues the service in the eyes of users. Patients may also perceive certain public sector drugs to be of lesser value than privately obtained drugs. The demand for particular medicines, and sometimes, injections may undermine rational drug use by health care providers and is a tension that needs to be managed through adequate communication with patients.



Reducing waiting times through better queue management would address another key need of public sector users.

Finally, in both surveys, respondents expressed great concern about the amenities and professionalism of staff in public hospitals. Thus, the quality of a Primary Health Care service is not seen as separate from the quality of hospital care. Hospitals represent moments of greater patient vulnerability and places where catastrophic, life-threatening illnesses are dealt with. Good quality hospital care is therefore more important for users than Primary Health Care.



### Reference

- 1 Palmer N. Patient choice of primary care provider. Chapter 8 in: Crisp N and Ntuli A (eds). South African Health Review 1999. Durban: Health Systems Trust; 1999.

