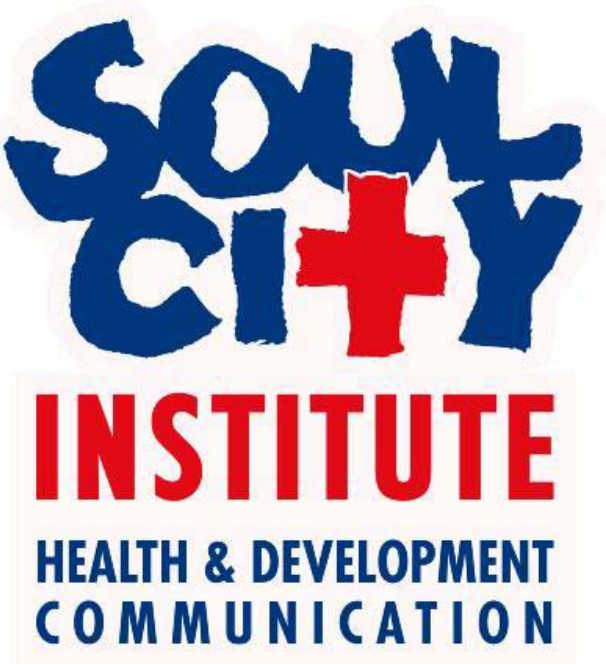
SOUL CITY 7



MESSAGE BRIEF

CONTENT

VOLUNTEERING AND COMMUNITY SERVICE

MESSAGES

1) SERVICE CAN BRING ALL SECTORS OF THE SOCIETY TO IDENTIFY AND ACT ON THEIR SOCIAL NEEDS. EVERBODY HAS SOMETHING TO CONTRIBUTE.

   Underlying Messages:

   - Each of us has some strengths and skills to offer.
   - Working for the community is working for yourself. A healthy society benefits everyone.
   - Young and old should work together to meet communities' social needs.
   - Respect and recognise the contribution of volunteers.

2) SERVICE IS NOT WOMEN'S WORK. EVERYONE CAN WORK TOGETHER TO BETTER THEIR COMMUNITIES.

   Underlying Messages:

   - Men are no less men when they do volunteer work.
   - Volunteering is another way men can provide for their families. Children learn from the behaviour of parents. You will be giving them a good example when you do volunteer work.
   - Society needs men to help in volunteering.

3) VOLUNTEERS NEED TO BE TRAINED, SUPPORTED AND MENTORED TO PROVIDE QUALITY SERVICE.

Volunteers are also in need. In many cases they face the same problems of those they serve. As volunteers they may also face barriers such as hostility from professionals who fear that they want to take over their jobs. They also experience cultural barriers, for example, a young female carer may in some cultures, not allowed to help an older man with bathing.

Underlying Message:

- Resources are necessary to enable people to serve. For example, transport, food, counselling and other support services.

4. STUDENTS LEARN MORE WHEN THEY PARTICIPATE IN SERVICE LEARNING.

Underlying messages:
Students learn to positively working in groups
Students form new relationships and challenge their way of thinking
Service learning helps students realise a South African identity
Service learning can helps students develop a sense of social awareness and civic responsibility.
Service learning equips students with leadership skills.

BACKGROUND

The United Nations International Year of the Volunteer in 2001 sparked renewed interest in voluntary service in South Africa. It led to President Thabo Mbeki's declaration of 2002 as the **National Year of Volunteering** and the launch of the **Vuku'zenzele** or **Letsema Campaign**. This campaign has highlighted the important work of volunteers and has stimulated a revival of the culture of community care. The Department of Social Development has also committed itself to the development of National Policy for Volunteering. Volunteer South Africa was tasked with driving the National Year of Volunteering and is promoting volunteerism through the African Union, NEPAD and SADC.

A wide variety of service programmes have been in operation for some time in South Africa, and continue to proliferate. A feature of service in South Africa is that the programmes tend to be 'bottom-up', driven by the initiating organisations, institutions and agencies, and responding to specific needs. The vast majority of South African service programmes are voluntary.

Defining Service: While there are a range of definitions, here is a useful starting point:

"Civic service is an organized period of substantial engagement and contribution to the local, national, or world community, recognized and valued by society, with minimal monetary compensation to the participant."
- Global Service Institute

TYPES OF VOLUNTEERING AROUND THE GLOBE

- **Cultural and traditional practices** of community solidarity and support networks. Sometimes called "informal volunteering". We choose not to call it this, as it tends to infer and inferior status on this, the bedrock of all volunteering activity.
    - Neighbours helping struggling neighbours
    - Taking care of sick relatives

- **Service [Formal] Volunteering** – or structured and organized volunteer programmes as run by NGO's, institutions and government.
    - Happens in a formal framework
    - Tangible
- **Governance and Participation** as reflected in committee work, etc., community forums – generally this kind of volunteering is dominated by men hence we see gender stereotyping in volunteering as well.
    - Management of organizations
- **Activism:** This more strident, "aggressive" kind of volunteering sees itself as rooting out the **causes** of social problems and not merely dealing with **symptoms**. A fine example of activism is our own struggle for liberation. The tradition lives on today in campaigns like the Treatment Action Campaign (TAC).
    - People addressing needs of society by addressing questions such as
        - Why are people poor
        - Why are people struggling

These types of volunteering overlap and compliment each other.

SCALE AND IMPACT OF VOLUNTEERING AND SERVICE IN SA

- Nearly 1.5 million volunteers contributed to SA non-profits in 1999
- Their contribution was equivalent to 316 991 full-time jobs with a value of R5.1 bn.
- Volunteer labour accounted for 49% of the non-profit workforce.
- Who benefited? Impact on students; made services available to vulnerable communities; had impact on higher education curricula.

REASONS AND BENEFITS FOR DOING SERVICE

Soul City conducted focus group research with target audiences to determine what communities know and understand about volunteerism and community service. Some of the focus groups were held with groups of people who had participated in community service.

There were many reasons for doing service, most of them related to people seeing a need and wanting to do something about the need. The need seen in the communities often felt overwhelming to the people who were involved in volunteering. Others wanted to keep themselves occupied, and still others are motivated by wanting to use service as a stepping stone to employment, finally some people had experienced a problem or issue within their family and wanted to help other people deal with the problem.

- Wanting to help

> "Mhh what I think about volunteerism and why do I volunteer is because there are needy services who cannot reach health services like the clinic and they stay far in a

way that they do not have taxi fare so, as one sister has said about home visits I am interested in doing home visits for those sick people"

"For instance there could be a group of people who help to look after sick people who are bedridden at home, especially since as we no longer have a clinic nearby, they could deliver medicines to their homes, that could be a good thing and it would show our dedication to the community."

- Give back to the community

It is actually what the spirit of voluntarism is all about, where you don't expect to benefit financially, but want to develop you own community.

What comes to my mind is that you know as an individual, I know that the community helped me, which has been there. A community, which has actually contributed towards my education looking in terms of percentage-wise, what the state pays for us and what do we pay. We know that doctors are highly subsidised and the community-they've been paying taxes throughout so, they have played a very important part in our education and to be honest I felt good about community service. We are actually ploughing into the community because they contributed so much to our education.

I used not to care about anybody except myself. I was a criminal killing people. I went to jail and it was there that I came to my senses about life itself. I wanted to pay back to the community, to be a member of the society. I had to be involved in community projects.

- Building or assisting the nation

Nowadays we have to look into what contributions we can make to build our communities.

It is a way of sharing and building community

- Having the skills and wanting to use them
- Seeing the need
- Wanted to be useful
- Extend services

Yes, what made me volunteer was so that I could speed the process of the people who sit here the whole day in the clinic and (pause) because in most cases you find that you come to the clinic, let me say you have come for flu and then you spend the whole day because there are only two nurses working. They also have to take blood pressure and all those wonders and then I mean (shyly giggles) they are also human beings so, that is the reason

To volunteer, I volunteered because I wanted to offer my services to help my community and then because you find that in the clinic the nurses cannot do home visits. There are others who are terminally ill and then they need someone who can accompany them home so, that the person can help them, bathe them. So, the nurses cannot assist them because they are in the clinic full time. They cannot go out and check them so, that is why I volunteered so, that I may assist those who need my help and so, that the service can be better. That is why I volunteered my services

- Moved to act

- Personal/ family experience

  Okay the reason why I became involved in the disability project is because of my sibling. She became disabled and then I noticed that I do not understand what isgoing on. Why is my sibling like that? So, I became interested in knowing what exactly is disability and I wanted to be involved in disability project because I noticed that there is a disabled child at home so, I do not understand her. So, I joined to understand what is really going on about disability. So, when I had already joined I realised that it is becoming more interesting then I continued with disability and I found that disability is broad.

- Expectations of employment.
  - In general these were partial motivators and the people doing service didn't immediately expect employment, though they felt that it should be a long term outcome
  - Most people found that volunteering had benefits to themselves, they felt uplifted, there were spiritual benefits, they had a number of good experiences, and found the successful projects or work satisfying.

- Uplifting

  It's good to be a volunteer. It's like those people who give their time to look after the sick and old people, they don't expect any remuneration. They do it just for the love of it. Some of them will never end up becoming nurses or getting jobs in hospital, they are just good-hearted people who want to help.

- Good experience

  You definitely won't get money but you will gain experience. You will also know how to relate with people. You will be doing a lot of consulting and in the end you will be able to deal with people's emotions, problem-solving etc. In the end you will know how to co-ordinate. A person needs to be involved, although there are a lot of theories but the practical side counts more.

- Learn about people, many things, AIDS

  Because of exposure, I managed to ask the principal of my children's school to allow us not to pay school fees. I was the first one at the school to ask for such a concession and many parents followed after that. I found out that the government subsidises those families who have no income. Volunteering has benefits.

  I noticed that in volunteering I am now aware of the things that I did not know. I can understand so, that even if someone had to fall on the streets one day I will know how to help that person.

  I would recommend people to come and do the voluntary work because in these jobs you are able to identify the problems you didn't know before. Is about I\finding out about yourself. You need to know more about people living in your neighbourhood.

- Help with getting a job later

  Yes, as you've already said, people expect to be employed after volunteering. The feeling is that they should be given first preference. That is why I feel they need to be taught, they need to understand what community service is all about. The important thing is that the person who volunteers must understand the purpose they are going to serve by volunteering. If they are not informed, there will be expectations. They definitely expect employment. Presently those that have volunteered, they have expectations.

- Keep busy
- Instead of crime / drinking
- Improve mental health
- Satisfaction
- Recognition
- Spiritual benefits

CHALLENGES OF VOLUNTEERING

1) Unemployment

Unemployment came up in two ways. Firstly it is difficult to volunteer if you are unemployed as you need to earn money to put food on the table. It is hard to work if you are hungry, you don't have money for transport. You need to provide for your family so you need to be looking for a job. Some people mentioned that it would be easier if food parcels were provided or a small stipend or other incentives.

> *Volunteerism is good and definitely has benefits but unfortunately our immediate need is money to be able to put food on the table.*
> *It's O.K. It's just that sometimes it is difficult- especially if there is no food at home. My children are still young and don't understand when there is no bread for lunch. They believe that I have gone to work and are expecting me to bring something. I started four months ago and I have not earned anything yet. It was nice when I started but now I am merely dragging myself there.*

The second way it was related to unemployment was as an avenue for employment, many people felt that volunteering should lead to employment or at least if the experience was recognised that could help people with employment later.

> *The government is presently trying to encourage people to volunteer their service as a way to create employment. If this is raised by a leader, for example, the president, a minister or a community leader you will find that people will respond to the call, but they will have expectations, although those expectations are about employment.*

They have expectations that they should volunteer for a certain period, after which they will be liable to be employed or compensate in some way or another.

The way I understand volunteerism, it's when you offer your services or skills to a firm and with the knowledge that after sometime you will be given a permanent post. This is usually done by those who have no financial problems. To volunteer without any benefits is futile. People who volunteer do it with the hope of being employed at a later stage.

The government is also not helping the situation in the sense that, for instance, especially in parastatals, they encourage people to volunteer their services and then eventually they are told not to expect anything in return. This creates problems. If people are expected to volunteer their services and not get anything in the end, it's a problem

2) Some of the work is psychologically difficult

You get psychologically traumatised because let me give an example maybe she is has AIDS (points to one of the participants) and I have to take care of her and I know her as my best friend (claps his fingers to emphasize his point) it will also be hard to cope

3) Sometimes the volunteers are not treated with respect, this complaint especially related to formal workers like nurses and police

What would discourage me is abuse from senior staff because if you are a volunteer you are nothing in their eyes. They can do whatever they want, they can send you around, to the shops, you can clean their shoes etc. It's true people are being abused simply because they are volunteers

People don't know how to talk to you; they're too rude and expect too much.

They need moral support because if I work for the community and I don't get any support, I will not be motivated to continue. I do not have to suffer alone. I need moral support from family, next of kind, friends and the community as a whole. The other thing is respect. People who do community service should be respected.

4) Lack of Supervision

Doctors in South Africa have compulsory community service after graduating and after their internship. During the focus group conducted with doctors doing community service, many felt that the service was imposed on them, and they felt bitter about this. Partly because they felt they were earning very little money and they need to repay their loans (this also partly justified the fact that some people are doing locums for private GP's to make money while they should be doing their community service.)

- Many resented being far from home

Oh like when I got my letter I was like before I even opened it to find out where I'm going I thought am never gonna see my family next year because last year I didn't you know like where am I gonna be, am I gonna make new friends like it's so difficult because you whole life is ripped out of where you are

- In some areas there are poor working conditions

  Like yesterday we didn't have drip sets and we had to….

- In some areas there are also poor living conditions

  and I don't personally stay in the doctors' quarters but, the stories I've heard about it is that it's not a pleasant place to stay and I mean if you've heard a frustrating day at the hospital you want somewhere nice to go and sleep (others laugh) you know, to rest and I mean given quarters like that obviously people are gonna recent doing it and it's gonna affect their performance

- However there was also a feeling by some that they want to give back to community and repay the community as they realise that medical training is expensive.

- Inadequate supervision

  It's not that we are saying we don't want to serve those communities but, you still feel like a junior doctor because there is a lot of things that you need to know that you need supervision on, you need to find someone you can trust. At 03h00 when this patient has collapsed and you have tried everything that you know, that you can do and there is nothing else and because at the end you are the one that's supposed to be responsible and sometimes that is a huge task for a new young doctor to take and that is what they are saying that "I don't mind going into those communities but, I feel, I feel

- The doctors felt ill treated by the hospital staff " and feel "like a doormat." They expressed that their own feelings had been disregarded and thought that the service should be voluntary.

  I think I understand their point to some extend that a, it shouldn't be like imposed on us, there should be some kind of voluntary because it doesn't matter how you think about community service at the end of the day uhhh, if you are forced to something you will find people who are loitering, who are not working because they feel "I shouldn't be here", it doesn't matter what the good intentions are for doing community service you will find people uhh, uhhh you know we are popular –the community service doctors for doing low-comes for instance.

5) Gender

- Volunteering was sometimes seen as women's work – men have to provide for their families and put food on the table.

  I agree. However, I do not understand. Yes, a woman has to be different from a man. A woman expects her husband to provide for the family. Your wife might appear to understand your position but when she wants to buy sugar, she will ask for money from you, when she needs two rand she asks you and yet she knows that you are unemployed. In the morning, she asks for bread money from you. Where is the money? She saw that around home all day and yet she asks for money from you. When you have a piece job, you bring the money home, but when you are around, where do you find money? When you can't provide you feel for your children and you almost lose your mind and one day the heart will stop.

  The second point is that it's difficult for a man who is unemployed to be a volunteer. It is not easy because we (men) see providing for the family as a priority. However,

if my wife was employed there would be some money at home and I could keep myself busy buy volunteering, helping to build our community

- Also seen as an extension of "women's behaviour – such as helping with catering at weddings/ funerals etc…

- Men less resilient than women

I want to add that men are not as resilient as women are. Many men have been retrenched from their jobs. They depended on the mine for their livelihood. When the mine closed down some of them lost their minds or developed mental problems ('bakhubazeka encqondweni'), some are sick, and others have died from heart failure because they could not accept that they won't be employed anymore. They could not accept that they have been retrenched. Some still have young children who are still at school and did not know how they would survive. Some have left their homes to look for employment far away from home and this something that they were not used to. The mine was nearby and they came home daily. Therefore, the men in this community are depressed. If there were workshops to help our men to gather their minds again, to keep them busy and make them accept the situation they are in, it would help. I think that would make them strong, men are not strong. I feel the pain too and I know how it feels like to lose your job, I lost mine too, but I have accepted it and I wish our men could do the same. There are some projects in the community but the men do not accept them. There is no money yet. With projects, you have to work for a long time before you earn and most men will not accept that. That is why many of them have left for far away places to seek employment and leave their "abantwana") children) (Used to mean family- in black terms the wife is grouped with the children as a dependent of the man.)

What Servers/ Volunteers Need

People involved felt that one of the most important things that they needed was respect and recognition for the work that they do. They also felt the need for the experience that they have gained through volunteering to be recognised as they believe that this will help them in the job market in the future. They also need training, incentives and or food parcels (as mentioned before) as they are often hungry and have no income. In order to increase the amount of people volunteering people felt that government should start projects and create structures to enable more volunteering.

- Most people felt that in order to get volunteering going people needed more information or knowledge about volunteering. They also need more money to start projects.

People should be in position to visit centres where they can obtain knowledge about community service so that they can know that help can be available to communities. People need to know that they need to do something in order to help themselves.

I am looking at the issue of information. If people are informed, then they can make decisions. Someone spoke about a centre where people could be taught, meaning that each and every resident or community member must be able to see where the community is lacking, whether specialised community care is required or not, the correct qualifications for certain tasks. If this is taken care of, I believe people will be able to avail themselves and volunteer whatever they know like the government expects us to do. I think it should go on like that, even at our schools, they should

encourage that so that things like poverty do not exist because people will be able to identify gaps that need to be filled. By doing so we would not only fulfilling our physical needs but also our spiritual needs. Some people look physically healthy but they want spiritual needs. It should be a give and take situation.

- Another theme was that of mobilisation, that people could and should take action together

Some of us do not know how to go about starting projects, we don't have the necessary qualifications, people are waiting for the government to do something, it doesn't happen like that. I was thinking let's say for instance 20 people can get together, people with teaching degrees, they can find office space and build a school and start teaching children. We can teach these children for a certain period with no salary and then after that start charging. If we run short of materials, we can ask the government for help. This will create employment, the school can grow and some of unemployed teachers will ultimately have a job.

- And that people need leadership

All of us can do community service but the most important is people with a vision. A person should be able to take us from a place of being disadvantaged. Most of us don't know how to do that. From there on we would know how to go about developing our community.

- Treat with respect

They have to treat us with respect, say we happy to be with you, we want you to be here, we want to be on good terms with you (others agree), we want to be your friend we don't want to treat you like the rubbish people at the bottom (others agree)

Elsewhere they shut the door on you and ask who told you that there was a patient at their place, you see what it is like (others agree)

Health Equity

MESSAGES

The community has a right to elect a clinic committee to represent them and their needs. It is the law.

Underlying messages

- Work together with your community to make sure that your clinic elects a committee.
- Get involved in community activities. This will make sure that your clinic committee represents your needs

Most health care workers want to provide a good service to their patients. The conditions they work under prevent them from doing so.

Underlying messages

- The community can work together with the healthcare workers for changes in the health services.
- The community can volunteer to help the healthcare workers with some services to improve the quality of care that the patients receive. For example; volunteers who care for the sick at home; volunteers who offer counselling before and after taking an HIV TEST, volunteers who clean the hospital or provide security etc.

Corruption and crime affects us all. It increases the inequities in health care provision. We must all work together to stop it.

Underlying messages

- Be vigilant! Work together with your community on how you will respond to thefts of medicines, furniture, cutlery etc.

Background

South Africa's first democratically elected government in 1994 prioritized increasing access to health services to redress past inequities. Decentralization of health services from central control to provinces and ultimately local government was initiated to facilitate closer ties between health facilities and communities.

However, South African health care is still burdened by gross inequities between the private and public health care systems, and inequities between

health services in urban and rural areas: more than 80% of the South African population rely on public health care, yet approximately 41% of the amount of money spent on health goes to the public health sector (R29 billion vs R42 billion spent on private health care).[1] Public-private inequities in health care translate into significantly less resources across the whole spectrum going to the greatest population segment - ranging from availability of beds to access to health professionals. Khosa (2003) describes the relative oversupply of health professionals in private health care as "one of the most intractable problems facing the South African health system".[2]

Poor infrastructure and shortages in equipment are some of the factors resulting in rural areas having the least access to services and resources. In 1996, 46.3% of the South African population lived in non-urban areas[3]. The National Primary Health Care Facilities Survey (2000) indicates that "in almost every single category rural clinics did not receive services or resources on a par with their urban counterparts." [4]

HIV/AIDS exacerbates health inequities in that it intensifies the cycle of poverty and ill-health. Poverty increases vulnerability to HIV/AIDS and HIV/AIDS significantly increases the percentage of monthly income that households spend on health care. A survey of the impact of HIV/AIDS on 771 households across South Africa indicated that AIDS households spent on average 34% of their monthly income on health care compared to 4% by non-AIDS households.[5]

To rehabilitate and develop a health system that meets health needs in a time of scarce resources demands difficult choices on how national resources are to be shared, where to spend public resources and on how to motivate and direct private health spending. To that end, participation of communities is widely argued to be an important aspect of improving health outcomes and the performance of health systems as it is the community that often knows its own priorities and needs. Therefore public participation and input is not only important, it's necessary.[6]

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[1] Berthiaume L and Padarath A. (2003) Health Care: A Right and a Responsibility, Health Systems Trust. (Unpublished literature review commissioned by Soul City)

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Access to HIV Treatment

General Public Messages

1. **Knowledge is power. You are in control if you know what illness you have.**

   Underlying messages
   - Voluntary counselling and testing (VCT) is important because if you know your HIV status you can take action and live longer and healthier.

   For example:

   Obtain support and guidance from health care workers, family members, and friends.
   Protect others.
   Plan for the future,(e.g. planning for the future of your children.)
   Find out what you can do you live longer and healthier

2. **We are all affected by HIV. We can only deal with it?**

   Underlying messages
   - Provide support for loved ones impacted by HIV/AIDS.
   - Be open to someone who discloses his/her HIV status.
   - We can work together with our health care providers to improve the health of us all.
   - Play an active role in your community, finding solutions together to deal with?fight the HIV/AIDS epidemic.

3. **HIV treatment is available. It is not a cure. But it makes HIV a manageable condition. Just like hypertension or diabetes.**

   Underlying message
   - We all benefit when people living with HIV receive treatment because
     - If they are working, they can stay healthy and be able to continue working
     - They can take care of themselves and their families
     - If the infected person is a breadwinner, he/she can still work and provide for his/her family this is a repeat – how about they can continue to be parents and this will decrease the number of orphans?
   - It is a myth that if you give people treatment they will behave irresponsibly. Studies show that the opposite is true

People living with HIV/AIDS

1. **It is your right to have access to health care**

    - Your health setting should offer you the following basic care if you are HIV positive; counselling, information on how to live a healthy life, treatment for opportunistic infections and information on HIV treatment.
    - You have a right to confidentiality, even if your health worker knows you.

2. **HIV Treatment/ARV'S is hope for people living with HIV**

<u>Underlying message</u>

- A positive result does not need to devastate you. With treatment, your chances of living a normal life are increased.
- Not everyone with HIV needs anti retrovirals at first – only when you start to get sick and your blood test shows your CD4 count low. When you start getting sick, ask your health care worker to take a blood test to determine your CD 4 count and advise you on HIV treatment.

3. **Treatment is for life – it is like a bond between a mother and child**.

    - Taking treatment is a serious commitment.
    - It is very important to take your medicine correctly – if you don't, the virus will get stronger (develop resistance) and the medicine will stop working for others if you pass the virus on.

4. **Your healthcare worker is your partner in treatment. Establish a good relationship with each other.**

    - When you take treatment you will need the support of your healthcare worker. It is important to be able to ask her any questions about your health.
    - You have a right do be treated with respect and dignity. If this does not happen lodge a complaint.

5. **Know your medicines**

    - In order to benefit from any treatment you should:
        - Know the correct names of the medicines you are taking
        - Know how and when you should take the medicines
        - Understand the possible side effects the medicines cause
        - Have someone close to you who knows that you are HIV positive and knows what treatment you are taking. This person will remind you to take you treatment and support

you if you have side effects with the treatment. He/she will be helped by the clinic to know what to do.

- It is important that you share with your health care worker all medicines that you are taking (including traditional medicines, immune boosters, or other things you get from the pharmacy or friends etc.). It is because some of the medicines may make the HIV treatment ineffective

Background

The South African picture of the epidemic: HIV Prevalence

Recent estimates suggest that of all people living with HIV in the world, 6 out of every 10 men, 8 out of every 10 women, and 9 out of every 10 children are in Sub-Saharan Africa. These figures provide sufficient evidence to make HIV/AIDS both a regional and a national priority.

It is estimated that by the year 2005, there will be 6 million South Africans infected with HIV and almost 1 million children under the age of 15 whose mothers will have died of AIDS.

While no sector of the population is unaffected by the HIV epidemic, it is the poorest South Africans who are most vulnerable to HIV/AIDS and for whom the consequences are inevitably most severe.

However in 2002 a survey of households affected by HIV/AIDS in South Africa and commissioned by the Kaiser Foundation was published"[6]. These are some of its findings:

- ***HIV/AIDS has an impoverishing impact of HIV/AIDS on households and causes an inordinate burden of caring for AIDS-sick family members.***
- ***Children are worst affected. HIV/AIDS increases childhood malnutrition – either breadwinners are too sick to work or the money available is spent on trips to the hospital, medicines or special food for the sick.***
- ***The longer-term ramifications of the HIV epidemic are:***
    - ***Deepening poverty among the already poor;***
    - ***Disruption and premature termination of schooling for children, especially girls;***
    - ***Increasing early childhood malnutrition;***
    - ***And increasing strain on extended family networks.***

The significance of this survey is that the finding makes compelling arguments for the provision of a comprehensive HIV/AIDS treatment and prevention programme

"The recurring hospital visits and treatment are a direct consequence of a lack of a proper response to the epidemic through the public health care system. So people have to pay for the cost of travel, repeat treatment for opportunistic infections that keep coming back and other related costs."[6]

This can all be reversed with a proper programme to manage HIV and AIDS. The person living with HIV will be able to live a life of dignity and will be healthy and able to carry on with his or her normal life.

"These guidelines [Scaling Up Antiretroviral Therapy in Resource-Limited Settings] offer a chance of hope to those who despaired. They affirm the human rights and dignity of people living with HIV. They represent an opportunity to build upon the solidarity and energy of the global movement against HIV/AIDS by redressing the inequalities between rich and poor in access to care."[6]

GOVERNMENT POLICY ON THE MANAGEMENT OF HIV AND AIDS

In 2000 the Department of Health developed a 5-year strategic plan to deal with HIV and AIDS titled: "**An Enhanced Response to HIV/AIDS and Tuberculosis in the Public Health Sector – Key Components – 2002/03 – 2004/05"**

The Strategic Plan is structured according to the following four areas:

- Prevention;
- Treatment, care and support;
- Human and legal rights; and
- Monitoring, research and surveillance.

Of relevance to this review is Priority area number two TREATMENT, Care and Support. The goals of this priority area is to:

- Provide treatment, care and support services in health facilities
- Provide adequate treatment, care and support services in communities
- Develop and expand the provision of care to children and orphans

The section on Treatment Care and Support, looks at the following as strategies to carry out the key objectives of this goal:

- Developing guidelines for the treatment and care of HIV/AIDS patients in health facilities and the community

- Ensure uninterrupted supply of appropriate drugs for the treatment of opportunistic infections and other related conditions
- Build capacity of health professionals to provide comprehensive HIV/AIDS/STD/TB treatment, care and support
- Establish strong links between health facilities and community-based support programmes
- Improve prevention and treatment of TB and other opportunistic infections
- No specific reference is made to the use of ARVs or developing appropriate protocols and guidelines for use and management in the public health sector. In a progress report entitled" "Tracking Progress on the HIV/AIDS and STI

Largely due to public pressure brought to bear on government by lobby groups like the TAC, the department of health was forced to review their current national policy for dealing with HIV and AIDS. The following comment was made in the review document published in 2002; "The Department of Health and the National Treasury formed a task team in late 2002 to look at the funding of HIV/AIDS interventions in the public sector, including the implications of provision of ART in the public sector. This document is due in April 2003". This document has to date not been made public and is awaiting cabinet approval.

This period in South Africa also saw an unprecedented ground swell of activism and mobilisation of people living with HIV and those affected by HIV, led by organisations like the TAC. Out of intensive battles on the street with pickets, and memorandums, government firstly was forced through a court battle to make drugs available to prevent mother-to-child-transmission of HIV [PMTCTP].

There has been a significant development that has come about largely as a result of this pressure being brought to bear on policy makers by civil society. On the 8th August 2003 the South African cabinet issued a statement[6], which endorsed the use of antiretorvirals [ARV] in public health facilities. The government has also set up a task team to ensure the effective roll out of ARVs in public hospitals and clinics. The terms of reference for this task team are very comprehensive and if they are carried out with political will and commitment, we could be seeing the impact of treatment and proper management of HIV.

What are the benefits of providing anti retroviral treatment?

Medecins Sans Frontieres [MSF] explains in a well researched paper[6] how it has developed nine treatment pilot projects in seven countries, treating approximately 1000 patients with antiretroviral therapy, with impressive results: after six months of therapy, patients had a 93% survival rate, an average weight gain of three kilos, and, where viral load was tested, 82% of patients had undetectable viral loads.[6] In one of these projects, in the

Western Cape township of Khayelitsha, dedicated HIV clinics have been providing treatment for opportunistic infections, counselling, and antiretroviral medicines."

The paper makes reference to the Medical Research Council [MRC] Medical Research Council report on the impact of HIV/AIDS on adult mortality which provides sober statistics on what will happen if we do not provide treatment for HIV and AIDS[6]:

> ***"[W]ithout treatment to prevent AIDS, the number of AIDS deaths can be expected to grow, within the next 10 years, to more than double the number of deaths due to all other causes, resulting in 5 to 7 million cumulative AIDS deaths in South Africa by 2010."***

The MRC report states that AIDS has "become the single biggest cause of death [in South Africa]."[6] The MRC report depicts a medical crisis that will only become more catastrophic in the coming decades unless significant political commitment unequivocally supports prevention, care*, and* treatment efforts.

Looking at the *Impact of HIV and AIDS on the health Sector***,** Maclean et al make reference to the following research commissioned by the Department of Health: "The Department of Health commissioned study of the impact of HIV/AIDS on the health sector predicts more than 3 million cumulative AIDS-related deaths by 2010.[6] The impact of such high—and rapidly increasing—levels of morbidity and mortality strains an already overwhelmed and under-resourced health sector. The aforementioned study, conducted by Abt Associates, estimates that approximately 500,000 hospital admissions in 2000 were HIV/AIDS-related. This figure stands to increase to more than two million annual hospital admissions by 2010, unless a significant decrease in the number of new HIV infections and HIV/AIDS-related opportunistic infections halts the trend.[6] The inpatient facilities of public hospitals will be most-affected, as increasingly immuno-suppressed patients require more frequent hospitalisations."

Treatment cannot be separated from prevention. McLean et al states that: "Besides being ethically inexcusable to entirely disregard the 40 million people worldwide who are *already* infected with HIV, focusing solely on prevention without a treatment option undermines the benefits of prevention messages." **McLean et all provides the following reasons for supporting the**

view that treatment is important for prevention:

- **Treatment as an option provides a motivation for HIV-positive people to be aware of their status: without treatment as an option, knowledge that one is HIV-positive can be seen as offering little more than stigmatisation.**
- **Treatment as an option promotes openness and reduces stigma as HIV is no longer an inevitable death sentence.**
- **Treatment programmes can fuel educational initiatives supported by a pool of HIV-positive people open about their status.**
- **Treatment as an option improves the efficacy and psychological health of health care workers who are able to offer something beyond temporary treatment for opportunistic infections.**
- **Treatment for HIV-positive people helps to keep families intact and economically stable, thereby minimizing at-risk populations such as orphans and commercial sex workers.**
- **Treatment for HIV-infected people minimises clinical risks of transmission at each unprotected sexual intercourse. (Long-term benefits of this are unclear though, as patients under treatment live longer and may change risk behaviours.) [6]**

McLean et al, draws on the experience in Khayelitsha to demonstrate the point of how treatment addresses stigma and is a critical as a prevention tool. The relevant paragraph reads: "While scant research has focused on this link, an analysis of the clinics in Khayelitsha provides some insight into the powerful relationship between treatment and prevention. In 1999, a provincial prevention of mother-to-child transmission (PMTCT) initiative in the Western Cape led to a dramatic increase in the number of women aware of their HIV status. Before the existence of PMTCT programmes in the province, few were aware of their status and even fewer were willing to disclose. PMTCT, for the first time, provided a motivation for pregnant women to be tested for HIV: the health of their babies depended on it. In 2000, three clinics began to provide treatment for opportunistic infections and, for those in the late stages of HIV/AIDS, antiretroviral therapy. These clinics likewise provided an incentive for others to be tested: their own health depended on an acknowledgement that their recurring illnesses were linked to a larger disease."[6]

Compliance is critical to prevent patients from developing drug resistance and of the increased risk of spreading drug resistant strains of HIV. What has been some of the recorded experiences of programmes providing ARVs in resource poor settings?

The most successful intervention in South Africa to date has been the experience of Médecins Sans Frontières (MSF) together with the School of Public Health and Primary Health Care, University of Cape Town.[6] The programme applies strict criteria for qualification to go onto HAART. This includes regular attendance to the HIV clinic in Khayelitsha, adherence criteria including disclosure of ones status to at least one family member or friend, social criteria, and a doctor assesses the stage of disease. Only patients

with a CD4 count of less than 200/mm² are eligible. From their experience promotion of adherence was based on a patient centred programme. Patients have access to trained counsellors for any questions related to HAART. Each patient is requested to identify a "treatment assistant" with home visits from the clinic. The centre has pioneered the development of support groups for people on HAART. Treatment literacy plays an important role, with patients being provided with information and pillboxes and other such support systems to help the patient monitor his or her drug programme.

Response to HAART is recorded through monitoring of CD4 counts, viral loads and weight gain. As an example, 54% of all patients registered on the programme started with a CD4 cell count of less than 50, and at 6 months only 2% have CD4 counts below 50, and 53% of patients have CD4 cell counts above 200.

Some of the lessons learnt is that if one analyses the survival of patients on the basis of their CD4 count at the time they started on ARVs, the pattern that emerged was that patients with CD4 levels below 10 were less likely to survive one year on HAART. The essential components of such a programme based on this experience include: careful selection of patients to go onto HAART, treatment adherence support and treatment literacy. This programme also demonstrates that the significant drop in the incidence of opportunistic infections as a consequence of HAART has important implications for costs and management of health care delivery.

Manhood/Masculinity

Background

Manhood is an issue for Soul City to deal with as an ongoing theme throughout all its series. As a guiding principle, within each topic and each series, space for dialogue and reflection needs to be created where different men question their attitudes and practices. Similarly, Soul City should celebrate the 5 in 6 men who do not support the abuse of power by men and who on a daily basis are supportive in their homes and in society at large.

The series needs to create a supportive environment for men to examine their own shadows and destructive potentials by challenging them to seek deeper, essential goodness and fairness, which is innate.

The formative research encouraged the promoters of positive masculinity to explore:

- **The *power* of communication or dialoguing and negotiation in any relationship.**
- **The role of men as part of the solution and not the problem.**

These could include:

* **Challenging all forms of masculinity that breed violence and conflict**
* **Encouraging fathers to encourage boys to assist in households chores along with their mothers and sisters**
* **Shared decision making between spouses**

At a structural level, these could include:

* **Opposing mobilization of gun ownership in government and on the streets**
* **Supporting laws that discourages violent behaviour**
* **Diversified school curricula to enable boys to choose from a wider range of masculinities and opportunities**

<u>Stereotypes that the series should challenge</u>

* Alcohol and drugs help men
* Men must have sex with lots of women to show power
* Boys are not supposed to befriend girls
* Real men do not cry

Challenges raised by the formative research include the need to deal with:

- The link between perceived masculinity based on power, violence and ownership of property/ people/ material things; violence against women, children and other men, and social acceptance
- Men's fears about women's empowerment, the blame syndrome, and excuses for violent behaviour.
- Socialization issues which prevents men from relating to feelings and accepting help from others, and as a result suffering pain in isolation

In promoting an alternate perspective on manhood, the following could be built on:

* Men's increased involvement in parenting
* Better interaction between men and women as equals
* Men who do not abandon family
* Women who are supportive of the 'new man'
* Men who acknowledge that there are gains in sharing power such as the development of mutual respect for men and women.
* Men who share their pain and speak out, highlighting the benefits of gaining support and strength from others
* Dual responsibility of men and women in sharing their different power roles
* Postive associations with strength and control such as : strength as an ability to walk away from conflicting situations and assume a power-full position by staying in control of the situation. Strength and control as an individual's choice not to engage in physical or verbal violence.

The series should acknowledge that *power* is everywhere, and throughout life, people alternate between being power-full to being power-less. The highlight should be on acceptance of the reverse situations, and acknowledging that by relinquishing power, we gain more. E.g., respect

The challenges are:

* Creating space for dialogue amongst men on what manhood means to all
* Finding what is common about men
* Enabling men to accept and learn to deal with rejection
* De-constructing male power as influenced by a patriarchal system
* Facilitating an enabling environment to increase men's involvement in parenting and other domestic chores
* Encouraging men to deal better with conflict caused by political, and economical transformation
* Unemployment – most men interviewed during the formative research were under a lot of pressure because they could not provide for their families. As a result they felt hopeless.
* Race and culture – most men felt that it is only okay for men outside their race and culture to behave differently.

Messages

1. **There are different ways of looking at masculinity. You can be a different man from what your peers expect you to be.**

This message is about exploring how society views masculinity and the harmful effects machismo can have on men, women, children and society as a whole. It is about promoting alternate perspectives of masculinity and encouraging the emergence of a "new man" as articulated in the background section of this brief. The series should also convey the benefits to men of redefining "manhood".

During the formative research discussions, a lot of men talked about masculinity as natural or God ordained. It is important to challenge this stereotype and show that manhood is socially constructed and therefore it can change.

2. **Men have rights and responsibilities, and deserve love, acceptance, recognition and security like everyone else!**

Men and women need each other .The society benefits when men play an active role in all activities that make a society strong like parenting, respecting women, speaking out about the problems in the society and working together to solve them. Children benefit when men give them positive guidance and become positive role models in their lives

3. **"Unemployed people can make other valuable contributions within their families and their communities**

Men who are unemployed still have a lot to offer. For example they are able to be there for their families helping their children to grow differently and/or volunteering their expertise and time in their community.

Cancer of the Cervix
MESSAGES

1. All women are at risk of getting cancer of the cervix.
2. You can prevent Cancer of the Cervix by getting your womb checked/tested.
3. A PAP smear is a test. It is used to test for problems with the cervix/womb.
4. You can obtain 3 free PAP smear tests in your life at your local clinic or hospital One in your 30's, one in your 40's and one in your 50's.
5. It is your right to ask for these tests, even if you feel healthy.
6. The test will not cure you. It will help the doctors know if there is something wrong with your womb.
7. You must go back for your results of the PAP smear test.
8. If the doctors find something wrong with your womb, they will treat you. This treatment will save your life.

WHAT IS CANCER OF THE CERVIX?

Cancer in general can be described as an abnormal growth of cells. Cancer of the cervix is cancer involving the squamous cells of the cervix. Thus, cancer of the cervix means there is an "abnormal growth" of the squamous cells of the cervix (commonly referred to as the mouth of the uterus). That is the squamous cells of the cervix start "behaving" in a way that they shouldn't – they grow at an abnormally fast rate, function differently and start looking different from the normal squamous cells of the cervix. At a more advanced stage, the cancer spreads to surrounding tissue such as the bladder, and even spread to distant tissue such as bones and lungs, through the blood stream.

WHAT CAUSES CANCER OF THE CERVIX?

The primary underlying cause of cancer of the cervix is Human Papilloma Virus (HPV). HPV is a common sexually-transmitted disease that does not

always cause symptomatic disease in infected individuals. Existing evidence indicates that more than 97% of all cancers of the cervix are associated with persistent infection HPV.

Cancer of the cervix is a disease with a long latent period, which means it develops over a long period of time. The natural history of the disease is such that the disease is induced by HPV and persistent HPV infection progresses on to a pre-invasive (pre-cancer) stage, characterised by the presence of pre-cancerous cells in the cervix) broadly called dysplasia). Women are most commonly infected with HPV in their teens, 20s, or early 30s, but it may take as long as 15-20 years for the disease to progress from HPV through low-grade to high-grade dysplasia and finally to cancer of the cervix. High grade dysplasia is a precursor for cancer of the cervix.

Simply put, the typical course of the disease is as follows:

- HPV Infection — teens, 20s
- Low-grade pre-cancer stage — late 20s, early 30s
- High-grade pre-cancer stage (the precursor of Cancer of the Cervix) — late 30s
- Cancer of the cervix — >40s-50s

Ca Cx: Global burden of disease.

- 80% of 500, 000 new annual cases of Ca Cx occur in the developing world
- Most common cause of cancer-related death in developing countries (ASMR twice those reported in developed countries)
- Southern Africa: Some countries with age-adjusted incidence rates >40/100,000

Burden of Disease: South Africa

- Approximately 5000 new cases of Ca Cx reported annually
- 2nd most common cancer in women (most common cancer in black women)
- ASMR differential distribution: highest in Black women (25/100,000) and lowest in White women (5/100,000)
- Leading cause of cancer death in women

Risk Factors

- Persistent infection with Human Papilloma Virus (HPV) (High risk types)
- Co-factors
    - Smoking: tobacco use may influence whether a woman with dysplasia is likely to develop cancer of the cervix.
    - Immune suppression: exact role is not known, but immune suppression, especially related to HIV infection, also plays a mediation role.
    - Hormonal factors: use of contraceptives, early age at first birth and high parity also play a role in mediating the disease.
- ***Age*** is the most reliable predictor of risk. Any woman who has ever had sex is at risk of developing cancer of the cervix, but the risk increases as a woman gets older. Currently age is the most reliable predictor of risk for cancer of the cervix. The risk is greater in women over 35 years of age.
- **NOTE** – Sexual behaviour: younger age at first intercourse and having multiple sex partners have frequently been cited as risk factors for cancer of the cervix, but these are now thought to be indicators of exposure to HPV infection and are not independent risk factors.

Prevention Strategies

- Primary prevention
    - Behaviour change (abstinence, mutual monogamy, condoms). NOT an effective prevention strategy at a population level.
    - HPV vaccines (research is on-going)
- Secondary prevention
    - Cervical screening: early detection and precursors of cancer of the cervix is the most effective and realistic prevention strategy.

SA cervical screen policy

- 1999: NDoH's National Cancer Control Programme (NCCP) adopted as official national policy. NCCP includes national cervical screening programme.
    - National cervical screening policy: three free screening Pap smears (in the public sector), per lifetime at 10-year intervals, starting at age 30.
- 2000: Policy decision articulated in the National Guideline for Cervical Cancer Screening Programme-broad national framework.
- 2002: NDoH establishes an advisory committee to oversee the development of a strategy for the national screening programme.

Screening Programme Requirements

- Well planned and organised cervical screening programs can effectively reduce incidence and mortality.
- An effective cervical screening programme must screen and treat women most at risk (older women) and must have a number of essential health care components:
    - Information, education, and communication programme
    - Education and training of service providers
    - Screening services
        - Appropriately equipped health facilities
    - System for delivering specimens to cytology laboratories and reporting cytology results back to health facilities
- The necessary Health Systems in place:
    - Cytology laboratory quality assurance
    - Mechanisms to ensure clients are given cytology results, and follow-up of those clients with abnormal results who do not return for results
    - Referral systems to ensure clients are referred to the appropriate facility for further tests/treatment
    - Record-keeping to keep track of positive clients and to monitor and evaluate the programme
- Diagnostic and treatment services:
    - Facilities for treatment of precursor lesions and cancer of the cervix must be in place (hospital-based)

Are Health Services Ready?

- Differential states of readiness across provinces

- Providers consider it "extra work"
- Still a great focus on performing Paps, with little emphasis on programme development
- Minimal investment in monitoring and supervision to ensure implementation of programme
- Concept of prioritising follow-up, referral, and treatment of clients with positive results not well adopted – many "lost" in the system
- Colposcopy and treatment services: need to expand availability – access limited for many women
- Huge Challenge – to prepare services and implement a cytology based treatment programme
- Modelling shows national goal is achievable: What is needed?
    - Political commitment to be translated into resource allocation
    - Shift in mindset – Mx and provider levels
    - Programme development: adequate investment of resources to establish and maintain an organised screening service (step-up approach)
    - Optimal and efficient utilisation of existing resources
    - Utilization guidelines/delivery models to facilitate national roll-out

Advocacy Issues: Programming

- Though limited resources and competing priorities, action is required to prevent numerous premature deaths annually. Impact of inaction:
    - Impact on the health of women: morbidity and mortality; persistent inequities across races and socioeconomic status
    - Social impact: loss of mothers, carers at a productive phase of their lives
    - Impact on health services: must more costly to treat women with established cancer than to treat early stages of disease (treating only invasive cancer would cost 80% more than screening and early treatment of precursors)
- Management and provider commitment essential (should translate into appropriate resource allocation) – a substantial injection of resources/infrastructure development required

- A successful cervical screening programme requires a whole lot more than "just taking Pap smears". Other components of a screening programme are essential.
- Cervical screening programmes should ideally be integrated within clinics and community health centres, utilising existing infrastructure where possible
- Need to channel resources to focus on / prioritise clients with positive smears (efficient use of existing resources for greater impact)
- Avoid missed opportunities for screening – providers must recruit women from within the health services
- Opportunity to strengthen health systems - entrench linkages between clinics and hospitals (to monitor positive clients)

Soul City Research Findings

- **Study Population, and research design**

Qualitative Interviews were conducted amongst Black, and Coloured adults. All groups were single sex.

A total of 8 Qualitative Interviews were conducted: 6 Focus Group Interviews in urban or, per-urban and 2 in rural communities. One female urban group was with women who have had PAP smears.

The objective of the study was to determine knowledge and attitudes and perceived barriers to screening for Cancer of Cervix, and the role the health services play. Knowledge and attitude about cancer of the cervix,

- **Knowledge**

In some groups people did not know anything about cancer of the cervix or womb, and in others there was often a feeling that they did not know enough. This applied to Pap smears too. Towards the end of a few groups some people said that they had learned a lot from the group, and would recommend that their partner go for a Pap or that they were going to go themselves.

*[pap] I have heard about it, but I don't know as to why is it used and when I cannot tell you.(*urban african men 20-25 years)

*Yeah, a womb related diseases are known mostly by other woman. So it is not easy for us (men) to know such diseases. Other peoples who posses such knowledge are the doctors. So it is up to her to ask for advice from the guys and to do a little research about where to get help.(*urban African men 20-25 years)

But I think the message that is coming out here is that we actually know very little about it. We are all saying this is what we think this is what we believe I think we are… somewhere but we are going around the…suppose to the cervix as well.(young coloured women)

- **Cause of Cancer of the cervix (or womb)**

The cause of cancer of the cervix or womb was discussed at length, there were a number of themes that emerged:

- **Causes that related to men**:

This related often to men believing that a large penis caused friction and thus cancer.

I know about the cancer of cervix Nn…! It has the cause, perhaps if I am to narrate this issue well, so that others can also know, this disease is very dangerous. More oftenly, it is caused by the male counterparts to develop around the womb of female counterparts, when they have larger penis, it causes friction inside the woman's private parts and that larger penis goes further to reach the mouth of the womb," where these are sometimes ,when you are having sex, a woman have to complain about pains" so if that thing happens time and again, that womb, infect, our discharges as men are not hundred percent healthy which might result in friction and because of that friction, it –it affects the womb of a poor woman. It goes further to such an extent that those wounds develop and if the woman is getting necessary treatment, they may fade away especially if they
may be discovered during early stages, but if detected later, it might be septic, and never get to be healed and come to the situation wherein the womb will have to be operated and removed or the woman dies. (rural African men 28-54 years)

Related to this if men drink imbizo this is a traditional type of sexual enhancer, the additional friction would then cause cancer.

> *And there is other fact about us men, we drink imbiza (traditional medicine) before having sex which is bad because sometimes you are too strong for that woman. The can also cause damage because sex is natural, you don't need some boosters in order to perform well.* (urban African men 20-25 years)

Other male causes were the ejaculate *"going the wrong way"* , the last person you slept with causing the cancer, having sex with an alcoholic, and having sex with more than one man, this is related to the "different sized penises" of the different men.

- **Causes relating to being sexually active**

The second theme was being sexually active it is believed that you cannot get cancer for the cervix if you are not sexually active. Having more than one partner was also seen as a risk.

> *Cause I mean if you are not busy you don't have to go for pap smears, because you didn't do anything*. (young coloured women)

> *One thing I forgot when it comes to the causes of this diseases, some say it caused by a*
> *woman who has multiple sexual relationships* (urban African men 20-25 years)

> *I think cancer of the cervix affects girls who have many partners because if you sleep around with many boys, you can develop sores in your womb and that can later become cancer.* (peri urban African women 20-25)

Starting sex at a young age was seen as a cause, this related to the man's penis being too large for a young girl,

> *The other cause which adds on that is that, more often the main cause is when a female person gets or start involving herself in sexual activities while she is still at a younger age. Involved in these sexual activities with a man who is physically too stronger for her or old men, that thing causes, infections in the womb, especially if "Vhavenda" (the penis) is to big it results in this kind of an infection. So on the mouth of the womb,*

normally develops a wound, that the girl may grow up with, that wound, becomes very difficult to heal, that wound is always wet, yes, the place is always wet, it does not get dry, yes, it comes to a situation where the infection disrupts the woman's chances of giving birth in future(rural African men 28-54 years)
You will find 12 year old child, who's parents cannot support her and the child starts selling her body, sleeping with older men, you will find that will cause it. She will feel the pain alone, as she gets older she will get cancer. (peri urban African women 20-25)

There seems to be a relationship in many people's minds between infertility and cancer of the cervix, abortion (or miscarriage) as well as contraception, other occurrences during birth such as "stitching", and being an elderly primup (having your first baby at an older age) or "womb scrubbing":

according to my understanding, cervix cancer is an old disease. It mostly attacks women from 30 years and above who are about to give birth for the first time.
(urban African men 20-25 years)

The way I see it that this thing can be caused by the contraceptives. Somebody told me that she used to use prevention pills, then she went to the doctor and the doctor told her that she must stop using those pills because they were no longer working. After sometime they would damage her womb. She stopped and now she is taking any pills.(urban African men 20-25 years)

I believe condoms also can cause cancer…… It causes cancer, it is a little bit fatty, you don't know what the fatty is for; you find it from the condom. Condoms are free you don't need to buy them, at least the ones that you buy have a nice odour, the free ones are dangerous. The other thing is that if you use it a lot you start smelling different, I think it might cause cancer. (peri urban African women 20-25)

[illegal abortion causes it]R: Yes they take in poisonous substances like detols, jeyes fluid mixed with jik

R: What is that going to do to the womb? (all laughing)

R: Obviously the womb will be damaged, they drink all these poisonous substances we are aware of that like jik, they take in jik. (urban African men 20-25 years)

Maybe it is causes by miscarriage, after miscarriage the doctors ask you to come in so that they can clean you, you don't go and start sleeping with your partner, maybe that's it; it causes cancer. (peri urban African women 20-25)

because you can go to the witch doctor for abortion for the second time, third time fourth time perhaps for the fourth time you wouldn't have babies anymore because of the damages that have happened during the process. (urban African men 20-25 years)

I am totally against womb scrubbing; it can sometimes cause cancer in one's womb. (urban African women 25-48)

- **Infections** were another group of causes and in fact many of the other causes related to infection (or STI's)

I believe germs cause it. For instance let me say when you go to the toilet, you might get germs, maybe someone messes on the seat or something and when you come you don't clean the seat, you just sit and then you get it. (peri urban African women 20-25)

it may only be coming from a man and detected later, realised later, and when all those dirt's, charges are assembled around that area it causes wounds due to the pimples inside and when they develop, they cause serious wounds and cause cancer that can never be healed that, is why they normally say a woman should always be checked so that these sexual transmitted diseases should be controlled (rural African men 28-54)

But I think that having more sexual partners does put you at risk to a certain extend because cancer is there but needs a trigger and in this case maybe constant infection. If you do pick up a STD it needs to be treated and that doesn't get treated properly it is like an on going thing. I do believe that your chances are for cervical cancer to be activated is greater than if you are in that kind of situation.(young coloured women)

- **Cysts**

One group felt that cancer of the cervix was related to cysts:

I recall also some cysts story that was being… the other thing that causes… it is also a sort of cysts on the womb. (young coloured women)

We don't know from the … story she had a cysts so that is why automatically in my mind when you have a cysts you need to be weary of cervical cancer, because that is how they picked it up so that is why I am assuming that a cysts is a by product of cancer. (young coloured women)

- **Sanitary wear and toilets**

A further theme emerging about the cause of cancer of the cervix was relating to the use of toilet paper or cloths as sanitary pads, dirty toilets, dirty baths and using the "wrong" soap.

They must use panty liners, toilet Paper is not good, even if you are just holding it with your hand, and it keeps waning. It is my believe that toilet Paper can cause womb cancer, I think it may block one's fallopian tubes. We should stop using toilet Paper and use panty liners so that we can protect our womb (urban African women 25-48)

If a woman must menstruate you will find that at times she has pains, some women menstruate very heavy and they use a cloth, I don't know whether that can cause cancer. I don't know whether the heavy bleeding causes sores (sebabo). (peri urban African women 20-25)

- **Chemicals**

Another group of causes was chemical or medicinal causes, people talked of alcohol abuse, tobacco, chemicals at work, traditional medicines and pills that young people take for constipation.

Another thing are the tablets that women take. They can also cause some sickness. I think women should stop using many tablets like laxatives and those tablets that we are taking to clean our wombs. I don't think they are good for anyone. When you take a tablet, it lands somewhere in your body, it forms a lump somewhere, and as you keep taking the tablet the lump will affect you somehow and create cancer for you. Cancer scratches you internally and the lump will grow bigger and cause cancer.(urban African women 25-48)

For I think, some people believe on traditional mutis, they could like go several times to the witch doctors and use these mutis. The womb can't be clean and thoroughly like those obtained from the hospital and clean it.
R: Sometimes are too strong
R: Sometimes they are too strong for the womb. Then that is why they could have that damage because some people they believe African things are better than the English things. (urban African men 20-25 years)

I think the decrease in alcohol abuse and smoking can reduce chances of cervix cancer. (urban African men 20-25 years)

Smoking affects the womb, so does working with chemicals, the smell can harm your womb.(urban African women had pap)

And they say if a woman smokes and she's on birth control, then it's very dangerous.(urban coloured women 40-60 years)

Maybe drinking African/natural herbs causes it. When you clean your blood system, not all the dirt comes out; the unwanted blood stays in one place and causes cancer. (peri urban African women)

- **Familial and age**

People linked the cause of cancer of the cervix to heredity and that it is generally found in older women:

But the other thing isn't it more medically relevant if you have a history of cancer in your family that something like that might happen if you are sexually active. (young urban coloured women)

My perception of cancer is that it is hereditary and if you are going to get it you going to get it. (young urban coloured women)

I can't speak for any one else here, but a genral perception is that cancer does not affect young people. The older you get you just start checking for your cancer, because you are now getting old you have been through menopause and all that crap. So it is just a standard thing that you need to start feeling your boobs you know, taking more precaution(young urban coloured women)

- **Clean and Dirty**

There was a lot of discussion about 'clean and dirty'. The womb or menstruation was seen as dirty, and sex was also dirty, a number of ways to clean the womb were discussed, in addition many mentioned that a Pap smear was to clean the womb.

My mother use to say you go to the gynea, the gynea keeps it clean and your father makes it dirty. (young urban coloured women)

*Because I mean if you are not doing anything[*sexually active*] it is still brand new you don't have to clean it*. (young urban coloured women)

Not really. I think what causes cancer is that we young girls in most cases don't consult with our doctors so that they can clean us, so most things block in our womb, so in most cases when you menstruate you don't know what is going on with you. (peri urban African women 20-25)

Is it not caused by a lot of sores, you know that a woman menstruates, maybe the "dirt" that comes out, the sores are aggravated by the dirt, so I believe this is what causes cancer (peri urban African women 20-25)

My perception of a STD is something that is dirty and dirty people get cancer. …(young urban coloured women)

What I understand about this cancer is that a woman cannot bare children anymore. The womb may be damaged or very dirty due to the reproduction process of the woman. Therefore the woman cannot bare children and can sometimes lead to death (urban African men 20-25 years)

He can't go into the womb doing a papsmeer so he will clean the outside where cancer can be…(young urban coloured women)

I don't know, but the way I understand it is that when you go to clean yourself, every year you go and clean your womb, it cleans the womb, you will be assured that you don't have cancer. (peri urban African women 20-25)

- **Pap Testing**

People had often heard of Pap tests, but the understanding of what they are for varied from understanding that they are a preventive

test for cancer to thinking that they clean the womb, test for infertility, or checking the status or condition of the womb.

A:The most uncomfortable thing ever!
A: Cleaning the mouth of the womb or cleaning the womb.
A: It is scraping.
A: You discharge as a woman, and I think basically what he does is clear the mouth.
A: He can't go into the womb doing a papsmeer so he will clean the outside where cancer can be…
A: I don't think it is cleaning it is just taking a sample and testing it.
(young urban coloured women)

Papsmear is when a woman gives birth, after giving birth they stitch her and after a while the doctors would check if her womb is back to it's original state.(peri urban African women)

In order to know whether you are sick or not, or whether your cervix is positioned correctly, you have to go for a Pap smear, that is the only way you are going to know, through Pap smear. Because otherwise you are just going to hang around not knowing what's going on with you, whether you are sick or not. Through Papsmear tests will be taken and you will know your condition after the results. You will know your condition, you will also know what is wrong with you if there is something wrong. So it is important to go for a Pap smear because without it you will not know if you do have a problem. (urban African women had pap)

I have hard of Pap smear but I thought that one goes when one has a problem. Now I know. (urban African women 40-60)

You do it when you have a (vaginal) discharge. (urban African women 40-60)

I am not sure, but I think Pap smear is like womb scrub, they clean you, at times we as girls get an infection that is smelly, the infection is not okay, if you go for a Pap smear you will be clean, the urine also is smelly.(peri urban African women)

There are a number of barriers to going for a Pap smear:

Firstly most thought that it is unpleasant, and secondly that the examination is intimate and related to sex:

I just think also with a pap smear the fact that you have to open your legs for anything besides sex. It put you off you are not going to be intimate with this person but you are going to lie there and open your legs. (young urban coloured women)

I think education would also help to dispel some of the myth around Pap smear that it is painful, that it is for older people, that it will make your partner less interested in you sexually. (urban African women had pap)

Fear was mentioned many times:

I was scared, doing something that you don't know about can scare you. I had heard from people that it is painful (young urban coloured women)

I won't go for it, I find it scary because of the irons, plus the fact that they don't sedate us; I won't go because they don't sedate me (peri urban African women 20-25)

I won't go, I am afraid of the irons in my vagina (peri urban African women 20-25)

That is why Pap smear is so important, most women are afraid to go for a Pap smear. It is very seldom that you find a woman going for a Pap smear. Cancer of the cervix is very common because women are afraid to go for a Pap smear.We only go when things are out of hand. (urban African women had pap)

I would say it's difficult because you keep telling yourself that there's nothing wrong with you, you then go for the Pap smear and the doctor tells you that you have cancer of the womb. You won't be able to handle something like; we are too young to be in a position to handle something like that. You will probably go alone without your parents; it is going to be difficult to tell them your problem. So think that is the reason why people
don't want to go for a Pap smear, they are afraid to know that they have cancer. Some people may even deny it and blame it on the doctor. A person like that will live with it, with no treatment, at the end of the day you die. (peri urban African women 20-25)

I think it is frightening having your vagina jacked up. (young urban coloured women)

I was just going to say now whether you are comfortable with your body or not the tools they are very intimidating.

Yes, but when you think of the person that is going for the first time for a papsmeer and I think that is why people are putting it off for such a long time, because you are thinking ok I am sleeping with this one guy now I have to go and the doctor is going to have to… I mean you know your doctor and he has done lots of things but now he is going to do the thing. (urban coloured women 20-35 years)

The association of cancer of the cervix with sex and multiple partners introduced the possibility of stigma to some:

so the minute you say pap smear they think she is sleeping around which is generally not the case I mean in some people cases its just I am having an issue and maybe I should go and see a gynea (young urban coloured women)

- **The health services:**

Many women had been to private doctors or clinics for their Pap tests. One woman had had an annual Pap at work, but stopped when she stopped working.
In general people talked about problems in the public health sector, but there was one plug for the family planning clinic

I think a lot of people don't go to the clinic anymore. There is a difference between family planning with your General Practitioner (GP) and the one at the clinic. The clinic is best, you are taught and given proper advice. The GP will let you in, check your blood pressure, some don't even check your blood pressure they just give you the injection and let you go. Family planning at the clinic is very important. We have to tell our children not to indulge, they have to go to family planning because they are indulging. They have no choice but to go for a Pap smear. (young urban coloured women)

I know it was told to me in confidence but one of the nurses at Reiger Park told me that "Beulah, you should never again go to these clinics for Pap smears. "That's because the instruments are not sterilized properly. (urban coloured women 40-60 years)

The cost of the examination was an issue, though some knew you could get it free at the clinic

> *I also went to the clinic and it was free. And I said to them that my sister was coming to the clinic and they could give her the results. Then they said to me no, it's personal.* (urban coloured women 40-60 years)

> *But that is just it the perception that I got from the clinics is that they are not as thorough as your normal GP. I beg to differ on the health care thing; because with health care being made such a big issue it is so expensive most people just opt for hospital plans. So when you need to go to the GP for that check up you still need to pay for it, so money can be an issue yes, because you can go to your GP he can tell you it is an infection, infection, infection yes* (young urban coloured women)

> *Yeah. Hmmm. You must make them aware. Yes, my mother told me not to go to the clinics. She went to ……(?) Park and paid R120,00. Hmm. And they do it so nicely…… clean instruments that are sterilised. She told me don't go to the clinic*. (urban coloured women 40-60 years)

Often the attitudes of nurses were cited as a barrier:

> *Another thing that I think will help is to allocate older nurses to us older women. These young nurses don't seem to understand us older women*.(urban African women 40-60 years)

> *Also, the nurses can be rough and unkind. If the nurses can change their attitude, more people can go. They pass remarks instead of treating you. The reason why we go there is for treatment so if they sneer at you because you have some illness is not right*. .(urban African women 40-60 years)

> *They scold you and ask you penetrating questions like why are you like this? Why do you do that? Embarrassing questions. Some shout at you and call their colleagues to come and see. Who would go there after such treatment? Besides, nothing is confidential- they shout at you in the presence of very young girls*. .(urban African women 40-60 years)

There was a lot of confusion about when one should go for a Pap, especially as many saw it as a cleaning or treatment in itself

Respondents talked about going annually, monthly, three monthly six monthly, when they have a discharge,

You do it when you have a (vaginal) discharge. .(urban African women 40-60 years)

*We know that you have to go for your pap smear annually. Your GP tells us tha*t. (urban coloured women 20-35 years)

if you go after 3 months how are you going to know, 3 months is too long, I think one should go just before menstruation or after taking it out so that they can clean you because you will have the cancer already (peri urban African women)

Some women talked about going when they were younger or employed , but that they have since stopped.

When I was still young I use to go regularly. When I stopped menstruating and my husband passed away, I stopped. I used to do it every year or two. .(urban African women 40-60 years)

I went for a Pap smear in 1994 when I went to be sterilised, it is not sore, I didn't feel anything – but I never went back after sterilising(urban African women 25-48 years, had pap smear)

Despite the fear expressed and the way people talked about "panel beating women" the men and women were positive about the idea of going for Pap smears. They all felt it was a good idea to be checked up and to prevent "further complications".

because if a woman is affected by the cancer of cervix it is very difficult for her to do any domestic work, especially after she has been suffering from this disease without consulting any doctors or nurses, it comes to a stage wherein by the time she consults, it is little too late and the doctors may be forced to remove the womb
(rural African men 28-54 years)

But to my opinion I don't see any reason that your wife should consult you for a PAP Smear, its her body. She has to decide whether she is going to do it or not. It matter whether you allow her or not it is her body and is able to decide for herself.(urban African men 20-25 years)

Yes: women should always get a check-up, because women always get checked and sometimes we do not know the purpose of check up only to

*find that they would be checking or examining her private parts. (*rural African men 28-54 years*)*

- **Protecting the womb**

The groups discussed what they do to protect their wombs. In the coloured group there was not much except going for regular check ups and using Lennon medicines:

Normally amongst the coloureds they usually use these Lennon medicines.(urban coloured women 20-35 years)

The African women talked about protecting their womb by keeping it warm, this is through wearing blankets around the abdomen, wearing pads and not walking barefoot.

I believe women are not supposed to walk barefooted because the cold can reach one's womb, sometimes this can cause some pain, especially on cement floor. (urban African women 25-48 years, had pap smear)

To protect my womb, when it is cold I would wear a sanitary pad to keep me warm or dress warm so that the cold doesn't get to me because women generally have a problem with the cold, sometimes this can cause internal pain or your whole body would just be cold(urban African women 25-48 years, had pap smear)

I believe you must go to the doctor to check yourself and do things like womb scrubbing, they must clean you inside. I am not exactly sure what womb scrub is but what happens is that you go for an appointment and they do it for you in order to protect you from other diseases.(peri urban African women)

You should not carry heavy objects that might affect your womb (rural African women 40-60 years)

I squat on an onion when my womb is sore and it feels better.(rural African women 40-60 years)

There was some discussion about having a hysterectomy, this was feared as some felt that husbands wouldn't want you after having a hysterectomy. Someone said that they had heard that when you have

a hysterectomy the womb is replaced with smelly rubber. Some talked about if you have a hysterectomy you feel cold without your womb.

There was some discussion about sex education and the need to discuss this in schools. Many thought that white people talk about these things more easily. Cancer of the cervix was discussed in the context of AIDS people said they know all about AIDS but little about cancer of the cervix, they are keen to learn.

but I don't know yet if I had education about it or knew anything about it I would know about it … with Aids now you know… I think with cancer they should go that way as well.(urban coloured women 20-35 years)

really do think the level of education needs to change…
A: And it has to have the same kind of status as AIDS. What you should say is that if detected early there is a chance that they can do something about it. But more than that prevention is better than cure, so if you know for a fact that you have a history of cancer you should be the one having yourself checked out.
A: Being pro active. (urban coloured women 20-35 years)

You can get Pap smear at the local clinic. I think the clinic should reach out to the community and inform them about such services. Perhaps some women would go. No one can go to a service unless one is aware of it.(urban African women 40-60 years)

I think education would help most people understand how important Pap smear is and that it is not painful at all. There is lack of education, most people do not know that they have to take care for their wombs by going for Pap smear. (urban African women 25-48 years, had pap smear)

We have to tell our children not to indulge, they have to go to family planning because they are indulging. They have no choice but to go for a Pap smear. Some parents don't sit and explain things to their children, they get information from their friends that can be dangerous. (urban African women 25-48 years, had pap smear)

- **Discussion and conclusion**

There seems to be a lot of confusion about cancer of the cervix and most respondents had only the vaguest idea about it. In most cases all types of cancer were confused. Many people had some ideas about how cancer of the cervix was caused but sometimes for

As part of the development of Soul City Seven, the Soul City Institute for Health and Development Communication conducted qualitative formative audience research in order to gain deeper understanding of community participation in health.

The following are some of the findings:

Key barriers to community participation in health:

1. The Relationship between nurses and patients:

The most prominent and immediate barrier to community participation in health was the quality of the relationship between nurses and patients.

> *"There's no communication. We have no relationship with the nurses or the people in charge of that clinic. We just go there when we need health care and it ends there."* (General population, Rural Limpopo)

In worse case scenarios, participants described nurses as rude, abusive, unsympathetic and cold – making them feel like a nuisance, and as if they are coming to beg for service. A fairly widespread observation across groups was that patients asserting themselves made the situation worse, and that it is better for patients to keep quiet and not to exercise their rights. Patients' lack

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> the wrong reasons (an example is sex at a young age, which they said was because of the penis being too big).
>
> Many respondents had heard of Pap smears but only a few had any idea what they are for. There is a strong misconception that Pap smears are for cleaning the womb. There is also a lot of fear of Pap smears and people use language which likens them to cars: jacks up the vagina, tools for the pap and panel beating a woman. The fear is not only about the act of the Pap but of the consequences, anxiety about cancer and dying and also that one might have to have a hysterectomy.
>
> On the positive side respondent were interested in the discussion and keen to know more about the issue, they were supportive of going for Pap smears in the future, and also of learning more about the whole subject.

of self-esteem or lack of confidence (reported by nurses as a barrier to community participation in health), and the observation by nurses that they do not show any interest and only have a user mentality could be seen in this context.

> *"If you complain too much you're a troublemaker. If you're quiet you'll get treated okay. But if you do complain you'll get treated badly. That is one thing for sure. … I am already at that point where I just say nothing. At first I used to talk and fight but then I noticed that that was when they treated you really badly. But because you're hard-up you just take it and go with the flow."* (General population, Urban Gauteng)

2. The larger health system in South Africa

Nurses' attitudes can largely be seen in the context of an under-resourced public health system. As mentioned earlier, in critique of health services both users and health care providers from all areas assessed health facilities as understaffed and elaborated extensively on the negative consequences thereof on service delivery and quality of care. In a fairly self-critical way, nurses generally acknowledged that the quality of care that they are offering is not good – as a result of being understaffed.

> *"Nurses sometimes are so stressed by the conditions they work under that they don't have patience for people. You have a long queue of people who are coming through to you only. There are no medicines to treat one person, how is she going to treat the queue? You find nurses snapping at people, and that's not nice because we are all stressed, the nurses and the people."* (Health worker, Rural Limpopo)

> *"All we are doing at this stage is killing fires. We are really not making a positive contribution to our community."* (Health workers, Rural Eastern Cape)

Patients' negative assessment of nurses' attitudes towards them was often uttered in the context of acknowledging that health facilities are understaffed and that nurses are over worked.

> *"Look, it's not the clinic itself. It's a shortage. I don't know how to say it…look they are doing ten people's work, do you understand? And that is overwork."* (General population, Rural Eastern Cape)

Nurses expressed concern that patients do not understand the broader context in which they work. They described being on the receiving end of bad attitudes from patients and of being mistreated by patients. They felt that patients sometimes come with what they (nurses) perceive as impossible demands (such as demands for unsuitable treatment and demands based on self-diagnosis). Patients also come to the clinic with bad attitudes and call nurses "bad names and say bad and untrue things" about nurses.

Health workers also alluded to a chain reaction of abuse in the system as well as mismanagement of resources culminating in inadequate service and unmet needs.

> *"It happens again sometimes when they* [patients] *should be getting their rights, and the people who should be giving them their rights are being mistreated - for example, as a service provider. The patient needs something that needs authorization and the authoriser abuses the service provider, ultimately the patient does not receive the help they need and when a similar problem arises the provider will not go back because they don't want to be abused…"*
>
> *"Which means that the patients' problems will remain unsolved until the authoriser has been dealt with."* (Health workers, Urban KZN)

3. Displacement of responsibility

A further key barrier to community participation was displacement of responsibility, with users of public health care placing responsibility on community leaders, government and on health workers to elicit community support. Health workers on the other hand place responsibility on local government and on the community.

"Nothing is ever done"

Discouragement and a sense of not having any effect (affecting users and service providers alike) act as a further barriers to community participation in health.

> *"But nothing is ever done when you report these things…. generally these cases end strangely, with nothing ever being resolved …"* (General population, Rural Limpopo)
>
> *"It's a frustrating issue for all of us. The nurses and the people want the conditions to improve, but things move so slowly if they are moving at all."* (Health workers, Rural Limpopo)

4. Lack of information:

There is a fair degree of clarity around what the community can do to supplement service delivery (through e.g. home based care and DOTS – explain this). However, lack of information on *how to become involved in decision-making in health*, what to do and which channels to follow to effect structural change is a further barrier to community participation in health:

"People don't know, we don't know if we are allowed to be involved [in decision-making]. *We are not nurses. We are not qualified in anything that has to do with health."* (General population, Rural Limpopo)

It is therefore important to address equity issues through community empowerment in a way that could impact on structural issues, and not merely to mobilize communities to supplement bad service delivery. Thus it is

important to provide information on an efficient health care system, on governance structures (local, provincial and national), on the role of communities in such decision-making structures and in monitoring service delivery at health facility level as well as through all tiers of governance. This information needs to be accompanied by a call for communities to participate in and support clinic committees and to engage higher order governance structures in ways that would result in broader systemic change – such as calling for greater transparency in resource allocation and the status of implementation plans.

As far as health rights are concerned, health communication could make a meaningful contribution towards greater collective efficacy and community capacity by promoting a shift from emphasizing individual health rights alone to emphasising collective or community health rights and responsibilities.

The National Health BILL
This Bill is currently in parliament and will be passed into law by the time soul city 7 is on air. The Bill's intention is to provide a framework for a structured uniform health system within the South Africa, taking into account the obligations imposed by the Constitution and other laws on the national, provincial and local governments with regard to health services; and to provide for matters connected therewith. The Bill's intention, amongst other things, is to address issues of inequity in the health services and provides mechanisms to ensure greater accountability of the health services to the communities they serve. These mechanisms include legislation around patient rights as well as around community participation in health service delivery.

THE HEALTH BILL

The following is the preamble of the Health Bill that may be an ACT by the time the series is on air.
RECOGNISING—

- the socio-economic injustices, imbalances and inequities of health services of the past;
- the need to heal the divisions of the past and to establish a society based on democratic values, social justice and fundamental human rights;
- the need to improve the quality of life of all citizens and to free the potential of each person;

BEARING IN MIND THAT—

- the State must, in compliance with section 7(2) of the Constitution, respect, protect, promote and fulfil the rights enshrined in the Bill of Rights, which is a cornerstone of democracy in South Africa;
- in terms of section 27(2) of the Constitution the State must take reasonable legislative and other measures within its available resources to achieve the progressive realisation of the right of the people of South Africa to have access to health care services, including reproductive health care;
- section 27(3) of the Constitution provides that no one may be refused emergency medical treatment;

- in terms of section 28(1)(c) of the Constitution every child has the right to basic health care services;
- in terms of section 24(a) of the Constitution everyone has the right to an environment that is not harmful to their health or well-being;

AND IN ORDER TO—

- unite the various elements of the national health system in a common goal to actively promote and improve the national health system in South Africa;
- provide for a system of co-operative governance and management of health services, within national guidelines, norms and standards, in which each province, municipality and health district must address questions of health policy and delivery of quality, health care services
- establish a health system based on decentralised management, principles of equity, efficiency, sound governance, internationally recognised standards of research and a spirit of enquiry and advocacy which encourages participation;
- promote a spirit of co-operation and shared responsibility among public and private health professionals and providers and other relevant sectors within the context of national, provincial and district health plans

In relation to the series messages, the bill proposes that

- Hospital Boards must be appointed for every hospital – functions determined by MEC
- Clinics (or groups of clinics) must have a committee
- If an establishment can't provide care then user must be transferred to another establishment
- All establishments must conform to quality & standards prescribed by Minister

MESSAGE BRIEF:

HIV/AIDS IN THE WORKPLACE

AIDS IN THE WORKPLACE

1. BACKGROUND

Disease management in the workplace is of critical importance in a country where the infection rate is escalating at alarming rates. Soul City Institute for Health Development and Communication (SC IHDC) has adopted HIV/AIDS and access to treatment as one of the five key topics to be researched and integrated into messages for Series 7(TV and Radio drama Series). As a development organisation, Soul City Institute is committed to supporting key government strategies and programmes, especially programmes aimed at decreasing and or preventing the spread of HIV infections. Furthermore, SC has agreed to lend its strategies and mass media vehicles to be the centre of the DPSA (Department of Public Service and Administration) communication strategy.

The DPSA which is the largest employer in South Africa, with approximately 1.1 million employees- with about 30% of employees in national departments, and 70 % in provincial departments, recognises the serious nature of the HIV/AIDS epidemic and its impact on the public service, and is committed to ensuring that the impact of HIV/AIDS on the efficient and effective delivery of services is minimised. The DPSA developed a guide for managing HIV/AIDS in the workplace in response to the Minister's Impact and Action Project developed in 2000, that originated as a response to the serious nature of the HIV/AIDS epidemic and the need to ensure that the Public Service is able to maintain quality services in the context of the epidemic.

The "Impact and Action Project" had three distinct phases:

- An impact study to establish the magnitude of the epidemic and its impact on the Public Service from a workplace and service delivery perspective.
- The development and implementation of a comprehensive programme of action which focused on mitigating the impact of HIV/AIDS on the Public Service.

- The facilitation and implementation of the policies and systems developed in the second phase as well as support for departments as they develop and implement their workplace policies and programmes.

A three year strategy has been developed by the Department to achieve the third and current phase. This includes building internal capacity facilitating the HIV and AIDS policy framework and improved health benefits for public servants ensuring a sustainable and co-ordinated response by government departments to HIV and AIDS in the workplace and evaluating this response.

- All Departments are already, and increasingly will be affected, though there is likely to be a wide variation of risk, due to the differing profile of each department's workforce and the nature of the services it renders:

- Service delivery will be negatively affected –not only due to the number of infected employees, but due to the increased demand for certain services, especially health and welfare, and the ability of the Public Service to attract and retain adequate levels of skilled staff(within the broader labour market);

- Services in remote areas and disadvantaged communities will be particularly vulnerable to absenteeism or death among staff, because of shortages of skilled staff and resource constraints;

- HIV/AIDS will increase the need for training of replacement staff, whilst at the same time comprising the potential for mentoring and skills transfer:

- Sick leave could increase dramatically.

According to the Department, the epidemic is thus likely to impact on many areas of the Public Service, such as:

- Skills development;

- Employment equity;
- Service delivery improvement; and
- Poverty alleviation

2. THE NEED FOR AN EFFECTIVE AND EFFICIENT STRATEGY

Soul City Institute is well renowned for its effective and efficient communication strategies that are well researched and suited for the target audiences. The Soul City brand is well-known and research has shown that people see Soul City as a credible and trustworthy source of information (Research International, 2000 Project Soul City: A look at the Value Association of the Soul City Brand).

Soul City print materials are distributed widely through the mass-media and through partnerships with NGOs, community-based organisations (CBOs), clinics, schools and other community groups. The Soul City and Soul Buddyz television materials are broadcast at prime time on SABC One and have a wide audience.

Soul City Institute and the DPSA has agreed that an effective communication strategy will be key to the success of the workplace policies, programmes and systems as they are implemented and supported by the various government departments.

A comprehensive communication strategy will need to reach the following groups:

- Public servants;
- Political and Administrative leaders within Departments;
- Organised labour;
- General public, opinion formers and community stakeholders.

To achieve the above, both internal (within public Service) and external communication with stakeholders is of outmost importance. An effective and efficient strategy needs to be developed based on thorough research and planning to allow the use of a variety of different tools and vehicles so as to reach the different groups with messages and information that are appropriate to their needs.

For some programmes, like the one for which this expanded communication strategy is envisaged, the communication strategy in itself is an important aspect of the implementation of the programme. Information sharing, awareness creation and other forms of health promotion are critical ingredients for any HIV and AIDS management programme.
The envisaged communication strategy will thus be used to achieve the following main purposes:

- To inform all stakeholders about the existing Public Service workplace programme;
- To solicit the views of all stakeholders regarding the existing programme;
- To spread the necessary information and create awareness about employee health and wellness issues;
- To promote the health and well-being of Public Service employees by exposing them to the necessary health promotion messages.

3. PARTNERSHIP BETWEEN SOUL CITY AND DPSA

The DPSA and Soul City partnership is effective to run over the next two years (January 2005 – December 2006). This partnership would form the

basis for a DPSA communication campaign to reach Public servants, Organised labour, Managers and Decision makers and the General public.

Objectives

To develop an effective communication strategy to communicate the comprehensive programme of action, which focuses on mitigating the impact of HIV/AIDS on the Public Service.

This will be achieved through the following vehicles:

- A colourful easy to read document outlining the DPSA HIV and AIDS document;
- Posters outlining key issues from the policy;
- Z-fold s with key issues from the policy;
- Dissemination of AIDS information through the Soul City (television drama series and Soul Expressions radio series) to public servants;
- Dissemination of AIDS information through the Soul Buddyz (television drama series and parenting book) to public servants

4. HOW WILL SOUL CITY FULFILL THE MANDATE

In terms of the SC-DPSA partnership, the DPSA would have access to all Soul City print materials, and the messages for public servants would be integrated into the Soul City and Soul Buddyz TV and radio drama series currently being developed. All messages would be based on the Soul City research process and would be developed in consultation with the DPSA.

The partnership would therefore involve the following deliverables:

- Soul City print materials: The development of Soul City print materials tailored specifically for the use of public

servants and co-branded with the DPSA logo.

- A workplace policy document (100 000 copies): The development of an HIV and AIDS workplace policy document specifically tailored to the needs of public servants.

- Posters and Z-fold pamphlets that use some of the messages and illustrations from the policy document above. These will be co-branded with Soul City and DPSA logos.

- A health-worker character: The inclusion of a public servant – i.e. a health worker character in the second set of TV episodes of SC 7. His/Her character would carry DPSA HIV and AIDS workplace messages developed through research and consultation.
- A teacher character: The inclusion of a public servant – i.e. a teacher character in the second set of TV episodes of Soul Buddyz. This character would carry DPSA HIV and AIDS workplace messages developed through research and consultation.

- Radio characters: The inclusion of a public servant character into both the Soul City and Soul Buddyz radio series. These characters would carry DPSA HIV and AIDS workplace messages developed through research

and consultation.

- The research and development of these characters and messages to be done by Soul City in consultation with DPSA.

- The management of all aspects of the print and broadcast materials by Soul City in close consultation with DPSA.

5. MESSAGE BRIEF-HIV/AIDS IN THE WORKPLACE

1. THE EMPLOYER

The employer has an obligation to create a supportive and permissive environment for all employees to be able to carry their duties regardless of the HIV status.
This can be achieved through:

- The creation of a supportive environment so that HIV infected employees are able to continue working under normal conditions in their current employment for as long as they are medically fit to do so

- The employer must ensure that HIV (+ve) positive employees are encouraged to continue to work.

- The employer must create an enabling and supportive working environment, and a culture for the disclosure, care and support of employees living with HIV/AIDS as well as the affected.

- Every employer must promote non discrimination and equality on the basis of HIV/AIDS.

- The employer must promote a gender sensitive programme that empowers its employees to be able to protect themselves from HIV/AIDS.

- The employer must create and sustain awareness and implement an HIV prevention strategy in the workplace.

- The employer has a responsibility to build capacity and skills development to enable employees to deal with the impact of the disease in a professional manner.

2. THE EMPLOYEE

An Employee or prospective employees with HIV/AIDS have the same rights and obligations as all employees and should be treated in a just, humane and life affirming manner. HIV/AIDS shall not be used as a justification for the non performance of duties.

- Should an individual be unable to continue to perform duties for which they are employed due to HIV/AIDS, suitable alternative employment should be considered.

- An HIV/AIDS infected employee is governed by the same legislation, regulations, codes and policies governing all other employees.

- HIV/AIDS status shall not deny an employee full participation in all activities of the organisation.

- No employee shall be dismissed or his/her services terminated based on his or her HIV/AIDS status.

3. CONFIDENTIALITY AND RESPECT

The Human rights and dignity of PWA who are employed have got to be respected and protected. Respecting the human rights and dignity of a PWA is essential to the prevention and control of HIV/AIDS in the workplace.

- An Employee who is HIV(+ve) positive has the right to confidentiality and privacy.

- An employee is under no obligation to inform the employer of his or her HIV/AIDS status, and have a right to confidentiality with regard to their HIV/AIDS status.

- A breach of confidentiality without written and expressed consent will be subject to disciplinary measures, (individual, e.g. supervisor who breaches confidentiality) and is punishable by the Law (company, e.g. that discriminates and share info).

- HIV testing without informed consent is a violation of any prospective employee's human rights, and should not be used as a prerequisite for access to work, travel or other services.

4. DISCRIMINATION

Each workplace must facilitate the provision of a comprehensive programme to improve health and safety at work, and not deal with it as an isolated issue for employees living with HIV. The programmes should reflect inclusion.

- Accurate and gender sensitive and understanding language that upholds human dignity should be used in all interaction with the affected and infected.

- The HIV/AIDS status of an employee shall not be used as a criterion to ID or influence the selection of employees for retrenchment.

- Refusal to work with an employee that is HIV/AIDS infected shall be regarded as an act of misconduct.

- An employee's status shall not be required on any routine medical or personnel report.

- No flags or symbols will be used on an employee's personnel records to indicate their status.

- Record keeping should be free of stigma and discrimination.

- An HIV/AIDS status shall not deny an employee full participation in all activities of the organisation.

5. HIV/AIDS AFFECTS US ALL

Everyone in the workplace has a role to play to make sure the policies and programmes are user-friendly.

- All employees must be provided with continued education and information about the modes of transmission of HIV, the means of preventing such transmission, the need for counselling and care, and the social impact of infection on those affected by HIV/AIDS.

- Consultation, inclusivity and encouraging full participation of all stakeholders are key principles which should underpin every HIV/AIDS policy and programme!

- Every employer must develop Information Management systems to confirm information regarding the link between protecting the rights of employees living with HIV/AIDS, and the prevention of further HIV infections.