“Most of us don’t want the reality check.”
– Mpintshi 2010

HCT & Youth:
Issues, Challenges and Lessons Learned

A Review of Literature relevant to South Africa
2010
LOVE\textsc{life}, \textsc{plz cal me} 083 323 1023

Ever had a pressing issue but no-one to talk about it with? Maybe it’s urgent you chat to a counsellor, but your cellphone has no umoya and there is no landline or payphone nearby? Now you can send a PLEASE CALL ME to the love\textsc{life} Youth Line and as soon as a counsellor is available they will call you back and help you. You can speak to love\textsc{life} about anything, not matter how big or small.

Send your please call me to 083 323 1023

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\item [VODACOM] *140*0833231023#
\item [CELL C] *111*0833231023#
\end{itemize}
About loveLife

loveLife promotes healthy, HIV-free living among South African teenagers. Organised under the auspices of the New loveLife Trust, loveLife combines a sustained high-powered multi-media campaign with nationwide community-level outreach and support programmes for youth. loveLife’s programmes are implemented by a national youth volunteer service corps known as groundBREAKERS and Mpintshis in partnership with community-based non-government organisations, schools and government clinics across South Africa. Major funding for loveLife is provided by the South African Government and the Henry J. Kaiser Family Foundation. Additional support is provided by Avis, Barloworld, BMW, DED (German Development Service), Dewey & Le Boeuf, Independent Newspapers, Mondi Shanduka, Murray & Roberts, National Lottery Distribution Trust Fund (NLDTF) Rapport, Royal Bafokeng Holdings, the South African Broadcasting Corporation, Ster-Kinekor, Tone Digital and the Vodacom Foundation.

For more information visit www.lovelife.org.za or call 0800 121 900.
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1. Introduction

It is a well-known fact that South Africa has one of the largest HIV epidemics worldwide. The 2008 HSRC survey, *South African National HIV Prevalence, Incidence, Behaviour and Communication Survey 2008*, found that 10.9% of the South African population aged 2+ years was HIV positive at the time of the survey. Among women between the ages of 25 and 29, one in three (32.7%) were found to be HIV positive. In reaction to these still alarming statistics, the South African government launched a massive HIV Counselling and Testing (HCT) Campaign in April 2010 with the aim of testing 15 million individuals from 12 years and older by the end of June 2011.

The South African National AIDS Council (SANAC) gave the following explanation for the objective of this campaign: “Based on the understanding that HIV Counselling and Testing (HCT) is an entry point to prevention, as well as treatment, care and support services, the campaign’s aim is to bring about positive behaviour change, encouraging individuals and communities to take responsibility for their health by knowing their HIV status.”¹ This aim is an important step in South Africa’s struggle against HIV and AIDS.

As part of the campaign, testing at public venues is planned which, controversially, includes testing at high schools (aimed at both testing teachers and learners). As loveLife focuses on HIV prevention for young people of school-going age, it welcomes the inclusion of this age group into the campaign.

However, children’s rights organisations have stressed the importance of taking children’s needs into consideration, and not to implement the campaign in schools before it cannot be guaranteed that the necessary safeguards are in place to observe child rights at all times.² In addition to these concerns, two further points must be noted: Firstly, HIV Counselling and Testing has already been implemented for some time and these experiences should be considered as valuable insights. Secondly, the campaign is aimed to function as an entry point to prevention. Thus youth-related particularities and needs should inform the campaign’s approach. Only once we fully understand what motivates and scares youth when it comes to HIV and testing, can the preventative function of testing possibly be achieved. As a result, the national HCT campaign, and the HCT schools campaign in particular, require the need for a closer look at HIV Counselling and Testing experiences and the needs of youth when it comes to HIV Testing.

This paper aims to identify these elements to contribute to an informed design for HIV testing among youth – at schools and in general. It includes a detailed review of literature and research in Africa and features, as a matter of illustration, information drawn from interviews and focus group discussions with young people, other stakeholders and role players.

The paper is divided into several sections which discuss the following aspects: Chapter 3 looks at general barriers to getting tested, with a distinction made between two main barriers – on the one hand, there is the external obstacle of stigmatisation and therefore the risk of being isolated from and abandoned by the community and beloved ones because of one’s status. On the other hand, internal motives – first and foremost the fear of death – are an equally strong obstacle to getting an HIV test.

¹ SANAC (2010).
² Yezingane Network (2010).
In Chapter 4, reasons why people get tested, despite previously listed obstacles, are examined. Chapter 5 gives an overview of the aftermath of actual HIV testing, distinguishing between negative and positive test results. Finally, chapter 6 focuses on youth-specific issues: Here, the association between HIV and sex, and its special implications when it comes to young people, are considered. In the then following paragraphs, the key role players in young people’s lives – and thus influencing factors in their behaviour, decision-making and learning processes – are also considered more closely. These include teachers, parents, and peers. The findings of Chapter 3-6 are then discussed in Chapter 7 and conclusions drawn.

Before the content is presented, some explanations as to the design of this paper shall simplify the reader’s understanding of the paper’s structure while reading.
2. About this document

a) The use of the terms HCT and VCT

Voluntary Counselling and Testing (VCT) is based on a voluntary approach by the person who wants to get tested for HIV. HIV Counselling and Testing (HCT) is the so-called provider-initiated approach. People seeking health services for reasons completely unrelated to HIV may thus be approached for an HIV test. While it remains voluntary, people are actively engaged to get tested for HIV through the HCT strategy. The provider-initiated approach includes making testing available at public locations like schools; however, the procedure – in terms of pre- and post-test counselling as well as the test itself – remains the same.

For the purposes of this paper, it is largely irrelevant whether people decided to get tested on their own or whether they were approached and encouraged to get tested. What is important is to identify the reasons why people decided not to get tested; what their experiences were; and what youth think about the procedures. For this reason, and because HCT is a rather new approach and most literature is thus still focused on VCT, the terms HCT and VCT are used interchangeably here, unless otherwise indicated.

b) Articles and interviews

The paper is first and foremost a review of literature based on studies conducted in Africa. Generally, the socio-economic and cultural differences between the continents are too significant to draw meaningful conclusions from studies conducted or based solely on the European or American contexts, for instance. However, a few studies, which were partly or completely conducted on other continents, have nevertheless been included as their focus or study population was too relevant to ignore. Furthermore, African – especially South African – studies with adult study populations have been included because various aspects examined and discussed in these studies are as relevant for 15 year olds as they are for 20 and 30 year olds.

While the bulk of this paper is based on literature, voices from the ground have also been added to not only illustrate study findings but also to give real-life insight into the subject at hand. While these voices are far too few to carry any significant weight in terms of research, they are interesting in that they echo the literature in surprisingly similar ways. The following voices have been included:

**Kutloanong, Free State:** On 4\textsuperscript{th} October 2010, a focus group discussion (FGD) approximately 90-minutes long was conducted with two loveLife groundBREAKERs and two Mpintshis\(^3\) (three males and one female, aged 18-21) at the loveLife Y-Centre in the township of Kutloanong in the Free State. All four were from that township and had finished high school for no more than two years. In addition, the principal of a primary school, also being the community representative at the Y-Centre in Kutloanong, was interviewed for approximately 45 minutes.

**Langa, Western Cape:** On 5\textsuperscript{th} November 2010, an approximately 90-minute-long FGD was conducted with 14 Mpintshis (nine males, six females, aged 11-26, half of them being 19 and 20) at the loveLife Y-Centre in the township of Langa in Cape Town. One went to primary school, six to high school and seven to university.

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\(^3\) groundBREAKERs are young people participating in a yearlong leadership development programme as peer educators/mobilisers. Mpintshis are youth volunteers assisting groundBREAKERs to reach out to young people in communities.
c) The use of footnotes and sources

To ensure that this paper is user friendly and easily readable by various audiences, all statistical information is quoted in footnotes. Statistical information and data of studies may be presented in different ways due to a variety of possible methods. Including this information into the main text would load the text with numbers and may be distracting for readers not mainly interested in the statistics. However, the footnotes also include references to the FGDs and other relevant information. The following scheme was chosen to enable the reader to easily engage with the footnotes: footnotes without a symbol refer to an article or study; footnotes followed by this symbol [] indicate a ‘voice from the ground’ (thus the illustrative quotes); footnotes referring to articles or studies indicate the authors, the year and the specific data related to the information given in the text, e.g.:\[4\]

If a footnote states just the author but does not give any additional data information, the information is part of a qualitative research sample and no statistical data is available. A summary on the general study settings and sample sizes may be found under 8.a) (page 26) in alphabetical order of the authors’ names.

\[4\] Francis (2010): 43% of the interviewees mentioned the desire to use a testing site far from home in order not to meet anybody they know.
3. General barriers to getting tested for HIV

HIV counselling and testing encounters challenges in two main areas when it comes to implementation: first, the high level of stigma related to HIV on a community level impedes people from getting tested due to their fear of being discriminated against and isolated. Second, on an individual level, the fear of death and/or an inaccurate personal risk perception are among the personal reasons why people do not seek HIV tests.

a) External threat: Risk of being stigmatised

The fear of being stigmatised or discriminated against by community members because of an alleged or actual HIV seropositive status was found to be a common reason to avoid an HIV test by various studies. In addition, there is a clear hesitation in the intention to tell others about one’s status in case of testing HIV positive.

“Other people are discovering that they have cancer – and it has destroyed people’s life. But when it comes to HIV/AIDS they start to speak to you like to the devil himself.”  

An often articulated fear was that just being seen approaching a testing facility could spread rumours among the community.

“If they see you going to the clinic they say: Oh, look, he has HIV.”

MacPhail et. al (2009) found that where no one talks about HIV and testing, the chance of people seeking a test is low. In combination with mentioning that one should hide HIV-related illnesses

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5 MacPhail et al. (2008).
6 [ ] FGD Kutloanong, 4 October 2010.
7 Mayhandu-Mudzusi et al. (2007).
8 Råssjö et al. (2007).
9 Horizons (2001): 21% of the Ugandan youth named their fear of others finding out about it as a reason to not going for a HIV test. In Kenya, only 3% of the young people named fear as a personal reason not to get tested. However, when asked about why they think other young people do not get tested, 85% named the fear of others finding out as a deterring reason.
10 Råssjö et al. (2007).
11 Mayhandu-Mudzusi et al. (2007): Nurses interviewed by Mayhandu-Mudzusi et al. 2007 particularly stressed the risk of people continuously infecting others by not telling anyone about their seropositive status.
12 Taylor et al. (2007): For the statement ‘I wouldn’t want anyone to know if I have HIV’ the mean score for tested youth was 2.84 (SD 1.14) and for the untested 2.72 (SD 1.21), p-value 0.52. While tested and untested students thus did not differ significantly in this statement (with all tending slightly towards not wanting people to know) more tested than untested students agreed with the statement ‘If I tested positive for HIV I would not tell anyone’ (mean score 2.89 (SD 1.16) for tested youth v 2.54 (SD 1.06) for untested youth, p=0.03).
13 [ ] FGD Langa, 5 November 2010.
14 MacPhail et al. (2008).
15 Francis (2010): 43% of the interviewees mentioned the desire to use a testing site far from home in order not to meet anybody they know.
16 Horizons (2001).
17 [ ] FGD Kutloanong, 4 October 2010.
18 MacPhail et al. (2009): The variable ‘ever having started a conversation about HIV’ was significantly related to having been tested for HIV for both male and female (females: OR = 1.29, 95% CI 1.0-1.65 (p>0.005); males: OR 1.41, 95% CI 0.99-1.99 (p<0.055).
19 Råssjö et al. (2007).
and suggestions to integrate HIV testing into other health services in order to make the identification of HIV testers more difficult\textsuperscript{20} this is a clear sign that high levels of HIV-related stigma are still very prevalent. Finally, wrong information about the transmission of HIV may increase the stigmatisation of HIV-positive persons\textsuperscript{21} and thus impede more people from seeking an HIV test.\textsuperscript{22}

“It’s still the same, even where we do speak about it. There are those ignorant people that don’t use the same toilet as that person or they don’t even drink out of the same glass as that person. Ignorance still exists.”\textsuperscript{23}[9]

As a result, a major concern when it comes to HIV testing is that of keeping the act of testing and the result confidential. This concern not only impedes people from testing at all; it also influences their preferences when it comes to locations, testing sites, set ups of the testing procedure and their choice of involving others in their choice to get tested. Particularly in smaller communities, fears have been expressed that testing personnel would not keep information about the person seeking a test and its result confidential.

The fear of one’s (seropositive) test result being disclosed can go so far as driving people to abort their post-test counselling session out of concern that the amount of time they spend in the counselling room will indicate their test result to those waiting outside.\textsuperscript{24} Young people feared nurses telling their parents about their testing and results, and would not even trust in their friends’ reactions and trustworthiness when telling them about a seropositive test result.\textsuperscript{25} As a result, they may choose to go for testing on their own: \textsuperscript{26,27}

“I went with my friends for testing because I knew I was negative. If I wasn’t sure I would never go with them – you don’t know what they do if they hear you are HIV positive.”\textsuperscript{28}[9]

In order to stay anonymous, youth would choose a testing site where the risk of meeting someone familiar is minimal.\textsuperscript{29} External service providers coming from another town or district increase the trust in the confidentiality of the testing procedure.\textsuperscript{30}

\textsuperscript{20} Bhagwanjee et al. (2008).
\textsuperscript{21} Taylor et al. (2007): Generally, there was no clear difference in knowledge between tested and untested students. They were generally fairly well informed about transmission through vaginal sex (mean score tested youth 4.18 (SD 1.11), untested youth 4.09 (SD 0.99), p=0.57), or blood contact (mean score tested youth 4.10 (SD 1.32), untested youth 4.21 (SD 1.05), p=0.52). Yet there was a comparatively high belief in both groups of a transmission risk through the use of the same cup (mean score tested youth 2.41 (SD 1.09), untested youth 2.29 (SD 1.05), p=0.43) or toilet. Interestingly, significantly more tested than untested students believed that the use of the same toilet could result in HIV transmission (mean score tested youth 2.82 (SD 1.32), untested youth 2.36 (SD 1.07), p=0.03).
\textsuperscript{22} Kalichman, Simbayi (2003): Participants were asked to agree or disagree to 13 items on AIDS stigma, reflecting negative beliefs about people living with AIDS, shamefulness of the behaviour of people living with AIDS and the endorsement of social sanctions against people living with AIDS. People who had not tested were significantly more likely to agree that people with AIDS are dirty, should feel shamed and guilty. They were furthermore more likely to believe that people with AIDS must have done something wrong and to rather not want to be friends with someone living with AIDS.
\textsuperscript{23} [9] FGD Langa, 5 November 2010.
\textsuperscript{24} Bhagwanjee et al. (2008).
\textsuperscript{25} MacPhail et al. (2008).
\textsuperscript{26} Horizons (2001): 36% of the tested youth in Kenya and more than 50% of those in Uganda went to have the HIV test by themselves.
\textsuperscript{27} Horizons (2006): Less than half of the tested youth were accompanied by someone when they went for a test.
\textsuperscript{28} [9] FGD Kutloanong, 4 October 2010.
Negative conceptions of testing facilities and their staff may equally impede people from getting tested. Unfriendly staff; lack of youth-appropriate services; mistrust in the quality of the counselling; and a perceived lack of confidentiality of the counselling and testing outcomes have been named as deterring people from going to a testing facility\textsuperscript{31} and may be seen as related to the general existence of stigma. Furthermore, inappropriate locations of clinics and testing rooms within the buildings where people could be seen walking in or coming out were named as obstacles for seeking an HIV test.\textsuperscript{32,33,34} In this regard, it was mentioned that by having people waiting right outside the counselling room, those waiting could be able to read the test result from the person’s facial expression when leaving the counselling room.\textsuperscript{35} The lack of information about testing options in local languages has been mentioned as a further obstacle preventing people from visiting the sites.\textsuperscript{36}

b) Internal motives: Fear of death and perceptions around personal risk and life with HIV

The perception that one was in no need of getting tested for HIV was based on views, such as the absence of any individual risk, that testing is unnecessary as long as one is feeling healthy, or that there is no point in finding out that one is HIV positive as there is nothing to be done about it and knowledge of one’s status would only cause depression:\textsuperscript{37}

“When you know earlier you die quickly.”\textsuperscript{38}

In addition to general negative perceptions of HIV and inappropriate testing sites, several individual perceptions may detain a person from seeking an HIV test. The general perception that testing is only for those who show signs of illness may deter those who feel healthy from getting tested.\textsuperscript{39,40} In this sense, and while general and rather broad knowledge about HIV seems to be widespread, deeper knowledge does show gaps, which may cause people to refuse testing.\textsuperscript{41,42,43,44}

\textsuperscript{29} Francis (2010): 43% would choose the testing site based on minimising the likelihood of meeting someone they know, 39% explicitly mentioned that they would choose a testing site far from home.
\textsuperscript{30} Bhagwanjee et al. (2008).
\textsuperscript{31} MacPhail et al. (2008).
\textsuperscript{32} MacPhail et al. (2008).
\textsuperscript{33} Francis (2010).
\textsuperscript{34} Horizons (2001).
\textsuperscript{35} Bhagwanjee et al. (2008).
\textsuperscript{36} Mayhandu-Mudzusi et al. (2007).
\textsuperscript{37} MacPhail et al. (2008).
\textsuperscript{38} Råssjö et al. (2007): 219.
\textsuperscript{39} MacPhail et al. (2008).
\textsuperscript{40} Horizons (2001): Interestingly, while the view that HIV testing was ‘only for the ill’ was expressed by all FGD of youth and parents in Kenya, only 4% of untested youth named feeling sick as a personal motivation for seeking an HIV test and merely 7% of those young Kenyans who actually went for an HIV test did so because feeling ill.
\textsuperscript{41} MacPhail et al. (2008).
\textsuperscript{42} Francis (2010): While all 29 out of 32 interviewees stated that it was “important to know one’s status”, only seven could explain what VCT was.
\textsuperscript{43} Kalichman, Simbayi (2003): Across all participants, HIV/AIDS knowledge was generally high: in a 12-item test the mean score of correct answers among tested participants (n=117) was 85.7% (SD = 15.2) for those who were HIV negative and 84.5% (SD = 17.7) for those who did not know their status (n=86). Untested participants (n=266) had a mean score of 82.3% (SD = 17.6). The difference in knowledge between tested and untested participants was not significant (OR = 0.49, 95% CI = 0.1 – 1.58). However, there was some evidence of important misinformation among tested and untested participants: The items which were most frequently answered incorrectly were: “Must a person have many different partners to get AIDS?” – 26%; “Is AIDS caused by spirits or supernatural forces?” – 43%; “Does washing after sex help protect against AIDS?” – 24%; and “Is
Another personal reason for not getting tested for HIV is fear of death:

“And the information that is communicated to us in regard to HIV/AIDS – it’s still scary. The first question that you asked us, what comes to our mind when someone says HIV/AIDS: death, death – like that.”\textsuperscript{45}\textsuperscript{[9]}

Learning that one is HIV positive appears as such to be a psychological burden – possibly even negatively influencing one’s health itself – so that people prefer rather not to know their status. \textsuperscript{46,47}

“There are other people who think that testing is a life-changing experience. It is either dying or not dying.”\textsuperscript{48}\textsuperscript{[9]}

Learning about being HIV positive may even result in depression and suicidal ideation. \textsuperscript{49} Learning about one’s seropositive status is related to desperation and distress. When it comes to personal feelings after learning about one’s HIV-positive status, suicidal ideation was indeed mentioned repeatedly.\textsuperscript{50}

“They think if they have HIV, their life is over, so they think about killing themselves.”\textsuperscript{51}\textsuperscript{[9]}

\begin{flushleft}
\textsuperscript{44} Horizons (2001): 21% of untested youth in Kampala, 28% in Masaka, and 44% in Nairobi named not being at risk as a reason for not going for an HIV test.
\textsuperscript{45} [9] FGD Langa, 5 November 2010.
\textsuperscript{46} MacPhail et al. (2008).
\textsuperscript{47} Horizons (2001): Fear of learning about one’s seropositive status was named as one reason not to get tested by 44% of untested youth in Kampala, 28% in Masaka, but – remarkably – only 4% in Nairobi.
\textsuperscript{49} MacPhail et al. (2008).
\textsuperscript{50} MacPhail et al. (2008).
\textsuperscript{51} [9] FGD Kutloanong, 4 October 2010.
\end{flushleft}
4. Why some people get tested

Reasons have been identified above for why people refrain from seeking an HIV test, yet it is equally interesting and important to consider the characteristics of those who did get tested in order to identify possible reasons for seeking an HIV test.

A significant relationship has been shown between having been tested for HIV and knowing someone living with HIV or having died of AIDS. 52,53

“They teach you in primary HIV kills, HIV this, HIV that... but it never really hits home until you see someone dying from HIV/AIDS.”54

Women who have been pregnant are also more likely to have been for an HIV test.55,56,57 Further reasons include seeking an HIV test because of being ill,58,59 and because the sex partner was knowingly or suspected HIV-positive.60,61

Furthermore, referring to youth specifically, a survey found that talking to the parents about HIV/AIDS was related to having been tested, as was the participation in a loveLife (HIV prevention initiative designed for youth) programme.62 Finally, it seems that knowing someone who has gone for an HIV test or is even just thinking about it, motivates youth to get tested themselves.63

52 Taylor et al (2007): Besides all other statements, Taylor et al. (2007) used a three-point scale for this question: yes/no/do not know. As to the statement ‘I know someone who is living with HIV/AIDS’ the mean score of tested youth was 1.52 (SD 0.62) as compared to 2.00 (SD 0.68) for untested, p<0.005.
53 MacPhail et al. (2009): The variable ‘knowing someone who died of AIDS’ was significantly related to having been tested for HIV among males: OR=1.68; 95% CI 1.14-2.47, (p=0.009).
54 [  ] FGD Langa, 5 November 2010.
55 MacPhail et al. (2009): The variable ‘ever being pregnant’ was significantly related to having been tested for HIV among males: OR=2.97; 95% CI 2.36-3.73 (p=0.000).
56 Francis (2010): Of the seven girls who had been for an HIV test, four named their pregnancy as the reason for it.
57 Skogmar et al. (2006): Of all tested women, 31% (n=37) tested during pregnancy.
58 Skogmar et al. (2006): 22% (n=32) named being ill but not hospitalised as the reason for testing, another 18% (n=26) tested during hospitalisation.
59 Mac Neil et al. (1999): 33.1% (n=51) of participants reported having been tested because they had symptoms, such as recurrent fevers, diarrhea etc.
60 Skogmar et al. (2006): 10% (n=14) of participants went for an HIV test because their partner was (suspected) HIV-positive.
61 MacNeil et al. (1999): 16.9% (N=26) of participants reported having gone for an HIV test because they had found out that their partner or spouse was HIV positive.
62 MacPhail et al. (2009): The variable ‘talking to parents about HIV/AIDS’ was significantly related to having been for an HIV test for both males and females (males: OR = 1.59; 95% CI 1.16-2.14 (p=0.003); females: OR = 1.67; 95% CI 1.80-2.37(p=0.004)). The same goes for ‘participation in a loveLife programme’ (males: OR = 1.66; 95% CI 1.17-2.34 (p=0.004); females: OR = 1.49; 95% CI 1.14-1.93(p=0.006)).
63 Taylor et al. (2007): The mean score for the statement ‘I know someone who is thinking of testing for HIV’ was 3.76 (SD 0.93) for tested and 3.29 (SD 0.89) for untested youth, p<0.001. For ‘I know someone who had a HIV test’ the mean score for tested youth was 3.89 (SD 0.83) versus 3.15 (SD 0.92) for untested youth, p<0.005. In both cases, there were thus significantly more tested than untested youth who knew someone who had an HIV test or was thinking about it.
5. The effects of having an HIV test

For those who do seek an HIV test, the question arises of what happens after it – of course, this is highly dependent on the result of the test. In both possible scenarios the post-test behaviour is highly relevant, especially when it comes to the sought-after preventative effect of HIV testing.

a) After a negative test result

Where an HIV test is negative, no clear behaviour change could be proven so far. While, worryingly, a negative test result is sometimes seen as a reason for celebration without any thought about future behaviour; potential behaviour change (such as abstinence, condom use or less sex partners) is also mentioned from time to time – yet not regularly. Thus, a negative test result is not clearly associated with behaviour change or even behaviour change intentions.\(^64,65\) In addition, when comparing (planned) risk behaviour of people who have tested HIV negative with that of untested people no striking differences could be identified.\(^65,66,67\)

b) After a positive test result

The need for intense and ongoing counselling in the case of a seropositive test result was mentioned repeatedly.\(^68\) This seems especially important as ‘the attempt to forget’ about one’s seropositive status has been reported as a reaction to the positive test result as well as suicidal ideation.\(^70,71\) Yet, counselling did not seem to have the effect of broader disclosure.\(^72,73\)

\(^{64}\) MacPhail et al. (2008).
\(^{65}\) Denison et al. (2008): VCT recipients were significantly less likely to engage in unprotected sex when compared to their behaviour before the test or to participants who had not received VCT (n=12.348; OR = 1.69, 95% CI 1.25-2.31, p<0.01). On the other hand, VCT did not seem to have an effect on the number of sex partners (n=8.803; OR = 1.22, 95% CI 0.89-1.67, p>0.05). However, the authors note that in both cases the findings across studies were not consistent. The most significant behaviour change was found in HIV-positive individuals and discordant couples in two further studies with very small sample sizes.

\(^{66}\) Kalichman, Simbayi (2003): As to the risk behaviour, more than 40% of both groups, untested and tested not-positive, had two or more sex partners in the previous three months; more than 10% of both had traded sex for money or food; 35% had had an STI and 13% had a history of genital ulcers. In total, 69% of those tested indicated at least one of seven described HIV risk factors, as did 62% of those who had not been tested.

\(^{67}\) Van Dyk, van Dyk (2003): Fewer than half of the participants (46.5%) said that they would change their sexual behaviour if they tested negative – 53.5% said they would not change their behaviour. Interestingly, of those who stated knowing someone living with HIV/AIDS, 53.4% were willing to change their behaviour after a negative test while only 38.1% of those not knowing anybody with HIV/AIDS stated the same.

\(^{68}\) Francis (2010): Of 32 youth, 29 said they would change their behaviour after a positive test result; only 17 mentioned the same for a negative test result.

\(^{69}\) MacPhail et al. (2008).
\(^{70}\) Bhagwanjee et al. (2008).
\(^{71}\) Skogmar et al. (2006): 33% of participants (n=47) reported that they were in denial initially, 8% (n=12) said they had not yet accepted their status and 9% (n=13) stated having suicidal thoughts.
\(^{72}\) Skogmar et al. (2006): No significant difference could be proven between patients with only pre- and post-test counselling in comparison to those attending professional counselling or support groups and those not attending any form of counselling.

\(^{73}\) MacNeil et al. (1999): While disclosure increased significantly during the time of the study, no significance in disclosure could be identified between the group receiving enhanced care and support, including home visits and education of family members and the control group, which had merely access to regular health services in local facilities.
As has been stated earlier, there is a significant fear of stigma, and trust in community support is hardly existent. However, in general, most people who are HIV positive report having disclosed their status to at least one other person. Yet, time periods between diagnosis and disclosure may vary significantly.

Young people articulated their fear to disclose their seropositive status to their parents and bringing ‘disgrace’ to their family. In addition, disclosure requires simultaneous acknowledgment of one’s sexual activity. However, trust in parents’ support was still regularly mentioned. Support by parents and other family members seems to be perceived as crucial as disclosure to them has been widely reported not only by minors but also by adults.

74 MacPhail et al. (2008).
75 Wolfe et al. (2006): Even though only 12% of participants had not disclosed their status to even one other person, 94% had kept their seropositive status secret from their community.
76 Horizons (2006): Out of the 13 HIV-positive youth interviewees only one had accessed a care and support programme, two were receiving services for the prevention of mother-to-child transmission. The remaining ten had not accessed any service following the VCT.
77 Skogmar et al. (2006): 92% of participants had disclosed their seropositive status to at least one other person.
78 Wolfe et al. (2006): 88% of participants had disclosed their status to at least one other person.
79 MacNeil et al. (1999): While at baseline, merely 18.8% had shared their results with someone, 84.4% had done so after six months.
80 Norman et al. (2007): 16 of 25 individuals had disclosed their HIV-positive status while another 3 were likely to be HIV positive as they were married to HIV-positive persons and had refused testing.
81 Deribe et al. (2009): Of the 705 participants, 94.6% of men and 94.3% of women had disclosed their seropositive status to at least one other individual.
82 Visser et al. (2008): Despite the fact that respondents knew their HIV-positive status for less than four weeks (median one week) 59% already reported having disclosed their status to one person other than health care providers.
83 Paxton (2002): Most respondents reported feeling shame, loss and worthlessness after diagnosis and kept their status a secret for some time. The average time between diagnosis and disclosure was 2.6 years (females 2.0 years, males 3.4 years).
84 Visser et al. (2008): While, given the very short time period since the diagnosis, a comparatively high percentage of women (59%) had already disclosed their status to someone else, among those who had not done so the main reasons were not feeling emotionally ready to disclose to their partners (27.8%), parents (21.5%) and other relatives (22.1%).
85 MacNeil et al. (1999): While at baseline, merely 18.8% had shared their results with someone, 84.4% had done so after six months.
86 Deribe et al. (2008): Of the 94.5% of participants (n=666) who reported having disclosed their status, most of them reported disclosure on the day of receiving the test result (73%), then within two weeks (12%), in 2 to 4 weeks (9%), in 1 to 4 months (4%) and the least in a period greater than four months (2%).
87 Horizons (2001).
88 MacPhail et al. (2008).
89 Horizons (2001).
90 MacPhail et al. (2008).
91 Horizons (2001).
92 Lam et al. (2007): Of the 66 youth participants, 88% (n=58) reported having disclosed their HIV-positive status to their immediate family, and 32% (n=21) to their extended family.
93 MacNeil et al. (1999): At baseline as well as after six months, parents had been the most frequent persons of trust with 14.9% sharing their results with them at baseline and 39.6% after six months. This is particularly interesting as participants were all over 18 years old and had a mean age of 32 years. Parental support thus seems to be important not only for youth.
94 Wouters et al. (2009): Of all participants, at baseline 77.1% had already disclosed their seropositive status to their parents.
95 Deribe et al. (2008): Among the 705 participants, 666 (94.5%) indicated that they have disclosed their status to at least one person; 33.2% named a relative.
Less trust and the fear of becoming the subject of gossip were sometimes associated with disclosing one’s seropositive status to friends and other people.  

“If I was HIV-positive I would want to learn it alone. He may be my best friend, I don’t know how he reacts if I’m HIV positive.”

On the other hand, high numbers of youth have shared their test results with others, namely with peers. The sharing of test results with friends seems rather unpopular among older age groups, although exceptions have been reported as well. When it comes to disclosure to partners, research findings have been inconsistent and no general tendency could be defined. However, in line with general considerations of stigma and fear of discrimination, people have been reported to be less likely to disclose their status to their partner if they had never talked about HIV previously; if they did not know their partner’s HIV status; or did not perceive the relationship as long lasting.

96 Paxton (2002).
97 Kalichman et al. (2003): 74% of participants had disclosed their HIV status to all family members; 79% had disclosed their status to their mothers and 65% had told their fathers.
98 MacPhail et al. (2008).
99 Deribe et al. (2009): 40% of participants identified someone to whom they did not want to disclose their status. Those people were neighbours (males 51.1%, 56.6% females), a relative (males 19.0%, females 21.0%), a partner (males 18.9%, 12.6% females), a friend (males 4.4%, 3.5% females), workmates (males 5.1%, 0.7% females), employers (0.7% females) or any person (1.5% males, 4.9% females). The reasons these individuals did not want to tell their HIV-positive status were fear of stigma and discrimination (males 73.3%, females 76.4%), not to worry others (males 17.8%, females 10.0%), fear of gossip (males 6.7%, females 6.4%), fear of negative reaction (males 1.5%, females 5.0%) and fear of job loss (males 0.7%, females 2.1%).
100 [ ] FGD Kutloaong, 4 October 2010.
101 Horizons (2001): Between 87% in Kampala and 95% in Nairobi shared their result with someone. More than one-third at each site shared their result with peers being the most common contact point. Fifty-five percent of tested youth in Kampala shared their result with their partner or spouse. Yet as tested youth have not been asked for their test result, it is not clear whether HIV-positive and HIV-negative youth shared their result to an equal degree.
102 Lam et al. (2007): 42% of the HIV-positive youth (n=28) had disclosed their seropositive status to their close friends.
103 MacNeil et al. (1999): Only 5.8% of all participants at baseline and 11.7% after six months had shared their seropositive result with a friend.
104 Deribe et al. (2008): Of 666 adult individuals who had disclosed their seropositive status to someone, only 14.2% did so to friends.
105 Kalichman et al. (2003): In this study, 88% (n=305) of all HIV-positive participants reported having disclosed their status to all of their friends. However, this study has been conducted in the United States and socio-cultural dynamics may differ significantly.
106 MacNeil et al. (1999): At baseline, 12.3% had shared their result with their spouse, 5.8% with a sexual partner. After six months, spouses had been informed about the seropositive status by merely 24.7%, as had 18.8% of sexual partners.
107 Deribe et al. (2008): In contrast to MacNeil et al. (1999), 90.8% of all respondents had disclosed their seropositive status to their partners in Deribe et al.’s study (2008).
108 Skogmar et al. (2006): 79% of those who reported having had one or more partners since diagnosis (n=115) said they disclosed their status to their partners.
109 Horizons (2001): While in Kampala approximately 55% of tested youth shared their result with their spouse or partner, only about 30% did so in Nairobi and just 15% in Masaka. In addition, it must be recalled that the test result of participants are unknown, disclosure might thus only have taken place in case of a negative test result.
110 Deribe et al. (2009): Men who did not report prior discussion about HIV testing with their partners were 86% less likely to disclose their result in comparison to those who reported having had a discussion (OR 0.14; 95% CI 0.05-0.40). Furthermore, men and women who reported not knowing their partner’s HIV status were 99% less likely to disclose their status to a partner then those who reported knowing their partner’s status (OR 0.01;
After disclosure, generally social support is reported, especially by family members and friends.\textsuperscript{111-116} This was furthermore supported by the responses of parents who articulated the wish to be a resource and help for their HIV-positive children.\textsuperscript{115,116}

Initial reactions of partners have reported to be mixed – some studies revealed mainly supportive reactions to disclosure, while in others, participants reported broadly negative reactions, such as anger, fear and disbelief – at least as first reactions.\textsuperscript{117,118} However, when it comes to the reactions of partners it may need to be taken into consideration that sexual partners may be directly affected by the seropositive status and may thus react more emotionally.

As far as behaviour change is concerned, increased condom use by HIV-positive persons has been reported.\textsuperscript{119,120} HIV-positive youth reported avoidance and refusal to sex as coping strategies, yet

95% CI 0.00-0.07 and OR 0.01; 95% CI 0.00-0.05 respectively). Women who perceived their relationship would end shortly were 92% less likely to disclose their status than those who perceived their relationship as long lasting (OR 0.08; 95% CI 0.01-0.77). Similarly, women who were not married were 92% less likely to disclose (OR 0.23; 95% CI 0.08-0.69).

\textsuperscript{111} Paxton (2002): In addition to support by friends and family members, respondents here also reported public disclosure and speaking out as community AIDS educators as a very rewarding experience – despite various negative consequences. ‘Putting a human face to AIDS’ was generally perceived as increasing community acceptance and support and as decreasing stigma.

\textsuperscript{112} Visser et al. (2008): 36.7% of parents (n=49), 48.3% of relatives (n=58) and 57.1% of friends (n=35) reacted supportive and accepting to the disclosure. Yet an equal amount of parents (36.7%) reacted with sadness, hurt and fear. While particularly the percentage of parents may seem comparatively low, it needs to be considered that in this study, women themselves knew their status for less than 4 weeks at the time of the interviews. Reactions to disclosure can thus only be considered to be short-term reactions and may not be indicative for long-term rejection or support. In any case, only a very small number of women reported negative consequences from their disclosure, such as abandonment by their partners (2.3%), physically hurt (1.7%) or threatened with death (1.2%).

\textsuperscript{113} Norman et al. (2007).

\textsuperscript{114} Skogmar et al. (2006): 96% (n=49) of told mothers, 93% (n=39) of brothers, 92% (n=24) of fathers and 88% (n=59) of sisters were reported to have reacted with acceptance and moral support when the seropositive status was disclosed to them.

\textsuperscript{115} MacPhail et al. (2008).

\textsuperscript{116} Skogmar et al. (2006): Respondents who had disclosed their status to their parents, reported support in the majority of the cases, for mothers 96% (n=49), for fathers 92% (n=24).

\textsuperscript{117} Deribe et al. (2008): Of the 90.8% of participants who disclosed their seropositive status to their main partners, 46.4% reported a supportive reaction; 38.4% responded in a reassuring way. Only in 2.4% of the cases were partners reported to have shown an annoyed reaction. In total, 80.3% reported a positive reaction and only 5.2% a negative response.

\textsuperscript{118} Visser et al. (2008): Only 11.9% of partners to whom the seropositive status was disclosed reacted supportive and accepting, while 30.5% reacted with denial and disbelief, 14.6% with shock and 15.2% with sadness, hurt and with fear. However, as has been mentioned in relation to parents’ reactions, it needs to be taken into account that these partner reactions can only be seen as short-term reactions and are no indicator for sustained rejection or support.

\textsuperscript{119} MacNeil et al. (1999): At baseline, 15.6% of participants had used a condom at last sexual intercourse, 31.2% had discussed condom use with their partner in the last three months and 31.2% had asked their partner to use a condom in the last three months. After three months, these numbers had increased to 55.8%, 61% and 59.7% respectively. After six months numbers had remained almost stable in comparison to the three months sample with 54%, 66.2% and 63% respectively. Thus, while there is a clear increase, condom use did not reach or even come close to 100% coverage among HIV-positive individuals.

\textsuperscript{120} Lifshay et al. (2009): 12 of 37 participants reported consistent condom-use since their diagnosis. An additional 10 participants reported non consistent condom use. Both groups however, reported having used a condom for the first time shortly after receiving their test result. The remaining 15 participants reported not
younger adolescents believed more strongly in abstinence than older ones, while older ones opted for condom use.\textsuperscript{121}
6. HIV Testing: Issues specific to youth

Approximately 42% of the South African population is under 20 years of age and mostly still HIV negative. This huge population group will be South Africa’s future working population. It is loveLife’s goal to substantially reduce the rate of new infections among these youth and thus ultimately change the prevalence rates in older age groups. Where HIV testing has a preventative effect, it is thus a laudable initiative among those who may, in their majority, still be HIV negative, but be at high risk to become HIV positive in the future. Yet, while HIV testing is always a sensitive issue, it is even more so when it comes to adolescents.

Some well-recorded reasons for taking risks despite knowledge of HIV and its transmission includes: Where sex may be used as a means to obtain money or other material goods – especially in an environment of extreme poverty, the abstract risk of HIV might not outweigh this chance of monetary or material income. This is especially the case between young girls and older men, in the so-called ‘sugar daddy’ relationships. These sexual relations may also involve sexual violence, where safe sex is mostly not a given option.

In addition, multiple sex partners are highly valued among adolescent boys among whom this is perceived as a sign of potency and manhood. Furthermore, and applicable to both boys and girls, motivations that may compete with safe sex messages are curiosity and insecurity. On top of the aforementioned reasons for not seeking an HIV test, underestimating the personal risk is a major reason why youth do not get tested:

“The information we give about HIV stays here in the Y-Centre. They don’t feel it has anything to do with them.”

A general feeling of invulnerability and ‘it can’t happen to me’-attitude is typical for adolescents. This is reflected in youth reporting risk behaviour by stating at the same time that they do not feel at risk.

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122 Statistics South Africa (2010).
123 HSRC (2008): The HIV prevalence among youth younger than 20 years (ranging between 2.0 and 6.7%) is significantly lower than for the total of the population (10.6%). Within this group females aged 15 to 19 have a much higher prevalence (6.7%) than males of the same age group and all children under 14 years (<3%). However, the prevalence increases exponentially in the next age group to 21.1% among 20 to 24-year-old females and up to 32.7% among females aged 25 to 29 years. The prevalence among males peaks in the age group 30-34 years at 29.1%.
124 Råssjö et al. (2007).
125 Campbell et al. (2005).
126 Råssjö et al. (2007).
127 Taylor et al. (2007): 19.6% of tested and 6.3% of untested youth reported experience with coercive sex (n = 936, tested = 51, untested = 885).
128 Råssjö et al. (2007).
129 Bakeera-Kitaka et al. (2008).
130 Råssjö et al. (2007).
131 Campbell et al. (2005).
132 Bakeera-Kitaka et al. (2008).
134 Horizons (2001): 44% in Nairobi named not feeling at risk at the reason why they had not tested so far, while at the same time reporting risk behaviour. 21% in Kampala and 39% in Masaka named not feeling at risk as the reason for not seeking a test. In Nairobi and Masaka this was the most listed reason for not testing.
“Most of us don’t want the reality check.”

a. **Stigmatisation of youth' sexuality**

The primary mode of HIV transmission in South Africa is (heterosexual) sex and this constitutes a particular challenge when it comes to dealing with youth and HIV testing. A youth-specific reason for not seeking an HIV test is the association of HIV testing with sexual activity and the associated fear of neighbours, community members and especially of parents finding out about the young person seeking an HIV test and thus being sexually active:

“Parents say: why do you want to know about HIV? You don’t have sex!”

Youth sexuality is stigmatised by parents, teachers and the community as a whole and considered to be “bad behaviour” and “immoral”. In this sense, ‘life orientation’ classes at school where pupils are supposed to be learning about sexuality and HIV/AIDS tend to be superficial and not helpful to youth in terms of finding an open way of discussing these topics:

“Honestly, life orientation for us is an easy grade – that’s what it is.”

When youth who had gone to testing were asked what they most liked about the testing experience, ‘advice’ was the most common answer. In combination with the seemingly poor quality of the life orientation classes at schools, it points towards the apparent need of youth to have access to contact persons whom they can trust with questions related to issues such as sex and HIV.

b. **Key role players in HIV testing for youth**

i. **Teachers**

Teachers report feeling unprepared and uncomfortable when talking during life skills sessions about topics like HIV and sex:

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135 Macintyre et al. (2004): Of 2 963 individuals, 20% were highly vulnerable, meaning that they reported risk behaviour but no perception that they were at risk. 14% reported risk behaviour and acknowledged being at risk.


137 Horizons (2001): This reason has been mentioned by some youth as an obstacle to seek an HIV test. In addition, the linkage between HIV testing and sexual activity has been discussed in all parental FGD.


139 Pattman, Chege (2003): In most countries of the study children and adolescents felt uncomfortable about the idea of discussing sex and HIV with their parents, especially their fathers.

140 Campbell et al. (2005).


142 Horizons (2001): ’Advice’ was the most common answer on all three sites given by 40% of tested youth in Nairobi, over 60% in Kampala and approximately 70% in Masaka.

143 Pattman, Chege (2003): In South Africa (research in South Africa included in-depth interviews with four life skills educators from schools in KwaZulu-Natal and Limpopo); Rwanda (research was conducted at 70 primary schools in 21 districts yielding a sample 164 female and 292 male teachers); and Tanzania (the sample in Tanzania included 40 teachers, 10 males and 30 females from five different locations).
“For me the other part that I have discovered is that even the teachers ... they wouldn’t want to get tested or anything, so they couldn’t talk about something that they cannot really relate to or understand it.”\(^{144}\)\(^{[9]}\)

“Our teacher said: you know about HIV, so we don’t have to spend time on that.”\(^{145}\)\(^{[9]}\)

They tend to send mixed messages by trying to appease all different stakeholders and fulfill their teaching obligations without teaching their pupils ‘immoral behaviour’.

Furthermore, the teaching style for topics such as sex and HIV needs to be different from that used to teach Maths or Literature, for example. Teachers struggle with this:

“They don’t teach the subject properly, they just... pass by the subject.”\(^{146}\)\(^{[9]}\)

“I think, it’s not because the children don’t want to learn, it’s because the teacher doesn’t take the subject seriously enough... Whenever we get to the subject it’s like, ‘ok you got to be doing this for what? Nine or 10 years, I think you guys have heard enough about HIV and AIDS, so you know what? I’m gonna give you a ten for HIV and AIDS.’ – They don’t go back to the details.”\(^{147}\)\(^{[9]}\)

Moreover, HIV education starts too late for many children – usually after they have had their sexual debut.\(^{148}\)\(^{[9]}\) While a general knowledge exists and the common ‘standard messages’ are known, the way education is done so far does not necessarily motivate youth to seek an HIV test\(^{149,150,151}\) or even behave in accordance with their knowledge.\(^{152}\)

“You know, you can be taught how much or how many times at school, it still depends on the person that you are... So, it doesn’t matter how much information you have on AIDS. That’s why life orientation now can be seen as just a free period, because you’ve been taught the same thing, that you know what is AIDS – from Grade eleven, you will know what is AIDS. So, it’s just who you are that’s gonna save you at the end of the day – it’s not whether you know this much or that much.”\(^{153}\)\(^{[9]}\)

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\(^{144}\)\(^{[9]}\) FGD Langa, 5 November 2010.

\(^{145}\)\(^{[9]}\) FGD Kutloanong, 4 October 2010.

\(^{146}\)\(^{[9]}\) FGD Langa, 5 November 2010.

\(^{147}\)\(^{[9]}\) FGD Langa, 5 November 2010.

\(^{148}\)\(^{[9]}\) Principal of Primary School in Kutloanong, 4 October 2010.

\(^{149}\) Taylor et al. (2007): The fact that more tested than untested youth thought that using the same toilet may cause HIV transmission while in all other statements used to determine knowledge about HIV transmission no difference was found between tested and untested youth indicates that knowledge about HIV does not necessarily motivate seeking an HIV test. See footnote 21.

\(^{150}\) Francis (2010): 29 out of 32 interviewees said that it was important to ‘know your status’ – however, only nine of them had been to an HIV test themselves.

\(^{151}\) Horizons (2001): Eight out of ten youth at all three sites could correctly name at least one VCT facility and the great majority says they want to get tested – 90% of the untested in Uganda and more than 75% in Kenya want to get tested and. However, in both countries the tested youth made up less than 50% of the sample size.

\(^{152}\) Shamagonam et al. (2006): Only on knowledge score could a significant effect of the intervention be shown (t (20.272) = 2.39, p<0.05). At T2 students in the intervention group had higher knowledge scores (M = 13.43; SD=3.28) than students in the control group (M = 12.45; SD = 3.80). On all other outcome measures no significant effects of intervention were found (ps>0.27). The findings at T3 replicated those of T2: the intervention effect on knowledge about spread of HIV was significant (t (17.802) = 2.99, p<0.001), whereas no effects for intervention were found on the other outcome measures (ps>0.10). The mean knowledge score was again higher in the intervention group (M = 13.70; SD = 3.45) than in the control group (M = 12.73; SD = 4.00).

\(^{153}\)\(^{[9]}\) FGD Langa, 5 November 2010.
What does seem to have an influence, on the other hand, is the knowledge of someone who is living with HIV/AIDS – thus dealing with the topic not only in theory, but also in practice.\textsuperscript{154}

“And then obviously I’ve seen a couple of family members and close friends going through that process, where you actually... it becomes real. Look, before it comes actually after you, you don’t quite even think about it, you know. Maybe you think, it happens out there, it’s fine.”\textsuperscript{155 [p]}

\textbf{ii. Parents}

Due to their age, family and especially parents play a significant role when it comes to HIV testing for youth. Very often, parents do not discuss issues like sex and HIV with their children, however:\textsuperscript{156,157}

“Parents don’t want to talk with their children about sex because they think that makes them have sex. At the beginning, people were angry at us because we talked about sex and they said we would encourage their children to do bad things.”\textsuperscript{158 [p]}

Indeed, the association of HIV with sex seems to be very strong\textsuperscript{159,160} so that the concern about the sexual activity may even become more dominant than the concern about their HIV status.\textsuperscript{161}

“Your parents will enforce their way of parenting on everything. Whether it’s for sporting, whether it’s for, like, talking about sex... Take those same people and turn them into teachers. Then they still have that same thing where, ‘yes, I give you information, but it must be in some way to make sure that you don’t engage in sex.’ It’s limited – information taken out and so limiting ways of actually seeing the truth of the whole information.”\textsuperscript{162 [p]}

While parents, when asked, usually indicate their willingness to support their children in case of a HIV-positive result,\textsuperscript{163,164} punishment for the disclosure of a seropositive status has also been reported.\textsuperscript{165} Generally, parents tend to advocate for the need of parental consent to an HIV test on

\textsuperscript{154} Taylor et al. (2007): In difference to all other statements, Taylor et al. (2007) used a three-point scale for this question: yes/no/don’t know. As to the statement ‘I know someone who is living with HIV/AIDS’, the mean score of tested youth was 1.52 (SD 0.62) as compared to 2.00 (SD 0.68) for untested, p<0.005.

\textsuperscript{155} [p] FGD Langa, 5 November 2010.

\textsuperscript{156} Pattman, Chege (2003): This has been stated for most countries of the study. Fathers especially have been identified as being very busy and their role as that of simple provider. This has been stated particularly for South Africa (the South African sample included 40 high school students and 20 non-school-going children from rural and urban areas of the provinces KwaZulu-Natal and Limpopo) and Kenya (the Kenyan sample included 56 pupils and 20 non-school-going children from one rural and one urban location).

\textsuperscript{157} Horizons (2001): When asked about who their source of information is about where to seek an HIV test, parents and teachers have rarely been named on all three sites. The highest percentages achieved are the following respectively: both parents are the source of information for 5% of untested youth in Kampala, fathers have this role for 12% of tested youth in Masaka, fathers are considered a source of information for 4% of tested youth in Masaka and for 4% of untested youth in Kampala. Teachers are asked for information about testing sites by 4% of tested youth in Masaka and 4% of untested youth in Nairobi.

\textsuperscript{158} [p] FGD Kutloanong, 4 October 2010.

\textsuperscript{159} Horizons (2001).

\textsuperscript{160} Campbell et al. (2005).

\textsuperscript{161} MacPhail et al. (2008).

\textsuperscript{162} [p] FGD Langa, 5 November 2010.

\textsuperscript{163} MacPhail et al. (2008).

\textsuperscript{164} Horizons (2001).

\textsuperscript{165} Campbell et al. (2005).
youth or expect the testing staff to inform them about the results.\textsuperscript{166,167} Especially where parents indicate to their children that sexual activity is unacceptable behaviour, this attitude may deter youth from seeking an HIV test or talking to their parents about it.\textsuperscript{168,169} These attitudes are especially problematic as a correlation has been shown between perceiving one’s parents as supportive and seeking an HIV test.\textsuperscript{170,171,172}

### iii. Peers

The fact that youth influence each other in their behaviour cannot be disputed. This has also been mentioned when discussing reasons for not practising safe behaviour despite better knowledge. Equally, (positive) peer pressure can influence the decision to go for an HIV test. When testing is implemented as a group activity at a specific site, for example, a slight sensation of compulsion might emerge, due to the fact that ‘everybody does it’ and further motivated by the doubt of whether refusing the test may appear ‘suspicious’.\textsuperscript{173}

“... Imagine eight guys sitting around here, like this. And you say: I am thinking about getting tested. Out of the eight probably seven will be like: ‘Are you crazy?’ And then afterwards: ‘Ok, so how did it go??’ ‘Nah, I can’t tell you guys: ‘Ah, you are HIV positive!’” \textsuperscript{174} [\textsuperscript{9}]

Yet, independently of whether peer pressure is considered to have a positive or negative impact, peers can also have a supportive function. Peer networks have been reported to be a crucial source of information, especially where parents refuse to have conversations about sex and HIV.\textsuperscript{175} While concerns about sharing positive test results with friends have been expressed,\textsuperscript{176} young people have also reported to share their results with peers.\textsuperscript{177} Knowing people who have gone for testing or

\textsuperscript{166} MacPhail et al. (2008).
\textsuperscript{167} Horizons (2001).
\textsuperscript{168} Horizons (2001).
\textsuperscript{169} Horizons (2006): Only half of the HIV-positive youth participating in the in-depth interviews disclosed their status to a family member.
\textsuperscript{170} MacPhail et al. (2009): The variable ‘talking to parents about HIV/AIDS’ was significantly related to having been for an HIV test for both males and females (males: OR = 1.59; 95% CI 1.16-2.14 (p=0.003); females: OR = 1.67; 95% CI 1.80-2.37(p=0.004)).
\textsuperscript{171} Taylor et al. (2007): On the statement ‘my family will support me to have an HIV test’ the mean score for tested youth was 4.00 (SD 0.78) versus 3.61 (SD 0.94) for untested youth. The p-value being 0.003 this means that significantly more tested than untested youth believed to be supported by their family in seeking a test.
\textsuperscript{172} Horizons (2006): Youth who discussed whether or not getting tested with their families were six times more likely to plan to take an HIV test (planning to go within the next year n=98 v not planning to go, n=341); those who had personal talks with family members were 4 times more likely to have reported an HIV test and those who believed their families would not be upset if they got tested were 5.5 times more likely to have tested for HIV (youth reporting an HIV test, n=36 v those who did not report testing, n=439).
\textsuperscript{173} Bhagwanjee et al. (2008).
\textsuperscript{174} [\textsuperscript{9} ] FGD Langa, 5 November 2010.
\textsuperscript{175} Horizons (2001): In Kampala peers were the second biggest sources of information to learn where to get tested (the first was radio): 57% of tested and 51% of untested youth named peers as source of information; in Masaka peers were the first source with 69% of tested and 62% of untested youth reporting this; in Nairobi, ‘other’ was the biggest source, followed by peers with 43% for tested and 37% for untested youth.
\textsuperscript{176} [\textsuperscript{9} ] FGD Kutloanoeng, 4 October 2010.
\textsuperscript{177} Horizons (2001): More than one-third at each site shared their result with peers, being the most common contact point. Yet as tested youth have not been asked for their test result, it is not clear whether HIV-positive and HIV-negative youth shared their result to an equal degree.
are planning to do so may also function as a motivator, especially when it is people of the same age and in the same life circumstances\(^\text{178}\) – at the end, the more are doing it, the more normal it seems.

\(^{178}\) Taylor et al. (2007): The mean score for the statement ‘I know someone who is thinking of testing for HIV’ was 3.76 (SD 0.93) for tested and 3.29 (SD 0.89) for untested youth, p<0.001. For ‘I know someone who had a HIV test’ the mean score for tested youth was 3.89 (SD 0.83) versus 3.15 (SD 0.92) for untested youth, p<0.005. In both cases, there were thus significantly more tested than untested youth knowing someone who had an HIV test or was thinking about it.
7. Lessons learned: Key strategies for youth and HIV testing

The issue of HIV/AIDS in sub-Saharan Africa in general, and South Africa in particular, has been broadly discussed and a large number of studies have been included in the review. However, there still seem to be specific areas – such as youth-related HIV research, especially when it comes to HIV-positive youth and their behaviour – where there is a lack of sufficient research-based knowledge. Nevertheless, it is believed that the literature review conducted here was broad and comprehensive enough to allow for the drawing of some conclusions. In order to do so, the main findings will be recalled:

As a first step, general barriers to seeking an HIV test have been identified. Among these, the strongest obstacle was a widespread fear of ‘others finding out’, based on a high level of stigma. The fear of being isolated and discriminated against is often so dominant that it prevents people from getting an HIV test in the first place. As a result, anonymity and confidentiality are crucial elements of testing facilities and staff, and may decisively influence people’s decision to get tested. In addition to the fear of stigma, personal reasons for not getting tested have also been identified, among them being the fear of death and a basic lack of personal risk perception.

As a second step, the reasons, which motivate people to go for an HIV test despite all mentioned obstacles, have been identified. These reasons may be divided into health related issues, such as getting tested as part of antenatal care procedures or because the person is feeling sick, and into social motivators, such as knowing someone who got tested for HIV or who died of AIDS.

Thirdly, the general effects of HIV testing have been observed, especially in light of the abovementioned obstacles. For negative test results, no clear pattern could be identified. While few people report actual or intended behaviour change, most of the times no difference in behaviour (including continued high-risk behaviour) has been found between negative-tested and untested people.

For HIV-positive test results, a clearer picture of safer sexual behaviour (increased condom use, fewer sexual partners, less sexual activity in general) has been reported more consistently. And interestingly, in light of the previously reported high level of stigma, there was consistent evidence that a large majority of HIV-positive people disclose their status to at least one other person, parents being among the most regularly named persons of trust, followed by friends and partners whose results were more inconsistent though.

Fourthly, youth specifics have been discussed. Here, after some general findings about why youth specifically may behave in a risky manner, the stigmatisation of youth’s sexuality has been identified as a crucial obstacle for young people to get tested at all. This has been furthermore confirmed in the next sub-section, where key role players have been examined. The reported inadequate sexual and HIV education in schools and the unwillingness of parents to acknowledge their children as sexual individuals seems to stop youth from seeking a test at all. On the contrary, reported conversations about HIV/AIDS and sex have constantly shown a significant relation to youth going for HIV testing. In this sense, peers have been identified as a third crucial group in the field of HIV and youth. The significance of peer pressure – in a positive or negative sense – has been confirmed.

In light of these observations, three levels have been defined on which the above findings are of relevance and should be part of any future considerations or points of intervention.
a. **Messaging: Address the fear**

A key element that can be identified when looking at all obstacles to seeking an HIV test is: fear. On the one hand, there is the fear of illness and death; in short – existential fears of the individual. On the other hand, there is the fear of being stigmatised and discriminated against; in short – fear of abandonment and isolation of the individual as a social creature. These forms of fear need to be addressed.

It has been observed that knowing people who went for testing or who are living with HIV/AIDS is generally positively related to people going for an HIV test themselves. Knowing that there are others with the same concerns, and/or feeling that one is not alone has a motivating influence. This could potentially work in the same way when it comes to fear. In this sense, what should be taken into consideration is the following: Everybody is afraid of being HIV positive – there is nobody out there who does not care. At the same time ‘the community’ is formed by individuals, who, taken one by one, are all afraid of being HIV positive themselves or may even already be so – at the end, we are all in the same boat. Fear is normal and based on the fact that we are human beings who a) care about being alive and b) are social in nature and are thus afraid of loneliness and abandonment. However, not knowing does not make it go away – it merely downgrades the chance to live a longer life and increases the chances of infecting others.

b. **Programmatic: Talk about it**

In addition to the need to address the fear of individuals, communities and society in general through HIV messaging, it should also be addressed programmatically. It has been shown that talking about HIV and testing is associated with a higher likelihood to get tested. By talking about it, stigma is automatically reduced, fear is addressed and the perception of support emerges. Thus, dialogues should be enhanced on various levels:

On one level, community dialogues – possibly in randomly divided smaller subgroups – could help people to confront the topic of HIV. The fact that knowing someone who is HIV positive is positively related with seeking an HIV test may motivate the increased involvement of openly HIV-positive people in these dialogues. Where, due to previous experiences, the risk of subsequent discrimination of the HIV-positive person seems imminent, external people – though from similar settlement types as to make their stories accessible – positively living with HIV could be involved.

On another level, it has been shown that – especially for youth – the openness of parents and talking with peers may have a significant influence on behaviour, especially when it comes to HIV knowledge and testing. When it comes to parents, two aspects should be taken into account: Firstly, parental support has proven to be a motivator for youth. In this sense, they should be engaged in talking to their children. While adolescence is a difficult age and youth usually start to take some distance from their parents, such talks should be enhanced, particularly at the end of primary school, shortly before puberty starts.

Secondly, children and adolescents have individual rights and are clearly deemed capable of making certain decisions on their own. In this sense, parent-independent dialogue possibilities must be offered to youth. As for the proposed community dialogues, HIV-positive people should be involved in these talks, possibly external youth, who are positively living with the virus. The ‘cooler’ they are (in terms of style, activities, etc.) under youth-specific considerations, the better.

When it comes to the content of such proposed dialogues, two aspects should be taken into account: first, they should be centred on the fact that the fear of being HIV positive is common to everybody.
Second, and crucial to decreasing the fear, is an answer to what happens in case of testing positive. As has been stated in Kutloanong:

“They say: don’t get HIV! Be safe! Use condoms! But nobody tells you what to do if you have it.”179

It simply does not make sense to ask people to go for a test, which has two possible results, and not provide guidance for the aftermath of one of the possible outcomes. People need to know what to do if they test positive. This is especially true for young people as they have less life experience and need more guidance and support.

c. Testing: Make it for and about them

Two major obstacles have been identified thus far in terms of HIV testing for youth: First, the general barrier which impedes all people from testing, fear. For youth, this fear is aggravated by their generally greater level of dependence on social surroundings, such as their family and friends and their community. Secondly, the lack of youth-focused and specialised facilities, which are accessible and confidential, makes it harder for youth who may be more willing to test and do so in a comfortable environment.

The locations of testing sites are an important factor influencing their use. When it comes to youth – in addition to the same risks of becoming the subject of gossip and isolation that older people may have – their constitution as young people adds another element: the possible perception of responsibility of community members and testing staff to inform the parents and family about the adolescents seeking an HIV test. Thus, youth prefer sites where they are less likely to meet someone they know.180 Yet, the further away the sites, the less likely it is they will end up going to test at all.181

As a result of their adolescence and still developing identities, young people need specially trained service providers. More sensitivity is required on the part of the health care or service provider and the counsellor needs to be able to act as a friend if needed.182,183 In case of a positive test result, the post-test support needs to be sustainable and able to alleviate the negative effects of learning about one’s status. This becomes even more important in light of the already mentioned risk of suicidal ideation in the light of a positive test result.

When delivering a positive test result, the link to a care and support programme should be established immediately as – once the young person has gone – there is the risk to not be able to get hold of them again. Especially where youth decide not to disclose their status to anyone, this would leave them without any future support. On the other hand, and as has been mentioned previously, youth tend to have a perception of personal invulnerability and are influenced by numerous factors surrounding them (e.g. multiple partners as a status symbol, and socio-economic dependence, particularly among female youth). So, in the case of a negative test result, the still existing risk of getting infected in the future needs to be strongly reinforced.

179 [ ] FGD in Kutloanong, 4 October 2010.
180 Francis (2010): 43% stated they would choose a testing site based on minimizing the likelihood to be seen by someone they know and 39% said they would go to a testing site from home.
181 Hutchinson, Mahlalela (2006): As to the distance from the next testing clinic: Every kilometre that a man lived further away from a clinic reduced the likelihood that he would be tested by 0.7%. For women, each additional kilometre was associated with a 0.4% reduction in the likelihood of being tested.
182 MacPhail et al. (2008).
183 Mayhandu-Mudzusi et al. (2007).
As a result, schools seem to be an environment with some potential for a testing campaign for young people. These would provide exclusively youth-focused spaces, where everybody is expected to be present – thus no genuine suspicion of the person’s purpose of being there can be raised. In addition, the proven effects of peer pressure may be used as a positive dynamic in enhancing more pupils to seek an HIV test. Some NGOs have already implemented HIV testing at schools and may provide good examples of how to take some of the raised concerns into account. In the following box, the NGO Shout-It-Now and its approach to HIV testing in schools will be presented as a practical example of how such testing could be realised:

**Shout-it-Now**

The organisation Shout-it-Now is based in Cape Town and primarily conducts HIV/TB education and testing in schools. Their approach is to use technology educate learners about HIV because it is scalable, inexpensive, and delivers a consistent message. Shout-It-Now ran a trial with 3 500 learners in five schools in 2008. The programme was implemented in schools in Khayelitsha and Soweto in 2009 based upon the very positive trial results. In a little over one year, Shout-it-Now has educated and tested 41 000 people in schools. Ninety-six percent of learners who complete the online programme go for an HIV test with a Shout-it-Now advisor. Shout-it-Now is working on getting the support of the South African and US government to test all learners in South African high schools each year, so as to normalise the procedure.

South African law allows for HIV testing without parental consent from the age of 12. According to Shout-it-Now’s lawyers, to ban a learner from testing would infringe upon their Constitutional Rights. However, an information letter is sent home with the learners shortly before the testing is implemented and parents are encouraged to call Shout-it-Now if they have any questions or concerns.

Learners are taken by class and brought to a marquee tent or classroom at the school where Shout-it-Now’s computers are set-up and the testing takes place. The entire procedure takes 90 minutes per class and is usually linked to a ‘life orientation’ class.

In order to provide learners a reason for participating in front of their peers, small incentives are offered in form of vouchers with a value of not much more than R10. Each learner watches a 13-minute MTV-style video on a Shout-it-Now computer and answers test questions about HIV/AIDS. They receive information about HIV and testing by popular South African celebrities (i.e. Zola, Lira, etc.) to enhance the student’s motivation to learn about and go for an HIV test. In the trial, there was a 13% knowledge increase between the online pre- and post-test. Furthermore, there was a behaviour (intention) change of 92% in ‘test today’, meaning that pupils who initially did not intent to test, changed their mind during the programme. After the computer session, pupils go into brief one-to-one counselling sessions where they are free to ask any questions. As learners are registered by fingerprint and given a bracelet with a number, anonymity is guaranteed, while individuals can be identified at the same time. This registration also allows for the identification of behavioural changes in each person when repeating the testing campaign at the same school the following year.

When going into the personal counselling session, the counsellor has the possibility of accessing the students’ answers from the computer test and thus personalising the counselling session. While students may opt out of the testing, the HIV test is provided immediately subsequent to the counselling session and by the same counsellor in the same room. Thus, others waiting outside are not able to tell whether the person inside decided to get tested or had merely the counselling session.
Students have to wait for about 20 minutes until they receive their test results. During this time, music videos are shown and learners are called by the number of their bracelets back into the counselling rooms. The same counsellors as before give them their results.

In case of a positive test result, learners are told that they have been randomly selected for research, a second test is taken and they are asked to come back for the test result after school. Two or three other learners of the same class, who tested negative, are also told that they have been programmatically selected by the software for research purposes – this ensures greater confidentiality and ensures that even counsellors do not know who tested positive and therefore do not have to lie to the learners when asking them for a second test. To ensure the learners are coming back, they are offered an additional voucher.

When coming back after school, those learners who tested negative are taken first, they are told their results and can leave the premises. Those who tested HIV positive are being told their result by a specially-trained care giver and further options are discussed. This session may take as long as it needs to and pupils personally accompanied to a clinic. HIV-positive clients are even taken to the clinic for CD4 counts and are monitored by Shout-it-Now until they receive their results from the clinic.

While Shout-It-Now is a very young organisation and impact assessment has not been conducted yet, their approach provides answers to many of the concerns raised in relation to HIV testing at schools.

Shout-It-Now: http://www.shout-it-now.org/

Whether HIV testing for youth will have the sought-after preventive effect remains to be seen. Yet, as long as youth specific safeguards are in place and their rights and needs are considered at all times, HIV testing can be seen as an active part of youth education – getting them used to being tested on a regular basis as a normal part of general health care. And between fear, stigma and avoidance, one aspect is clear: The more normal it becomes to talk about HIV and get tested for it, the more HIV will become a part of life which can effectively be dealt with – with the ultimate end of a dramatic decrease of its prevalence.
8. Sources

a. Description of studies referred to in this paper

Bakeera-Kitaka et al. (2008) conducted anonymous self-administered questionnaires and FGD with 75 HIV-positive youth (35 females) aged 11-21 years in urban (n=26), periurban (n=39) and rural (n=10) Uganda.

Bhagwanjee et al. (2008) conducted 75 individual semi-structured interviews with mining employees, who participated in an HIV workplace programme where mining employees receive HIV testing and counselling at their workplace, provided by external testing personnel. In addition, 33 individual semi-structured interviews were held with employees receiving HIV-related treatment and three FGD were conducted in order to triangulate the data sources.

Campbell et al. (2005) conducted 44 individual interviews, 11 FGD with a total of 55 people and used fieldworker diaries in KwaZulu-Natal.

Denison et al. (2008b) compared seven studies conducted in Uganda, Rwanda, Kenya and Thailand in a meta-analysis in order to assess the effectiveness of VCT in reducing HIV risk behaviours.

Deribe et al. (2009) conducted individual interviews with 705 HIV-positive individuals (353 females and 352 males) in Ethiopia. The mean age for men was 34 years, for women 29 years and over 70% of both sexes reported living in an urban area. In addition a total of 22 in-depth interviews were conducted with 11 key informants and 11 persons living with HIV.

Deribe et al. (2008) conducted individual interviews with 705 (353 females, 352 males) HIV-positive individuals between 26 and 35 years in Southwest Ethiopia. Over 70% of the participants resided in urban areas.


Horizons (2006) conducted 40 in-depth interviews with HIV-tested adolescents aged 16-19 years in Ndola, Zambia. Half of the interviewees were female and one-third reported being infected with HIV (n=13). In addition 11 in-depth interviews with family members (being parents or siblings aged 18-61 years) who knew the young person’s HIV status were conducted and a household survey with 550 randomly selected 16 to 19 year olds 62% females). Thirty-six reported having taken an HIV test, five of them reporting being infected with HIV. 341 had never taken an HIV test and did not plan to within the next year (yet only 47% of the sample reported having had sex).

Horizons (2001) conducted in depth interviews and focus group discussions in Nairobi, Kenya and in Kampala and Masaka, Uganda with 14-21 year olds. In Nairobi, 105 tested and 122 untested youth were part of the interviews, in Kampala 86 tested and 111 untested youth and in Masaka 49 tested and 99 untested youth. Furthermore, 12 FGD with 120 persons in Uganda and seven FGD in Kenya with parents (although not necessarily the parents of the youth surveyed) were conducted. If no specific numbers are indicated, information stems from the FGD.

Hutchinson, Mahlalela (2006) used data from a household survey with 2.075 females and 1.445 males aged 15 years and older (590 and 527 respectively being aged 15-24) in the Eastern Cape as well as information from 210 government clinics being in proximity to the areas surveyed. They
examined the likelihood that a person received VCT services as a function of the characteristics of the individual, the household, the closest clinic and the region.

Kalichman et al. (2003) conducted interviews with 233 HIV-positive men and 98 HIV-positive women with a mean age of 37 years in the United States.

Kalichman, Simbayi (2003) let 224 males and 276 females complete an anonymous self-administered survey in different community venues in a black township in Cape Town. Seventy-four percent were 35 years or younger with the mean age being between 21 and 25 years. After excluding those who refused to answer whether they have been tested for HIV (n=12) and those who tested HIV positive (n=19) responses of untested (n=266) and those who tested negative or did not know their result (n=203) were evaluated.

Lam et al. (2007) conducted individual interviews with 66 HIV-positive youth between 16 and 25 years in a US metropolitan area (51% were male, 47% female and 2% male to female transgendered).

Lifshay et al. (2009) conducted 37 in-depth semi-structured interviews with open-ended questions with HIV-positive individuals (17 females, 20 males), aged 25-58 in rural Uganda.

Macintyre et al. (2004) conducted individual interviews with 3.052 adolescents between 14-22 years in KwaZulu-Natal.

MacNeil et al. (1999) conducted semi-structured individual interviews based on a 57-item questionnaire with 154 newly diagnosed HIV-positive sexually active individuals (two-thirds females, one-third males) aged 18-55 years in a rural area of Tanzania. Interviews were conducted at baseline (within a maximum of four weeks after the post-test counselling session), after three months and after six months.

MacPhail et al. (2009) conducted structured interviews with 4.058 sexually experienced females and 3.609 sexually experienced males between the age of 15 and 24 years. The goal was to explore the correlates of HIV testing among sexually active South African youth (p<0.05).

MacPhail et al. (2008) conducted 24 focus group discussions with 240 adolescents aged 12-24 and 12 with 120 parents in two townships in Gauteng.

Mayhandu-Mudzusi et al. (2007) conducted 20 individual interviews with nurses providing VCT services in Limpopo Province.

Norman et al. (2007) conducted 25 in-depth interviews with 25 individuals (88% females) in a rural area in Western Cape (n=14) and an urban area in KwaZulu-Natal (n=11).

Pattman, Chege (2003) collected in-depth, mainly interview-based research on the experiences and identities of boys and girls aged between 6 and 18 years from the ESAR countries of Botswana, Kenya, South Africa, Tanzania, Rwanda, Zambia and Zimbabwe.

Paxton (2002) interviewed 75 HIV-positive individuals (43 females, 32 males) from 20 countries in Eastern and Southern Africa and the Asia-Pacific region (Australia 14, Botswana 3, Guam 1, Hong Kong 1, India 1, Indonesia 1, Japan 1, Kenya 3, Malaysia 1, Singapore 1, South Africa 4, Swaziland 1, Taiwan 1, Tanzania 1, Thailand 9, the Philippines 12, Uganda 12, Vietnam 1, Zambia 4, Zimbabwe 3) who disclosed their seropositive status publicly among groups of people or in the media.
Råssjö et al. (2007) conducted 22 semi-structured interviews (11 females aged 15-22 years, 11 males aged 16-21 years), five FGD (3 groups with a total of 20 females aged 13-19 years; and two males with a total of 21 males aged 12-24 years) in Kampala, Uganda.

Shamagonam et al. (2006) evaluated the life skills programme on HIV/AIDS among Grade 9 students (n=936, aged 12-21 years, 48.5% males) in 22 schools in KwaZulu-Natal. The Life Skills Programme was implemented at 11 schools with at least one lesson a week over a period of two school terms, thus 20 weeks (intervention group), the students at the other 11 schools received merely odd lessons about aspects of HIV/AIDS in a non-structured way (control group). Questionnaires were distributed before the intervention, immediately after it (T2) and as a follow-up four months after the intervention had ended (T3). Knowledge was measured by 18 statements to which the answers were measured by recoding them into ‘correct’ (1), ‘incorrect’ (-1) and don’t know (0). Possible scores could thus range from -18 to +18. In addition, attitudes towards condom use and towards people living with AIDS, perception of social support and past/intended and general sexual behaviour as well as communication about HIV/AIDS and safer sex were measured.

Skogmar et al. (2006) conducted individual interviews with 144 HIV-positive individuals (118 females) between 20 and 57 years of age (mean age 34 years) in Johannesburg. 72% of participants had known their status for more than a year.

Taylor et al. (2007) distributed a structured questionnaire to 1,192 students between 14 and 20 years at 28 high schools in KwaZulu-Natal (544 male, 645 female, three did not provide gender information). Students were asked whether they ever had been tested for HIV and were then divided into ‘tested’ (n=57) and ‘untested’ (n=1042). Students were asked to use scores from ‘strongly disagree (1)’ to ‘strongly agree (5)’ to rate different statements and when comparing the answers of ‘tested’ and ‘untested’ the level of statistical significance was taken to be p<0.05.

Van Dyk, van Dyk (2003) distributed a semi-structured questionnaire to 1,422 persons (37.8% males, 62.2% females) of an average age of 32.2 years. The questionnaire was distributed in rural and urban areas in all nine provinces of South Africa. 51.4% of the participants had been tested for HIV, yet they were not asked to disclose their status and question about their behaviour referred to hypothetical situations.

Visser et al. (2008) interviewed 293 pregnant women between 17 and 41 years (mean age 26 years) in two communities in Tshwane, South Africa shortly after they found out they were HIV positive.

Wolfe et al. (2006) conducted interviews with 112 HIV-positive persons between 30 and 50 years (50% females) in Botswana.

Wouters et al. (2009) conducted a series of open-ended questions with 268 ART patients (mean age 38 years, 66.8% women) in Free State. Participants had been diagnosed with HIV from six months to 15 years previously.
b. **References and further bibliography**


Yezingane Network (2010), open letter to the Minister of Health presenting the children’s sector’s concerns about HCT in schools, 21 September 2010.

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