

# Dying of AIDS, Dying of Fear

Barriers to VCT uptake in a Lesotho Garment Factory

*By*

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For

**ALAFA - Apparel Lesotho Alliance to Fight AIDS**

# ALAFA

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# 1 Introduction

Lesotho, with a population of around 2 million people, has one of the highest HIV prevalence rates in the world. Every fourth woman and every fifth man (age 15-49) is infected with the virus.<sup>1</sup> In urban areas, where Lesotho's industries are concentrated, infection rates are the highest, at 28.8%. Rural rates are somewhat lower (21.8%), but remain significant due to high levels of mobility and migration. Prevalence rates also vary according to age and gender: younger women (aged 15-29) are nearly twice as likely as their male counterparts to be infected. The rates for both sexes reach a peak in the 35-39 age category, with just over 40% of women, and just under 40% of men, being infected. From this peak the rates decline, but male prevalence now remains consistently higher than that of women.<sup>2</sup>

The high infection rates resulted in the deaths of 13,000 women and 11,000 men in 2005. One reason for this is that, by 2005, less than one fifth (19%) of those with advanced HIV infection were receiving antiretroviral combination therapy.<sup>3</sup> Nearly 100,000 children have been orphaned by the pandemic, placing a considerable burden of care on one of poorest nations in the world. Less than 25% of orphans have access to external support provided by the State or other agencies.<sup>4</sup>

The prevalence rates are associated with poor understanding of HIV transmission and high risk behaviour. In 2004, only 18% of males and 26% of females aged 15-24 were able to correctly identify the key ways of preventing the sexual transmission and reject major misconceptions about HIV transmission. In this critical age category, 89% of males and 42% of females had sex with a non-marital, non-cohabiting sexual partner in the last 12 months. In only half of the cases was a condom used.<sup>5</sup> The use of voluntary counselling and testing (VCT) services is low, with less than 1% of the population thought to have used VCT services by 2006.<sup>6</sup>

The high infection and mortality rates have devastating impacts on households already struggling to make ends meet in a low-employment economy. The loss of wage earners, through illness and death, undermines the health, education and well-being of all household members. At the macro-level, there are concerns that the loss of productive workers will "lower the country's economic growth rate and output, and thereby hinder its development prospects".<sup>7</sup>

The garment sector, which generates the bulk of Lesotho's exports and employs around 47,000 people, will be particularly hard hit by the pandemic as it employs large numbers of women in vulnerable age categories.<sup>8</sup> In response, a private sector initiative, known as the Apparel Lesotho Alliance to Fight Aids (ALAFA), was launched in May 2006 to provide education and prevention, VCT, and management of the disease through the roll-out of antiretroviral drugs.

This report documents the findings of an in-depth investigation carried out in one of the ALAFA-supported factories (Precious Garments) into the use of VCT and related services now being offered by the Project. It begins with a brief description of the Project and then gives an account of the study methods. The findings are described in relation to the key research questions. Each section includes concise text boxes that consider the key programme implications of the findings. The final chapter summarises the findings and presents the overall recommendations for the ALAFA project. Given the widespread interest in issues related to the uptake of VCT and ARV services, the report is likely to be of value to other work-based VCT/ARV projects, as well as to those working more widely in the HIV/AIDS sector.

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<sup>1</sup> UNGAS, *Status of the Lesotho National Response to the United Nations General Assembly Special Session Declaration of Commitment on HIV/AIDS*, 2006.

<sup>2</sup> *Ibid.*

<sup>3</sup> *Ibid.*

<sup>4</sup> *Ibid.*

<sup>5</sup> *Ibid.*

<sup>6</sup> <http://www.iavireport.org/vax/primers/vaxprimer26.asp>

<sup>7</sup> [http://www.centralbank.org.ls/publications/03\\_04\\_Economic\\_Review.htm](http://www.centralbank.org.ls/publications/03_04_Economic_Review.htm)

<sup>8</sup> 80% are aged between 20 and 35 years (ALAFA, Seroprevalence Survey, 2007).



## 2 The Project

The ALAFA project is described as “a comprehensive private sector response to the pandemic in the textile and clothing industry in Lesotho...that will be one of the biggest private sector interventions in the world”.<sup>9</sup> It is an industry-wide health intervention programme, designed for ComMark Trust with funding from the UK’s Department for International Development. A pilot project is being supported by the US clothing house Gap Inc, which sources garments in Lesotho.

The initiative is expected to help approximately 47 000 Basotho workers in the industry. A related ALAFA study found that seroprevalence rates in the industry exceed 40%, and it is estimated that the disease kills around 2 300 apparel workers every year, presenting a major threat to the industry.<sup>10</sup>

ALAFA aims to be inclusive in its approach and to involve government, service providers, industrialists, labour, garment sector clients (brands and retailers), donor agencies and multinational organisations in the fight against the pandemic. The project is part of the move to make the Lesotho apparel industry more robust and to enhance its reputation as an increasingly socially responsible source of clothing for some of the world’s biggest brands. It will provide education and prevention, voluntary testing and counselling and, ultimately, the management of AIDS through the roll-out of antiretroviral drugs.

Precious Garments, an apparel factory in Maseru, was the first company to benefit from the HIV treatment component of ALAFA. Precious Garments employs about 4 500 people and has an internal HIV voluntary counselling and testing service. By September 2006, 497 employees had been tested and about 60 were on ARV programmes.

With the establishment of the Alafa treatment programme, HIV positive employees are now able to access treatment and laboratory services from the private sector. After being diagnosed with HIV, employees may register with ALAFA and choose a doctor from a list of eight private doctors. ARVs and laboratory services are free and the patients only pay R10 per consultation with the doctor.

By the end of September 2006, only 83 employees had registered with ALAFA and, of these, only 18 had actually visited the doctor of their choice. Many reasons for the low uptake of registration and treatment were suggested but these were anecdotal and provided little hard data with which to understand and address the barriers to registration and treatment. As a result, it was decided to undertake an in-depth investigation of the issues at hand.

It should be noted that the field research took place at over some six months (April-Sept 2007), with different research activities being spread over this time. This was a dynamic period for the ALAFA project during which the number of workers making use of the VCT services at Precious Garments rose to 762 (by Oct 2007).

The next chapter describes the objectives of this study and looks at how it was undertaken.

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<sup>9</sup> <http://www.commark.org>

<sup>10</sup> Survey conducted for ALAFA by Sechaba Consultants, 2007.



## 2.1 Key Objectives and Research Questions

The objective of the study was to determine the constraints that existed with regard to:

- the uptake of VCT services;
- registration for treatment;
- seeking of treatment once registered.

Three simple research questions related to the objectives were formulated:

1. Why do people not test?
2. Why do people who come for VCT and who get a positive result not register for treatment?
3. Why do people who register not always go for treatment?

As will be seen, for each of these key questions different research tools (interview guides, questionnaires) were developed and aimed at particular target groups (general workers, VCT users). All activities were carried out with the full consent of participants and under conditions that guaranteed their anonymity. The different activities which were undertaken are described below in some detail.

## 2.2 Activities Undertaken

### 2.2.1 Meetings with ALAFA

Although the research questions appear to be straightforward, it took a series of meetings between the ALAFA management and the consultants involved to formulate the questions in a precise manner and to agree on the methods to be used for each one. This is because there are numerous HIV and AIDS-related knowledge, attitudes and practices (KAP) issues that could potentially influence uptake of VCT and treatment services that had to be considered. For example, the workers' basic knowledge of the disease could influence their understanding of VCT services. Of equal importance, from the service provision point of view, is the fact that there exist many programme factors that could be influential, such as the capacity of workplace staff compared to those of other service providers. However, as interesting and important as these are in their own right, it soon became apparent that a comprehensive study of all of these was clearly not possible, and would have detracted from the main objectives of the study. This resulted in the early drafts of the research instruments, which were wide-ranging, being reworked and discussed a number of times before the focus on the key questions listed above was agreed.

### 2.2.2 Literature review

Before any of the research instruments were finalised, the consultants undertook a review of available literature. The reports reviewed covered the following areas:

1. National socio-economic surveys
2. Lesotho garment sector reports
3. Overviews of the HIV and AIDS situation in Lesotho
4. HIV and AIDS in the workplace
5. Private sector responses to HIV and AIDS
6. Government of Lesotho response to HIV/AIDS in the Garment sector
7. Factors influencing the uptake VCT and ARV

This activity resulted in a 32-page summary document covering literature on the above issues relating to the use of VCT services and HIV and AIDS in Lesotho. The review was finalised after comments from ALAFA and was used, in part, to draw out issues for exploration in the field investigations.

### 2.2.3 Design of instruments and revision of the approach

Using the literature review, the research team produced detailed FGD and interview guides. These were reviewed by ALAFA, and it was felt that they were still not focused enough on the key research topics. For this reason it was felt that it would be useful to revisit the proposed approach and refine it. In the third week of February 2006 this exercise was completed, sent to ALAFA and approved. Annex 1 contains a copy of the Revised Approach, including the detailed main questions to be asked to different categories of participants. The Revised Approach then served as Terms of Reference for the remainder of the study.

### 2.2.4 Focus Group Discussions

The first primary data collection activity, which focused on the first research question, involved FGDs from a random selection of general workers using a room provided by the factory. The following FGDs were organised:

- 2 FGD of men (mixed ages)
- 2 FGDs of younger women (under 30)
- 2 FGDs of older women (over 30)

To encourage full participation and to enable some quantification of results, a 'card sorting method' (fully described in the Revised Approach) was devised. This involved FGD participants individually writing the reasons why they believe people do not go for testing on separate cards (one reason per card). The cards are then put out on a table and are sorted (grouped into logical clusters) by the participants. The role of the facilitator is primarily to encourage the FGD members to describe why they think given reasons (cards) have been put forward and why they are being allocated to particular groups. This discussion brings out some of the attitudes and thinking behind the cards that would otherwise not be made explicit. If time allows the cards can be ranked within groups, and then the groups themselves can be ranked. The cards in their final groups are carefully collected and a record is kept of the cards, the grouping and the discussion that went on during the exercise.

The card approach generated a huge amount of information. The first challenge was to capture as much of the discussion as possible in notes. This was not easy as the tape recording was not always clear due to background noises and the lively participation of many people, often speaking at the same time. Nevertheless, much of the discussion was eventually transcribed and used in the analysis of the cards.

Other challenges arose due to the fact that:

- a few hundred cards were created and grouped, requiring considerable time and human resources to process;
- translation of the cards was difficult as the linguistic nuances are complex;
- many of the cards only implied information that was made explicit during the discussions, requiring referencing back to FGD notes and/or tapes.

To facilitate the processing of the FGD data, a spread sheet was created containing each card in the original Sesotho, sorted by FGD and by the 'concept groups' created during the discussions. Columns and rows were then created showing (a) the original Sesotho version; (b) a full translation and explanation, bringing out the implied meaning; (c) a concise interpretation and (d) a categorisation of the card. The spreadsheet enabled the research team to then sort the cards in different ways for the purposes of analysis. Working examples of the spreadsheets are provided in Annex 2.

### 2.2.5 Follow-up interviews

On completion of the FGDs, 20 follow-up interviews were held with the following objectives:

- to verify, in a one-on-one confidential setting, some of the issues that emerged during the FGD;
- to go into more detail to explore particular points raised during the FGD;

- to seek out actual examples of how constraints to accessing VCT or going for testing have been experienced.

The follow-up interviews were completed in the second week of April. Again, as can be seen from the example in Annex 3, these generated a huge amount of information, which, like the FGD cards, was very informative but required more time than anticipated to process.

### 2.2.6 Qualitative data processing

Processing qualitative data is always a challenge. After the FGDs and follow-up interviews had been transcribed and translated a way had to be found to process the information gathered. Originally, it was anticipated that the software package 'NUD\*IST' would be used for this. However, given the fairly structured outcomes derived from the use of cards and the spreadsheets, this was no longer thought to be necessary. Instead, a way of sorting and visualising the results was explored and it was found that the software package *Mindjet Mindmanager Pro* could be effectively used for this purpose. The findings presented in this report (see next chapter) draw directly from the analysis carried out using the Excel spreadsheets, to sort categories of cards, and the Mindjet to visualise the relationships between concepts.

### 2.2.7 The 'General Worker' Survey

The objective of the General Worker Survey was to *quantify* key findings emerging from the FGDs and follow-up interviews. The results from these exercises were analysed and then used to draft a self-completed questionnaire that could be administered to workers.

The General Worker questionnaire remained focused on the first key research question (Why do people not test?). The use of a self-completed questionnaire was considered to be feasible as one third of factory workers have completed primary education and two thirds have secondary education.<sup>11</sup> Nevertheless, it was necessary to produce a very short and easily understandable questionnaire that could be completed within a limited period of time (so as to limit disruption to the factory).

The first draft was pre-tested on a relatively small group of workers (about 10) who were then questioned about its clarity. This was then revised and re-tested before the final version was produced (see Annex 4). In all 1,000 questionnaires were distributed, with free pencils, for workers to complete at a time agreed with factory management.<sup>12</sup> Each questionnaire had a unique number and a small 'lottery' was held at the end with 10 small prizes, consisting of cell phone airtime, going to the winners. This encouraged participation and 967 valid questionnaires were returned, being an exceptionally high rate for a self-completed questionnaire.

The data was entered and analysed using the Statistical Package for the Social Science (SPSS). The results have been used to validate those obtained from the qualitative research methods described earlier.

### 2.2.8 Interviews with VCT users

This activity focused on *constraints to registration and seeking treatment* with the two key questions being "Why do people who come for VCT and who get a positive result not register for treatment?" and "Why do people who register not always go for treatment?".

For reasons of confidentiality, the interviewees were sampled by ALAFA from a list of all those who have come forward for testing. A two-staged approach was then used which presented willing participants with an opportunity to volunteer information about their status in a confidential manner.

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<sup>11</sup> ALAFA Seroprevalence Survey, 2006

<sup>12</sup> It had initially been planned to distribute the questionnaire to all 4 500 workers at Precious Garments. However, as management had concerns about this disrupting production it was agreed that this would only be done in one of the four areas that the factor is physically divided into. The section selected, Precious IV, was chosen because it represents a typical mix of the work force in terms of age, gender and work experience. About 1 000 people work in Precious IV, representing just over one-fifth of the total workforce. Questionnaires were distributed to all workers in this section.

This then opened the way for questions to be asked openly about going for treatment. Those who said they obtained a negative result, or who were not prepared to share information about their status, were only asked a limited set of questions; those who openly said they were positive were asked further detailed questions about seeking treatment (see Annex 5 for the final questionnaire used). The method is elaborated upon at the start of Chapter 6.

### 3 Findings from the Literature Review

The findings from the Literature Review are contained in a stand-alone document of some 30 pages. In this section the most relevant findings, i.e. those which shed some light on the three research questions, are summarised.

#### 3.1.1 Socio-economic conditions

Factory workers in Lesotho are in a peculiar position. On the one hand, they are extremely fortunate to have waged employment in a country where 66% of rural women and 45% of urban ones are unemployed.<sup>13</sup> Indeed, the large number of job seekers *outside* the factory gates is testimony to the high demand for employment in an environment where there are few viable alternatives.

On the other hand, those inside the factory report that their monthly earnings are barely enough to make ends meet. Less than one-fifth of the workers (18%) are able to make any savings from their minimum wage of M710<sup>14</sup>, with the bulk of their earnings being spent on immediate needs such as food, clothing, transport, rent and childcare.<sup>15</sup> Just over half of the factory workers interviewed in 2002 said their lives had not improved since they started work; one third said their lives had improved “a little”, with the remainder (about 10%) saying things were a lot better.<sup>16</sup>

Any extra need - such as having to pay secondary school fees - results in difficult trade-offs having to be made between competing household needs. As many workers are often the only ones in their households with waged employment, they are under considerable pressure to assist, often resulting in high levels of stress.

The dilemmas created by being employed and responsible for others, but not being well paid, emerged clearly in the Focus Group Discussions held in 2002 at the start of the Commark Project. The reported noted that:

*“Some of the ex-factory workers seeking re-employment said that when working they had been unable “to save a cent ... the money is hardly enough to pay for food, clothing and school fees”.*

*“Although all groups agreed that the garment workers barely earn enough to keep their families alive, one community member made a point that underlines the relative nature of poverty. “If anyone has a relative working in the factories, he or she will go to the worker to beg or borrow many things, like salt.”<sup>17</sup>*

What is the relevance of these socio-economic and attitudinal findings to the key research questions? As will be seen later in this chapter, the sense that many workers have of living on a knife’s edge, in terms of their daily survival, makes them extremely reluctant to take any step which they believe will push them over the edge by creating additional stress in their already precarious lives.

#### 3.1.2 Lesotho documents discussing VCT services

Many reports were found that discuss the HIV and AIDS situation in Lesotho. However, only a few of these addressed the question of access to VCT in any detail, although this has become a high priority with the launch of the “Know Your Status Campaign” for universal access to VCT by the Minister of Health and Social Welfare in December 2005.<sup>18</sup> Most of the Lesotho documents that do discuss VCT

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<sup>13</sup> Lesotho DHS, 2004

<sup>14</sup> LNDC, 2006

<sup>15</sup> Salm, Andy *et al*, *Lesotho Garment Industry Sub-sector Study for the Government of Lesotho, 2002*

<sup>16</sup> *Ibid.*

<sup>17</sup> *Ibid.*

<sup>18</sup> “This plan is the product of a multi-sectoral and multi-organisational effort, highlighting the importance of continued collaboration with development partners and government. The plan promotes the need for enhancing an enabling policy environment along with appropriate training and capacity building for effective service delivery”. See <http://www.undp.org.ls/hiv aids/default.php> for more details.

tend to focus more on the implications of not testing, rather than the reasons for not doing so. Examples are given in the paragraphs that follow.

### **The implications of not testing**

The Strategic Plan of the new Lesotho Network of People Living with HIV and AIDS (LENEPWHA) notes that people's reluctance to know their HIV status creates the false belief that the virus is not prevalent and leads to high-risk behaviour. It goes on to argue that refusal to test increases transmission as the infected persons continue to have sex with their partners without protection. However, unfortunately it does not shed light on the *causes* of this reluctance to test.

### **The need to establish 'right conditions'**

A number of documents describe initiatives undertaken in recent years by both the private sector and government to establish workplace policies and services, including VCT. These tend to assume that if the right conditions are created (awareness, accessibility and affordability) workers will make greater use of the services, but offer little analysis of what constrains VCT use *from the workers' point of view*.

### **VCT as an entry point**

Government recognizes the importance of VCT "...as a strategy to promote (an) early entry point to care, treatment and support services including anti-retroviral treatment and prevention of mother to child transmission".<sup>19</sup> However, again, there does not seem to be any in-depth analysis of the causes of reluctance or refusal to test.

### **Factors constraining women**

Internationally, research indicates that women who consider themselves at risk of violence and abuse are less likely to volunteer for a HIV test<sup>20</sup>. Although there does not appear to be any research in Lesotho on this, it is likely, given the relatively high levels of gender-based violence, that this is a factor constraining women from using VCT services either at the workplace or elsewhere.<sup>21</sup>

### **Stigmatisation and reluctance to test**

There is some evidence from Lesotho that stigmatisation of people thought to be HIV positive contributes to reluctance to use workplace services, including VCT. A study conducted in 2005 found that there are high levels of stigmatisation and discrimination among workers in the textile industry in Lesotho. It argued that the main consequence of this was that workers were reluctant to utilise HIV/AIDS workplace services because they did not want to be labelled as a result of such use. As a result, some continued with risky sexual behavioural practices.<sup>22</sup>

### **Reluctance to use workplace services**

According to the ILO, in Lesotho most workers are reluctant to utilise workplace VCT services because they believe that the services are not confidential and effective enough to guide personal decisions to undertake an HIV test.<sup>23</sup> On the other hand, studies in Africa have shown a dramatic increase in the demand for VCT where services are accessible, affordable and safe for people who wish to know their HIV status.<sup>24</sup> Further findings from elsewhere in Africa are discussed below.

## **3.1.3 Barriers to VCT identified in other countries**

### **Fear of exposure of status followed by social exclusion**

Some studies on barriers to VCT use were found from other African countries.<sup>25</sup> These suggest that reluctance to test is strongly associated with high levels of stigmatisation. In Ethiopia, Zimbabwe and

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<sup>19</sup> See *National Guidelines for HIV Testing and Counselling*, MOHSW

<sup>20</sup> [www.unaids.org](http://www.unaids.org)

<sup>21</sup> WILSA, *Beyond Inequalities in Lesotho*, 1997

<sup>22</sup> ILO/USDOL HIV/AIDS, *Workplace Education Programme Lesotho: The Baseline Survey, Qualitative Assessment among Four Sectors and Eight Enterprises: A basis for development of BCC strategy for the ILO/USDOL HIV/AIDS Workplace education project in Lesotho*. 2005

<sup>23</sup> ILO, *World of Work in Lesotho: Status Report & Situational Analysis*, 2004

<sup>24</sup> SAfAIDS, *Health Link Worldwide*. Issue No. 52, 2002

<sup>25</sup> e.g. Corbett, E. et al. 2006. *Uptake of Workplace HIV and Testing: Randomised Trial in Zimbabwe*. *Plos Medicine* 3(7):e238). Dejene, M. 2001. *Study on Factors Affecting Accessibility and Acceptability of VCT Services for Bahir Dar Town, North Western Ethiopia*. Reed, Christian. *Workplace Initiatives in South Africa: A Case Study Approach*.

South Africa, researchers found that people are still generally unwilling to test as they fear that rejection and social exclusion will follow any disclosure of their status. However, there are clear indications that on-site (workplace) VCT significantly increases up-take of services (by as much as 12 fold) when compared to the provision of off-site services offered through vouchers. Proximity and convenience appear to be key reasons for this.<sup>26</sup>

### **Mistrust in the company motives**

In South Africa, Reed found that even though companies had obtained medical insurance for workers that provided access to ARVs, uptake of these services was still very low. Workers were reluctant to test due to a lack of trust in the motives of companies. Fear of reliance on the company for on-going medical support after testing HIV positive was indicated as a barrier to VCT use.<sup>27</sup>

### **Findings from another literature review**

A study by Mundy and Dickinson conducted in South Africa looked specifically at factors affecting the uptake of VCT services in the workplace. This involved a literature review and a quantitative survey of some 370 workers in a medium-sized manufacturing company using an anonymous, self-completed questionnaire. Results were analysed from the perspective of 'best practice intervention findings'.

The study found that there is only limited literature on the factors affecting VCT participation in the workplace. Nevertheless, from the literature identified, a number of critical points emerged that are worth listing in full as they are very relevant to the current study.

- ✓ Information and education initiatives alone have a transitory effect, but VCT promotes risk reduction through increasing perception of risk and through reinforcing social responsibility.
- ✓ Workplaces offer a stable and conducive environment for the effective provision of information, education and skills development.
- ✓ VCT uptake, as well as perceptions of exposure to risk, increases with "proximity" to someone who has (or had) HIV/AIDS
- ✓ Believing that a positive VCT test will lead to societal rejection is a critical barrier to VCT.
- ✓ VCT services are likely to be under-utilised if perceived threats outweigh perceived benefits.
- ✓ Employers must go to great lengths to establish an environment in which employees perceive the benefit of knowing their serostatus early.
- ✓ Perceived confidentiality and quality of counselling are critical: test services must be perceived to be highly accurate, timely (same-day), non-invasive and anonymous.

Key findings from the quantitative survey by Mundy and Dickinson indicated that:

- ✓ Peer-pressure may develop sufficient momentum to overcome many of the barriers to the use of on-site VCTs, resulting in high levels of participation over relatively short periods.
- ✓ It is vital that post-VCT benefits are understood, are accessible to all staff and their families and involve active employee representation.
- ✓ Many factors combine to affect VCT participation, and indeed interventions that encourage one employee to participate may fail to encourage, or even deter others.
- ✓ Despite the high levels of knowledge demonstrated, it was proven that knowledge alone is insufficient to change behaviour and encourage regular testing.

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<sup>26</sup> Corbett *et al*, *op.cit.*

<sup>27</sup> Reed, *op.cit.*

- ✓ Third party VCT involvement should be long-term for the establishment of the trust required for successful VCT.

### **Limitations to the VCT users, even with effective programmes in place**

No matter how effective VCT programmes are in overcoming access barriers, it must be recognised that universal testing is unlikely, even in a workplace environment. This is because many women are unable to modify their sexual behaviour for a variety of reasons, including lack of decision-making powers within their relationships; dependence on income obtained in exchange for sex and a desire to have children. All these contribute to risky behavioural practices and a reluctance to test.<sup>28</sup>

### **Perception of death following testing**

There is evidence from the literature that many HIV positive workers wait too long to be tested and seek treatment. It is only once AIDS has manifested and their condition has deteriorated that they seek help.<sup>29</sup> At this point the medication is not effective and their demise can be rapid. As will be seen, this results in a perception that their death is somehow associated with having been tested and being informed of a positive result. For many, this negative association becomes a deterrent in itself. This, and other findings from the current research, is elaborated upon in the next section.

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<sup>28</sup> Anderson, J. *Care of Women with HIV Living in Limited Resources*. John Hopkins Women's Programme. No date.

<sup>29</sup> *Treating HIV Infected Employees*



## 4 Reasons for Not Testing

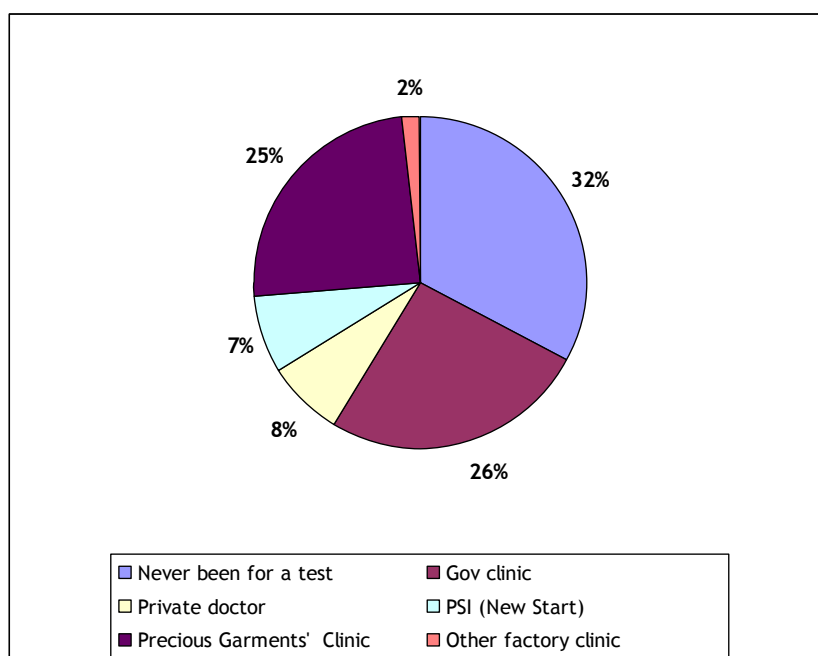
### 4.1 Introduction

This chapter focuses on the first of the key research questions: Why do people not test? It draws on information collected in the course of the FGDs, the follow-up interviews and the general worker survey (described in the previous chapter). The possible implications of the findings for the ALAFA project are discussed in clearly marked text boxes.

### 4.2 Testing Elsewhere

It is a fact that the on-site VCT services are not reaching all workers at the Precious Garments factory. Only 25% of the 967 workers who completed the General Workers' questionnaire said they had used the facility. This figure, however, is somewhat misleading, as many of the remaining 75% have in fact used VCT services, but elsewhere. The figure below shows where, if at all, workers have been tested.

Figure 1: Where workers have tested



As can be seen, only about one third (32%) of workers say that they have never been tested. Just over one quarter (26%) have been to a Government facility, while 15% have been to a PSI or private clinic, and a small percentage have been to a testing facility at another factory.

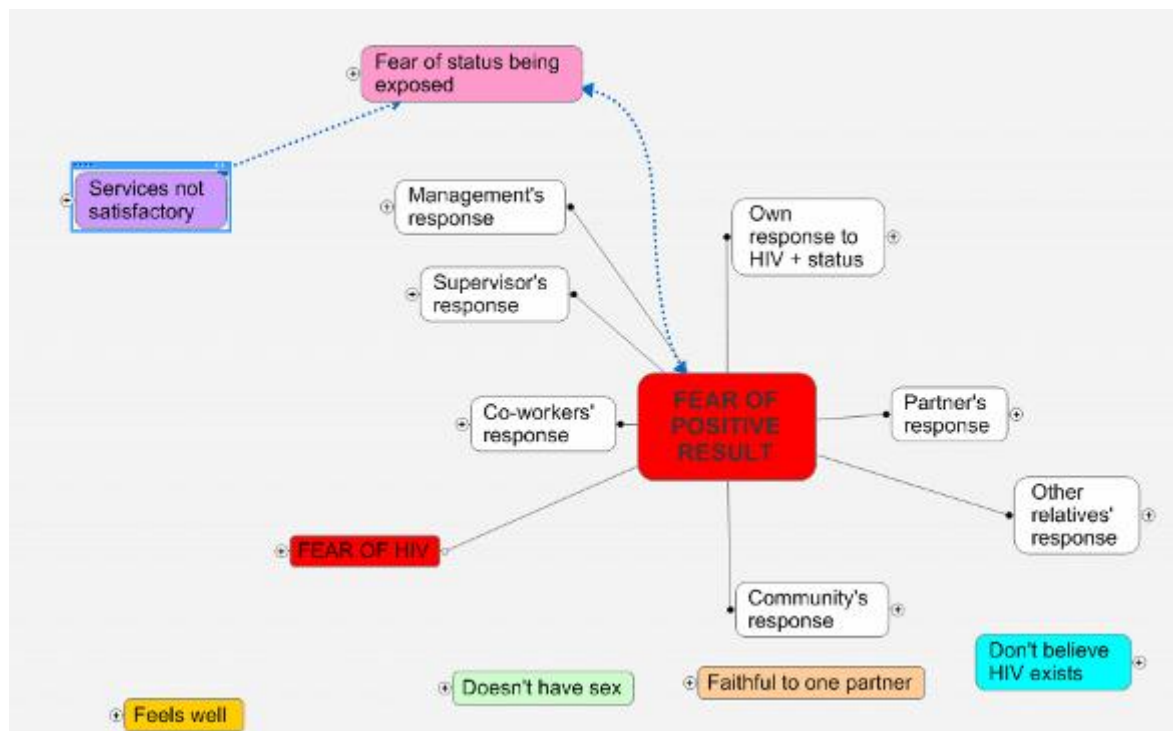
The proportion of Precious Garments workers who claim to have been tested (68%) is significantly higher than the proportion in other factories. In the related ALAFA Seroprevalence KAP survey, carried out in eight other factories in 2006, the proportion that had tested was much lower (41%). This suggests that Precious Garments may already be an exceptional factory due to the work of ALAFA and/or other initiatives. In the sections that follow, we look at the reasons for not testing in detail. We then examine the other side of the coin - why people have tested - as this is, in many ways, equally informative.

### 4.3 Fear

If there was a need to summarise all the reasons for not testing into one word it would be "fear". This fear has multiple dimensions, which, when unpacked, reveal a great deal about the people's

reasons for not wanting to test. In this section, these dimensions are examined in turn, using the mind map as a tool. The figure below provides an overview of the key reasons given:

Figure 2: Main Reasons for Not Testing



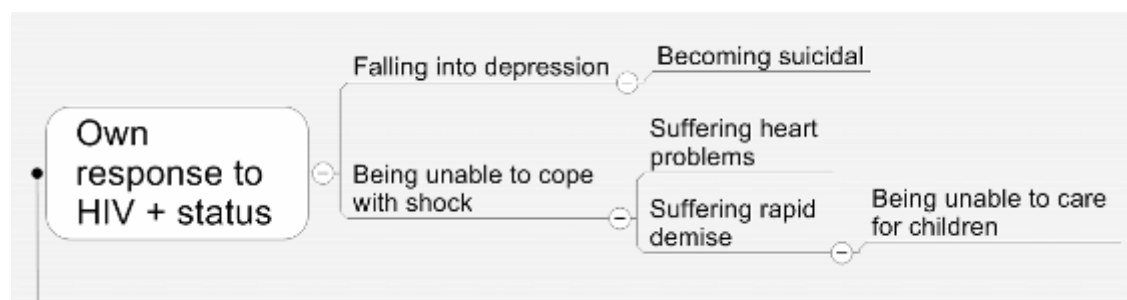
As can be seen from Figure 2, *fear of a positive result* (at the centre of the mind map) is the dominant factor discouraging people from testing. The factor most immediately associated with this is a *fear of the disease itself*. Participants explained that the way in which HIV/AIDS was introduced to them through various channels has filled them with dread. Lesotho’s information and education campaigns have clearly had an impact in terms of generating fear of the disease: AIDS is broadly seen as an incurable, deadly disease transmitted through “bad behaviour”. While the intention may have been to promote behavioural change, the outcome has been a level of fear that is so deep that many people would “rather not know” than ever confront the possibility of being infected.

#### 4.3.1 Fear of one’s own response

The card sorting shows that workers are reluctant to test because they are afraid of how they, and others around them, would respond to the knowledge of being HIV positive. These fears can be conceptualized as a series of concentric circles, starting with how the individual fears he or she would respond to a positive result, followed by fears of how those closest to them (spouse or partner) would respond, moving out to fears of how relatives, those in the community and those in the work place would respond.

The immediate fear is that one may not be able to cope psychologically with the news of a positive result, and that the shock may be so great that it would itself cause a rapid demise. The figure below shows how various fears (recorded on cards by FGD participants) were associated with fear of one’s own response to a positive result.

Figure 3: Fear of one's own response



During the discussions, many FGD participants claimed that they knew of people who “looked well” who had gone for testing and had reacted so badly to the news of being positive that they had fallen into a depression, become suicidal or suffered a rapid demise because of “heart problems”. An ultimate fear was that of declining so quickly (as a response to shocking news) that one would soon be unable to care for one’s children. Essentially, participants argued that *people were reluctant to test because they feared accelerating their own deaths by way of exposure to shock*.

The follow-up interviews confirmed the FGD results. They also emphasised that many workers already feel so stressed by their daily struggles to survive that they do not test for fear that a positive result would push them ‘over the edge’. In the words of one interviewee:

*“The problem is that you are already stressed trying to pay for basic needs. After you pay school fees what do you live off? You are so afraid to test because you don’t think you could handle another burden in your life.”*  
(Married woman, 38 yrs, 6 children).

Another simply said: *“I don’t want to test because I don’t want to put my life at risk (through shock)”*.

One male interviewee said: *“I don’t want to test because then I won’t be able to make future plans. It will be as if I am already dead.”*

In the minds of some interviewees, AIDS is seen as *a source of other diseases*. Initially, it appeared that they were describing how opportunistic diseases take hold when the immune system is compromised. However, in their view, it is the shock of discovering one’s status that causes the system to collapse and become vulnerable to other diseases. In other words, not knowing one’s status is seen as a way of preventing illnesses that would otherwise be provoked by the shock of knowing.

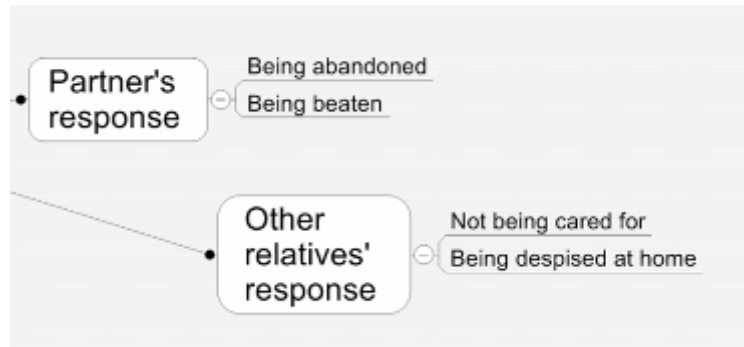
#### Text Box 1: An ordinary disease

Less emphasis should be placed on AIDS being a “killer disease” associated with “bad behaviour”. Campaigns should encourage people to think of it as any other disease that needs regular “check-ups” (i.e. testing).

#### 4.3.2 Fear of partner’s, relatives’ and community’s response

The FGD participants suggested (through cards and discussion) that some women do not come forward for testing because they are afraid that if their (positive) status becomes known to their partner they will be abandoned and/or beaten. The General Worker survey confirmed that this a very common reason for not testing, mentioned by just of 50 of those who completed the questionnaire.

Figure 4: Fear of partner's and other relatives' response



In the follow-up interviews, enough actual examples of abandonment were given to confirm that this is a real prospect for women to fear. A few examples are given below:

*“One of my neighbours tested at work. When she told her husband that she was HIV positive he left her. One of my co-workers also told me another story where the husband abandoned the family. They have not heard from him ever since.”*

*“There is a woman whose husband abandoned her and she was sick and needed help; that’s when she went to the radio to ask for help to be able to go to hospital and meet other needs.”*

*“One of my relatives came from prison. He was sick and he infected his wife. When she tested and found she was positive she confronted him. He told her he had done it on purpose and then he left her.”*

In another case, the wife was not abandoned, but insulted:

*“I had a neighbour who tested positive. She told me about her status and I advised her not to tell anyone. But she told her husband and children. Later on, the husband started insulting her about being HIV positive.”*

In only one of the follow-up interviews was an example given of a husband being supportive.

#### 4.3.3 Fear of relatives and community’s response

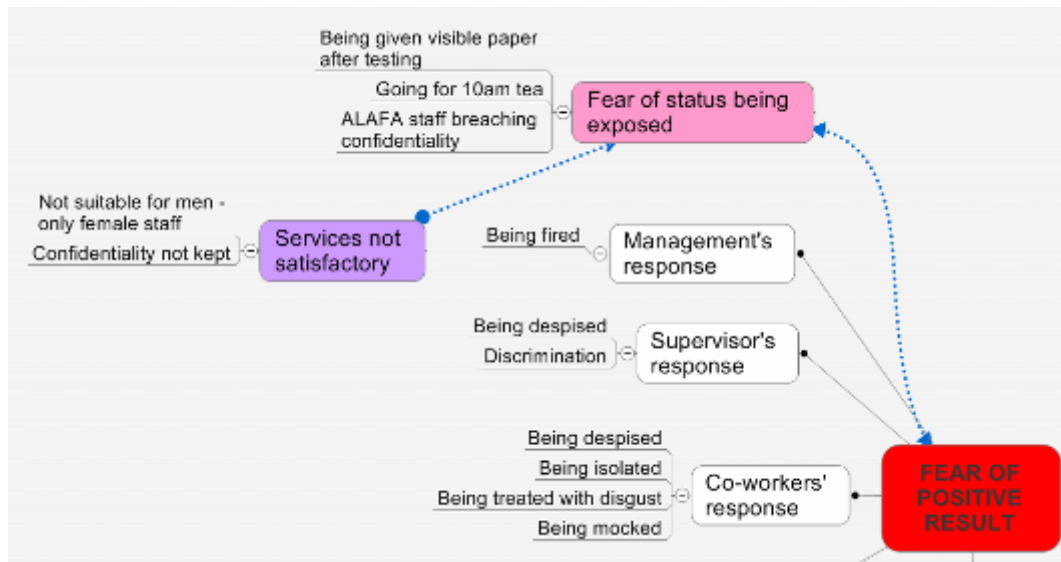
Fears of responses from other relatives “at home” are associated with being despised (because of the sexual connotations) and “not having anyone to care for you” once the disease reaches an advanced stage.

There are similar fears associated with community members finding out (by whatever means) about one’s positive status. Here the concern is that going for a test might eventually result in a loss of one’s *reputation* if the news of a positive result becomes public. This is obviously closely linked to fears of *stigmatisation*. A number of people then linked loss of reputation in the community to depression and thoughts of suicide which were originally associated with the individual’s reaction to their test results.

#### 4.4 Fear of Workplace Responses

The cards generated and sorted by the FGD participants make it apparent that fears of workplace disclosure and the subsequent reactions of co-workers, supervisors and management are a major barrier to testing. They worried that such disclosure would result in them being stigmatised and ridiculed at various levels. These fears are visualised in the extract from the mind map below:

Figure 5: Fears of workplace response



Some workers clearly fear that if they use the on-site VCT services there is a risk of their status being exposed to others. Although these concerns were justified with the specific reasons given in the next sub-section, further analysis of the data shows that this fear was expressed almost exclusively by those who have not actually made use of the services. Further, when this issue was quantified in the course of the General Workers' Survey it was mentioned by only 15% of participants. It is important that the qualitative findings presented below should be considered with this in mind.

#### 4.4.1 Fear of on-site counsellors breaching confidentiality

During the FGDs some participants expressed a concern that the project's on-site peer counsellors do not keep their clients' confidentiality, and wrote cards that clearly expressed this. For example:

- We do not test because you (the service providers) do not know how to keep a secret.
- We do not trust the people who do the test.
- We do not like testing at work because we do not want our results and status to be known by co-workers.

In the discussions, FGD participants discussed these views at some length. They generally agreed that the on-site counsellors "lacked confidentiality", but argued about whether or not this was due to "human error in executing ones' duties" or "lack of professional ethics and skills". Those who felt that human error was to blame pointed out that, in some cases, the counsellors may have information they want to give to a person who has tested positive (PLWHA), but they do this while the person is still at his or her work station on the factory floor. "While you are working, they come and say they have been sent to ask you why you have not been to see a doctor to get treatment." Inevitably, they noted, neighbouring workers on the line hear what is being said and as a result the person's status is disclosed through human error. Those who felt lack of ethics was to blame said that this was done maliciously, as a deliberate attempt by the counsellor to embarrass the person.

A related problem is that once a person has tested positive they will frequently get called from the line "for some business" (*E tlabe e sale joale o bitsoa ho thoe ho na le eng le eng*). While this 'business' might be very well intentioned (training, support, counselling, etc) it is seen as a way of exposing people and it becomes another deterrent to testing.

Those who saw disclosure in more malicious terms complained that "the counsellors" gossip and ridicule people who had tested.<sup>30</sup> They maintained that the counsellors were the first to tell others about a worker's status if that worker was involved in something perceived to be "unsatisfactory behaviour and trouble making". The counsellors are reported to make remarks such as: "When you see

<sup>30</sup> The reference to counsellors could be to any of the five staff working at the clinic, including one coordinator (HIV focal person), three counsellors and one nurse.

so-and-so, she causes problems and yet she is sick the way she is. She is HIV positive.” (*Ha u bone nyeo, o etsa likhathatso, feela o oa kula a le tjena; o se a le HIV positive.*)”

As a result many participants, through their cards or through the discussion, clearly stated that they would rather not test, or at least would prefer not to test at Precious, “...because people will start pointing and gossiping about me”.

To confirm the above FGD findings, in-depth questions were asked during the follow-up interviews. The results from this showed a more nuanced range of opinions. For example, when one interviewee was asked: “Some people have said they do not trust Precious Garment counsellors. Is that the case with you too?”, she gave the following reply:

*“No. It’s not that I do not trust them; I do trust them. Some people don’t (trust them) because they think if they get a positive result the counsellors will laugh at them. But this is only their thinking, it has never happened. Even the management is supportive of people who have HIV”. (Widow of 38 yrs)*

Another interviewee also affirmed his confidence in the counsellors:

*Q: Many people during the FGDs and one-on-one interviews report that counsellors talk about their status and lack skills. Were you not afraid that they may do the same to you?*

*A: No. I did not even think about it. The fact is I never have such thoughts because I believe they have been through training and would therefore not do anything they were not taught.*

*(Married man, aged 38).*

However, by contrast, others confirmed the negative perceptions presented in the FGD groups, as can be seen from the following extracts:

*Q: How well are VCT services used here at Precious?*

*A: They are used, but not very well because people do not trust the employees of the VCT because they say they lack secrecy, and everyone who tested is said to be HIV positive.*

*(Married woman, 31 yrs)*

*Q: Is there anything else that could be done to encourage people to test?*

*A: I think most people would like to be tested by people from outside; not the ones here because they might share our secrets with their friends and gossip about us.*

*(Married woman, 42 yrs)*

*Q: The FGDs indicated that people feel ashamed for being known to be HIV positive. Do you know what could be the reason for this?*

*A: People are afraid that the staff (counsellors) will gossip about them. (Married woman, 33 yrs)*

*Q: How well do you think people are using the VCT services here at work?*

*A: It is not good to test here because I don’t have confidence in the staff that work here. Why do you think we know about people who have tested positive? It’s because somewhere, somehow the information was leaked.*

*Q: Is there anything you do not like about services here?*

*A: Change the staff that works here (in VCT); they should be re-assigned somewhere and neutral people or the ones we don't know should be brought in, maybe people would test here.*

(Man, 32 yrs).

While the above concerns have to be considered as legitimate, when VCT users were asked if they were satisfied with the services used (see Chapter 6) they vast majority (98%) said they were and nobody raised any concerns about confidentiality.

Clearly there are mixed views about the extent to which the current on-site counsellors maintain confidentiality, with some interviewees being very supportive of the counsellors and others not. The issue that emerges is *not* whether one side or the other is correct, but *how to deal with the perception - held by at least a few people - that the counsellors do not maintain confidentiality.*

At this stage, it appears that the counsellors credibility has suffered a set-back, and that the negative perceptions that have emerged (even if these are based on very few incidents or rumours) could act as something of a deterrent to the greater uptake of VCT services. Given the evidence (Corbett, 2006) that on-site VCT is far more effective than off-site VCT (at least for workers), it is clear that a way has to be found to increase confidence in the on-site counsellors. A number of options are discussed in the box below that may help to overcome this breakdown in trust.

## Text Box 2: Increasing confidence in counsellor confidentiality

**Option 1:** Replace all Precious Garment counsellors with a new set of **external** counsellors who pay regular visits to the factory.

**Advantages:** External counsellors would not be in a position to gossip about the clients. A new start may significantly increase confidence in the VCT services. External counsellors could be rotated frequently.

**Disadvantages:** Could be costly. Could be a set back to the programme with ground gained by present counsellors being lost.

**Option 2:** Replace all counsellors with a new set of **internal (peer) counsellors**.

**Advantages:** Would demonstrate that concerns about breaches of confidentiality (as expressed in this study) have been taken seriously and acted upon. Would provide an opportunity to enforce the need for confidentiality with the new group of counsellors. Less costly than Option 1.

**Disadvantages:** May still be difficult to convince workers that their peers will not gossip and breach confidentiality. Would take time for new counsellors to get to know VCT users and establish trust.

**Option 3:** Maintain the status quo, but with a demonstration that some action has been taken (e.g. investigate known breaches, discipline, dismiss counsellors implicated).

**Advantages:** Maintains those counsellors who have already gained experience. Not costly.

**Disadvantages:** Investigations will be difficult and the results may not be adequate to regain the full confidence of the workforce.

**Option 4:** Keep existing counsellors, but investigate cases of concern where possible, but also add external services as an alternative, e.g. a special HIV testing week, or regular service days.

**Advantages:** Maintains those counsellors who have already gained experience. Not costly. Offers an alternative

**Disadvantages:** Investigations will be difficult and the results may not be adequate to regain the full confidence of the workforce. External services may be costly and might not result in greater uptake.

### 4.4.2 Fear of supervisors breaching confidentiality

In discussing problems of disclosure of status, interviewees sometimes included Line Supervisors, either because of an overlap with some counsellors also being supervisors, or because of the counsellors having a close relationship with the supervisors. Here, again, the suggestion was made that disclosure may actually be used as an intentional 'weapon' in situations of disagreement or conflict:

**Q:** What do you think makes people gossip about others?

**A:** I think the management should enforce secrecy (of test results) because we would also like to test, but you find that when supervisors get into arguments with staff they end



*up disclosing someone's status. So if someone does that, regardless of who they are, there should be action taken against them.*

**Q:** *So does it mean there is no confidentiality of test results?*

**A:** *Yes, there is no confidentiality. If our management can do away with gossiping, then everything would be OK. That's why some people test outside of the factory. If gossiping would be punishable by laws, then I think people would test here. When you talk to people here about why they do not test they say they are concerned that people here are going to gossip about them.*

*(Single male, 26 yrs old).*

### **Text Box 3: Dealing with breaches of confidentiality by Supervisors**

Breach of confidentiality by Supervisors should be taken very seriously, with demotion or dismissal as a punishment. Although this is already catered for in the HIV Policy of Precious Garments, there is a need to promote awareness of the Policy and to ensure this aspect is implemented.

#### **4.4.3 Fear of exposure by other workers**

Perhaps more than anything, workers seem to fear being exposed (or simply gossiped about) by their fellow workers. Because of the stigmas associated with the disease, such gossip appears to be common and, as is usually the case with gossip, it is often not necessarily founded on real information. One trigger for gossip about people's status is the use of a facility well known for its HIV/AIDS services. This now includes the Precious Garments' clinic, although this is a multi-purpose health centre:

**Q:** *Have you tested for HIV?*

**A:** *No*

**Q:** *Why not?*

**A:** *I am afraid to test here at work or Sankatana. I prefer to go somewhere else where there is privacy.*

**Q:** *Why is this so?*

**A:** *Because I am afraid of meeting people I work and live with who will talk to others about my being at the centre and testing. On my own, if I know my status is secret, I can live with it. It becomes a problem if the news comes out in the form of gossip. I do not want my child to know that I am HIV positive because he will worry that I'm dying and that he is going to become an orphan".*

*(Widow, 33 yrs)*

The provision of multiple health services has made a difference, even though the above concern still exists. This is evident from the following interview:

**Q:** *How easy do you think it is to access HIV testing at Precious?*

**A:** *It has become a lot easier because now the testing and the clinic are at the same place.*

**Q:** *Does it mean it used to be difficult for people to go for a test while they were still separate?*

**A:** *Yes. Now it is easier to access because people feel no one will know whether they went for testing or for other reasons.*

(Married woman, 32 yrs).

Nevertheless, it is important to appreciate that even the smallest external sign can set fire to gossip. For example, in the FGDs participants complained that those who go to the Precious Garments clinic for VCT are given a “certain paper” and this clearly marks them as having gone to the clinic for that purpose, as opposed to having gone for a medical ailment. In this way, even the well-intentioned distribution of brochures (to a particular group using the clinic) can be damaging to the goal of increasing VCT uptake.

#### **Text Box 4: Maintaining the multi-purpose character of the Clinic**

Every effort should be made to promote and develop the multi-purpose character of the PG clinic. Care should be taken when providing those attending for VCT purposes with documentation or other materials which may become a source of gossip.

#### **A real dilemma**

Another example of the fact that well-intended actions often have unintended and possibly damaging consequences is the extra optional break (at 10am) that is provided for “sick people”. This provides those living with HIV/AIDS and/or TB with an opportunity for extra rest, food and time to take their medication - all critical to their health and productivity. However, because this results in very visible movement on the factory floor, gossip circulates about those departing for the extra break.

*Q: You have a VCT facility here at work. Is it well used?*

*A: Yes, people do come and test but not in large numbers. People are afraid that others will gossip about them because they (positive people) go for an extra break at 10am, so that's what makes people reluctant to test.*

While some are concerned about the gossip associated with the 10am break, others are very positive.

*Q: In the discussions we heard that Precious runs a number of health services. What do you like most about services here?*

*A: The sick are well taken care of. They normally take breaks at 10am and their sick days off are paid in full. I like everything they do here.*

With such contrasting views the break privilege creates a dilemma. To do away with it would be unfair to those who need it and are prepared to withstand the gossip. On the other hand, because it is such a visible mark, it does act as a deterrent to those wishing to come forward for testing.

## **4.5 Reasons for Fearing Having One's Status Known**

There are very good reasons for why people do not want their status to be known. The interviews show that there are still so many negative associations with the disease that *there is a high risk that anyone thought to be HIV positive will be treated unkindly*. In the literature this is known as ‘stigmatization’, but the term is used in such a general manner that it has now entered the realm of jargon and has lost its sharp edge. Dictionaries come closer to the harsh reality of stigmatization by defining it as ‘to label somebody or something as *socially undesirable*’. In Sesotho, a variety of terms were used, which have been translated in Figure 4 as:

- Being despised
- Being isolated (from others)
- Being treated with disgust
- Being mocked

These terms are inevitably an inadequate summary of the deep concerns expressed by the FGD participants about the fear of ‘being labelled as social undesirable’. The table below gives a more

detailed extract of the cards used. The first column gives the full Sesotho version, followed by the facilitators' interpretation which, in some cases, adds what was implied (as explained in the FGD discussions). The next column gives a more precise translation, while the third places the results in a 'fear category' for later analysis.

**Table 1: Fears of stigmatisation in original Sesotho with translation**

Sesotho card with English explanation /First translation	Concise translation	Category
<i>Ba tla u tenehela.</i> People will be fed-up with you.	People will be disgusted by you	Fear of isolation
<i>Ba re li-supervisa li tla ba khesa.</i> They say the supervisors will stigmatise them.	Supervisors will despise you	Fear of being despised (at work)
<i>Hobane ha u hlahloba e be u fumana e le teng; batho ba bua ha u feta ba o shebile ba bua ka uena.</i> Because when you find that you are HIV positive, people talk about you when you pass by and look at you and talk about you.	People will gossip about you as you pass-by	Fear of gossip
<i>Ba lula ba u tsoafa; ba ruta ba bang ka uena.</i> They will sit and ridicule you; they will teach others about you.	People will tell others of your status	Fear of gossip
<i>Mohlomong ke na le mokhotsi joale ke nahana hore o tla nts'eha ha ke re ke ts'oeroe ke lefu lena.</i> Maybe I have a friend & if I tell this friend that I have this disease then they will laugh at me.	Friends will laugh at me	Fear of being mocked
<i>Basebetsi (ba bang) ba tla ba nsola.</i> My co-workers will not like me anymore.	Co-workers will dislike me	Fear of being rejected (at work)
<i>Ba re batho ba tla ba ts'eha hore ha ba its'oara hantle.</i> They say people will laugh at them and say they are not well behaved; that they are promiscuous.	People will mock you because of bad behaviour	Fear of being mocked
<i>Hobane o tla ntsoafa; ha a sa tl'a nthabela</i> Because they will no longer like me; they won't like being around me anymore	People won't want to be with me	Fear of isolation

Although the cards speak for themselves it is worth adding a few extracts from the follow-up interviews which illustrate why workers are so concerned that stigmatisation will be a *consequence of exposure following testing*:

**Q:** *Do you know or have you heard of someone who stigmatised someone with being HIV positive here at work?*

**A:** *Yes. There was this girl whose friend was HIV positive. But later the friendship went sour and she started talking about the friend; they eventually had a fight about the issue and the friend was taken for disciplinary action.*  
(Widow, 38 yrs)

**Q:** *Why do you think that you taking a test will give you stress?*

*A: Discrimination! If people would stop gossiping and get used to the idea that HIV is just like any other illness (it would be OK). But, once it is known that you are HIV positive people don't maintain that eye contact they used to have with you; they look down as if they are embarrassed or something.*

*(Woman, separated, 31 yrs)*

*Q: How well are people using the VCT services here at Precious?*

*A: They do use them but they think the VCT staff will disclose their status to general staff and use their knowledge to launch personal attacks.*

*(Woman, married, 33 yrs)*

*Q: You said you do not want to test at Precious. Others are saying they are afraid to test generally. What is it, if you know, that makes people reluctant to test?*

*A: I think mostly they are afraid to be discriminated against. Usually people like to tell their friends about their status; and that friend normally starts telling other people about it. In no time, the whole factory knows about your status. The friend may also start looking down on you and usually that's where the trouble starts; people start fighting.*

*(Widow, 33 yrs).*

*Q: There is a lot of talk about people being afraid to be known to be HIV positive. What do you think makes people feel ashamed?*

*A: Maybe like me people are afraid for others to know their positive status; maybe they fear discrimination more than anything else. People here at work talk you know...How do you think we end up knowing that certain people have HIV? It is because we heard people gossiping about them. So wouldn't you be afraid of disclosing?*

*(Male, 32 yrs).*

It is clear, therefore, that the overwhelming feeling to emerge from both the FGDs and the follow-up interviews is that stigmatisation is both common (and used as a 'weapon' in personal disputes) and a key reason underlying the fear of disclosure, and hence the fear of testing. Can this be combated? The following extract suggests that it can be:

*Q: Is there a lot of talking about those testing HIV positive here at work?*

*A: It used to be like that, early last year – but it has changed.*

*Q: What has changed? What brought the change?*

*A: After trainings that people have attended on HIV/AIDS for the different categories of staff, I think a lot of negative attitudes have changed.*

*(Married woman, 32 yrs).*

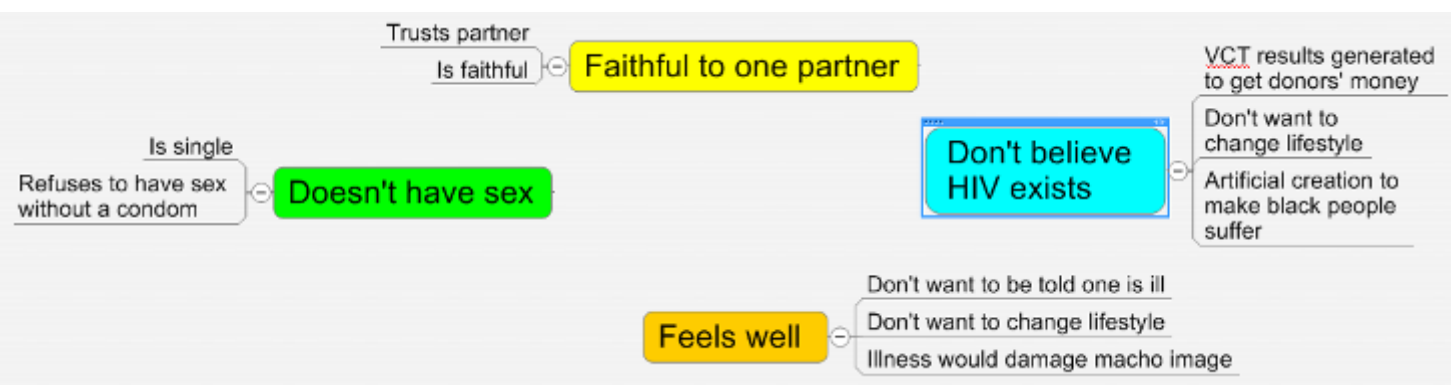
#### **Text Box 5: Fighting stigmatisation**

Stigmatisation is real, common and hurtful. It is a serious barrier to VCT use and must be combated through a multi-pronged and prolonged campaign.

## **4.6 Other Reasons for Not Testing**

There are other reasons besides fear (in all its incarnations) that explain why some people do not test. These are summarised in the following extract from the mind map:

### **Figure 6: Other reasons for not testing**



The above reasons could be summarised as ‘minority reasons’, as they seem to apply to a relatively small proportion of the work force. For confirmation of this - and the relative importance of other results - the qualitative findings can be triangulated with quantitative findings from other exercises.

#### 4.7 Triangulation of Results

A related KAP survey of over 2,500 workers by ALAFA in eight factories in Lesotho<sup>31</sup> confirms that the key reason for not testing is fear of a positive result and that the other reasons listed in the last section apply to a minority of workers:

**Table 2: Reasons for not testing from KAP survey**

Category label	Code	Count	Pct of Responses	Pct of Cases
Have tested before	1	8	3.5	3.6
Afraid of getting a positive result	2	173	75.9	77.9
Do not think I need to test	3	18	7.9	8.1
Afraid of gossip	4	1	.4	.5
Do not see the benefit of being tested	5	7	3.1	3.2
Do not feel sick	6	1	.4	.5
Partner objects	7	5	2.2	2.3
Know my status	8	5	2.2	2.3
Doesn't like	9	6	2.6	2.7
Afraid of dying	10	1	.4	.5
To repeat after 3 months	11	1	.4	.5
No medication for HIV people	12	1	.4	.5
He needs one week counseling	13	1	.4	.5
		-----	-----	-----
Total responses		228	100.0	102.7

Source: ALAFA, Seroprevalence KAP Survey, 2007

Further quantification of the reasons why people don't test can be obtained from the ‘general workers’ self-completed questionnaires done as part of the current study. As this was designed on the basis of the FGDs and the follow up interviews it is possible to now give a sense of *relative importance* to the issues discussed earlier. The questionnaire was designed to allow respondents (those who have not tested) to tick up to three responses which they felt applied to them. The table below shows the results first as a percentage of cases (the proportion of workers who ticked a reason) then as a percentage of the total responses given.

**Table 3: Reasons for not testing from the General Worker Survey**

<sup>31</sup> Data collected by Sechaba Consultants in 2007.

Reason for not testing	% of cases	% of responses
I don't believe HIV/AIDS exists so I don't need to test	8.9	3.7
I don't have sex so I don't need to test	9.8	4.0
As a man I don't like being examined by women	3.3	1.3
I don't trust the people at the clinic they might reveal status	15.1	6.2
I won't be able to cope with knowing if I am positive	68.0	28.0
I fear I will die/kill myself if I know I am positive	37.1	15.3
I am afraid of being abandoned or beaten by my partner/spouse	53.7	22.1
I am afraid my family will not care for me or support me	9.8	4.0
I fear if my status gets known my community will think badly of me	9.5	3.9
I fear if my status gets known at work I will be despised	11.0	4.5
If my status gets known at work I will be accused of promiscuity	12.8	5.3
If my status gets known by my management I will be fired	3.9	1.6

The table confirms that those who “don’t believe HIV/AIDS exists” or who “don’t have sex” are, indeed, a minority. It also affirms the significance of the other fears presented earlier, with the top three being:

1. Fear of not being able to cope with the news of being positive (68%).
2. Fear of being abandoned or beaten by partner or spouse (53.7%)
3. Fear of dying (rapid demise) or of committing suicide (37%).

These immediate fears are followed by others relating to one’s reputation and fears of stigmatisation in various forms.

However, it should be noted that the percentage stating that they do not trust the “people at the clinic” is relatively low (15.1%), which indicates that this fear might have been over emphasised by FGD participants.

From the survey of 100 workers who used ALAFA VCT services for testing, similar findings emerge. These are discussed in more detail in Chapter 6.

## 4.8 Conclusion

Precious Garments is doing well in encouraging the use of VCT services, whether on site or elsewhere. Nearly two thirds of the workers have tested, considerably higher than the average for the Lesotho garment sector. Nevertheless, one third have not tested and their unknown status remains a threat to themselves and to the wider community.

AIDS is perceived with dread. It is seen as a killer disease that is almost certain to result in a rapid demise. It is associated with promiscuous behaviour and those thought to be HIV positive are frequently the victims of verbal torment and disdain.

*Workers feel that they are already living on a knife’s edge and fear a positive test result would push them into an abyss from which they would never escape. Ironically, workers who do not test ultimately die, because of their fear of dying. They die from not knowing they are infected because they are so afraid that discovering they are infected will kill them. Their fear of death becomes a self-fulfilling prophecy with the most dreadful consequences.*

### Text Box 6: Staying alive

People's fear of not being able to cope with the news of being positive must be tackled head-on in a vigorous campaign. The key messages should be along the lines of:

- ✓ AIDS is manageable...if you know your status.
- ✓ Those who test first, live longest.
- ✓ Save yourself, test now before it's too late.
- ✓ Be responsible to your family, test to live long.
- ✓ Testing is the start of treatment and care...not death!
- ✓ I've tested, have you?

The main 'weapons' in the campaign should be the testimonies of people who have tested, are positive, are living well and planning for the future. There are increasing numbers of these unsung heroes who are emerging to speak publicly in Lesotho, shattering stereotypes and prejudices as they do. ALAFA should make full use of them in the garment factories.

The campaign should also place emphasis on post-testing survival through regular health checks, counselling, training and medical care. ALAFA should actively promote the formation of support groups where those who test positive for the first time can meet those who have been living positively for years.

## 5 Reasons Why People Test

At the start of Chapter 4, it was noted that over 60% of Precious Garment workers have, in fact, tested for HIV. The general workers' survey provides an indication of why they did so, as can be seen from the table below.

**Table 4: Reasons for testing**

Category label	Count	% of Responses	% of Cases
Encouraged by company policy	180	13.2	28.6
I was feeling sick	189	13.8	30.0
I was afraid I had been exposed to HIV	108	7.9	17.1
Persuaded by someone HIV +	200	14.6	31.7
Seen others dying not knowing their status	190	13.9	30.2
Advised by doctors	118	8.6	18.7
Encouraged by training	246	18.0	39.0
Set an example	109	8.0	17.3
We all went	28	2.0	4.4
	-----	-----	-----
Total responses	1368	100.0	217.1

The first observation to make from the results from the various surveys is that there is no one single reason that stands out above all others. People are motivated by a mix of negative factors (feeling sick, fearing exposure, seeing others die) and positive ones (company policy, advised by doctors, encouraged by training, setting an example, good service delivery, encouraged by PLWHAs). The five top responses from the Precious Garments general worker survey all fall within close to a 10% range (on the percent of cases), so clearly, people's decision-making rests on a range of issues. A similar mix of responses was obtained from the interviews held with VCT users (see next chapter).

The project will have little control over some of the factors influencing the decision to test, but there are other factors which are certainly well within the project's area of influence. Most striking, for example, is the 39% of workers who indicated that they had gone somewhere for testing because they were "encouraged by training". Equally impressive, 28.6% said they went because they were "encouraged by company policy".

To what extent do these claims of "encouragement" by policy and training hold out? To double check, it is necessary to go back to follow-up interviews where more in-depth questions were asked. About two thirds of those interviewed were well aware that the company has a policy and were able to give some examples. From these some interesting quotations can be extracted.

**Q:** *Do you know if Precious has any AIDS policy? What does it contain?*

**A:** *It states the rights of HIV positive people; that we should be treated as equals here. We have breaks anytime we feel weak or if you are sick you get a full pay for the days you were absent. Generally it states the company's position as far as HIV/AIDS is concerned.*

**Q:** *Is everybody aware of this policy? What could the company do if they are not?*

**A:** *They are already doing everything right; it's just that people are ignorant and do not want to read and learn. Information is all over the walls around here and they could get more information from the clinic.*

*(Male, Single, 27 yrs)*



**Q:** *Do you have an HIV and AIDS policy here at work? And how does it work?*

**A:** *We do have a policy. You have to declare yourself (positive status) in order to receive support like taking a break at 10; or when you were ill and did not come to work you will be fully paid for that day even though you were absent.*

*(Female, 31 yrs)*

**Q:** *Are you aware of an HIV policy here at work?*

**A:** *Yes I am.*

**Q:** *What does it contain?*

**A:** *It talks about discrimination against positive people. It protects them from abusive employees, who might verbally abuse them. It talks about access to health facilities like Sankatana. When they go to clinics or to consult doctors their money is paid in full for their day of absence. They also have breaks at 10am to take their medication.*

*(Female, Married, 33 yrs).*

While some people expressed awareness of company policy this far from universal. This is apparent from the extract below:

#### **Focus Group Discuss with men:**

**Facilitator (F):** *Let's talk about policy. Do you have an HIV/AIDS policy here at work?*

**Participants (P):** *There are some organisations that come here & hold workshops about HIV*

**F:** *So there are workshops that are held for employees here? OK. So what about the policy on HIV and AIDS?*

**P:** *I have never heard of it*

**F:** *How about others? Anyone seen or heard about what Precious intends to do for those employees living with HIV and AIDS?*

**P:** *Silence*

**F:** *OK. It seems you do not know much about this policy.*

#### **FGD with women:**

**F:** *"Ok. I am going to ask you another question. Is there any workplace HIV/AIDS policy here at the Precious? Guidelines on HIV/AIDS for workers? (Na hona le leano la HIV & AIDS moo mosebetsing? Melaoana e tsamaisang litaba tsa HIV & AIDS mosebetsing?)"*

**P:** *"I think that it is there because there are some people who sometimes come here and hold workshops for others on HIV/AIDS".*

**F:** *"So you have only realised trainings...?". "Is there any thing written down showing how to approach an infected employee, do you have it?"*

**P:** *"No, we really don't know"*

Nevertheless, the extent of knowledge of the Company policy, even if not always 100%, is sufficient to support the evidence that it does, indeed, motivate people to test.

What about training? The responses below suggesting that training also plays an important role in encouraging use of services:

**Q:** *Would you recommend someone to use Precious services, why?*

**A:** *Yes. I like it here because people get a chance to see private doctors at a low cost. They also get training on how to cope with HIV/AIDS and all other necessary support. For example, the company car takes you to the doctor or to the hospital, and home if you need that service.*  
(Married woman, 43 yrs)

**Q:** *Some people do not know about this policy. What could be done to ensure that everyone knows about it?*

**A:** *The Company is already doing something; they keep on training staff on HIV, so that is enough.*  
(Woman, 31 yrs)

**Q:** *What made you want to test?*

**A:** *I think what contributed most are the trainings that I have attended and I felt I needed to know my HIV status so that when I am ill I would know what I'm treating; and also because I am in this committee, I wanted to make sure of my status so I could talk/teach others about HIV/AIDS.*  
(Married woman, 33 yrs)

#### **Text Box 7: Living policies and frequent training**

Policies easily die. Unless they are frequently revisited they become outdated and stale. Precious Garments has done well to develop a policy that is relatively well known among workers. The policy does encourage people to test and so does training. These aspects of the programme must be kept alive, as much by the workers themselves as by management. In other words, workers should actively participate in discussing policy options and training ideas. Knowledge of the policy should be passed to those on the factory floor through varying the medium as frequently as possible: sometimes posters, sometimes drama, sometimes a leaflet, sometimes invited speakers (Mundy, 2006).

## 6 VCT Users: Factors Influencing the Uptake of Services

In Chapter 2 it was noted that, by September 2006, ALAFA management were concerned about the relatively low ratio between those positive VCT users who registered with the programme and those who actually made it to see an ALAFA-listed doctor (18 out of 83, or 21%). This concern resulted in the formulation of the two key research questions described in the introduction:

- ✓ Why do people who come for VCT and who get a positive result not register for treatment?
- ✓ Why do people who register not always go for treatment?

In this chapter these questions are explored from different perspectives. Before presenting the results the methods used are described below.

### 6.1 Recap of Methods

The two research questions were investigated primarily through *structured* interviews with a sample of those who have made use of the VCT services at Precious Garments. As a result, the information provided by interviewees was quantifiable, but far more concise than that obtained through the FGDs and follow-up interviews described in previous chapters.

#### 6.1.1 Sampling and confidentiality

The interviews took place in two rounds. This was deemed necessary as the first round did not generate as much information as expected and did not have quite enough interviews for the purposes of statistical analysis. As a result, a more substantial questionnaire was drawn up, and a new round of interviews was conducted with a freshly drawn sample. In the first round 51 VCT users were interviewed and in the second 100. Although 100 is still a relatively small number it allows for basic quantification of results to obtain a sense of the relative importance of responses. *It should be noted that all results presented in this chapter are based on the second round of interviews, unless otherwise indicated.*

For both rounds, the sample of VCT users was drawn by ALAFA staff. This was not an entirely random sample as it was important to ensure that enough of the respondents were positive to provide adequate numbers to investigate the two key questions. At the same time, it was important to include enough negative respondents so that the status of interviewees would not be known to the interviewers, at least until they voluntarily chose to disclose this in the course of the interview.

As the key objective of the exercise was to interview VCT users who obtained a *positive result* a way had to be found for them to voluntarily disclose their status. The approach used was to begin by asking interviewees a series of general questions about Precious Garments' VCT services, their pre-test concerns and their reasons for eventually testing. These questions opened the way to a key question that provided interviewees with an opportunity to disclose their status, being: "How did you feel when you got your results?" In response to this question all interviewees voluntarily disclosed the status, thus qualifying themselves to participate in the remainder of the interview.

### 6.2 Record Keeping and use of ALAFA services

One reason why the proportion of positive VCT users going on to see an ALAFA doctor is lower than expected has to do with record keeping. It appears that a significant proportion of those who registered with ALAFA (on receiving a positive result) have not been to an ALAFA doctor *simply because they no longer work at Precious Garments*. In other words, not long after taking their tests they left the factory (for a variety of reasons) *but remained on the ALAFA register - creating a false impression of the uptake of the medical services offered by the programme.*

To understand how this occurred, it must be appreciated that the ALAFA register at Precious Garments is a *handwritten* record in an exercise book kept by the VCT counsellors. It includes, in chronological order, the names of all those who have used the VCT services. As the register is not in alphabetic order it is cumbersome to use and cannot be searched, sorted or summarised as would be possible with an electronic file. If one is searching for a particular individual one has to flip through the entire exercise book to find the person's record.

Critically, there is no systematic communications between the counsellors managing the register of VCT users and the Precious Garment's Human Resources office that keeps an electronic record of the work force. In other words, when a worker leaves the factory the ALAFA counsellors are none the wiser. As this happens frequently in a factory with over 4,000 workers the discrepancy between the ALAFA register and the human resources record of the factory grows daily.

The absence from work of some VCT users in the ALAFA register became apparent as preparations were undertaken for the second round of interviews. This entailed trying to identify, on the factory floor, the 120 VCT users in the ALAFA register who had been initially sampled for interview. The research team kept a careful record of the whereabouts of all those selected for interview and the following results were obtained:

- ✓ 69 workers were found and were available for interview
- × 28 were confirmed as having permanently left the factory
- × 13 were 'temporarily absent' - their future at the factory being uncertain
- × 10 were not available for other reasons (e.g. sick leave).

Until this exercise was done, ALAFA counsellors were not aware that nearly one in five (23%) of the VCT users in their register had permanently left the factory. A detailed analysis of the whereabouts of these 28 individuals (through interviews with the Human Resource officers and other staff) showed the following:

- × 12 had resigned
- × 2 had been dismissed
- × 4 had died
- × 3 had deserted
- × 6 could not be found<sup>32</sup>

To reach the target of 100 new interviews for round two of interviews, an additional sample had to be drawn. However, more significantly the exercise revealed a need for the ALAFA register to be transformed into an up-to-date electronic record, closely linked to Precious Garments main Human Resources data base, that can be properly queried to determine critical information such as the extent of service uptake *in relation to the number of VCT uses actually present within the workforce*.

This can be achieved through the provision of a basic computer together with training focused for the Counsellors specifically on operating a spreadsheet. External assistance may initially be required to transfer all names on the ALAFA list (about 1,000) to the computer. From that point it should be possible to work with Human Resources to determine the status of all workers on the list in the factory and to establish ways in which information available to Human Resources can be transmitted on a regular basis to the ALAFA counsellors for them to keep their records up-to-date (this will give current uptake rates).

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<sup>32</sup> This was possibly because of the use of alternative names or because of transfers between departments that were yet not reflected on supervisors' lists.

## Text Box 8: Record keeping and monitoring uptake of services

For ALAFA to determine the success of its interventions an efficient monitoring system is required. One key indicator is the proportion of positive VCT users who go on to make use of the medical services offered by the ALAFA-registered doctors. This proportion can only accurately be determined if two critical figures are maintained: the number of positive VCT users at work (being the denominator) and the number seen by ALAFA-registered doctors. For the denominator to be accurate ALAFA needs to maintain an up-to-date record on the whereabouts of its VCT users. This can only really be achieved with a computer record and frequent communications with the Precious Garments' Human Resources Department.

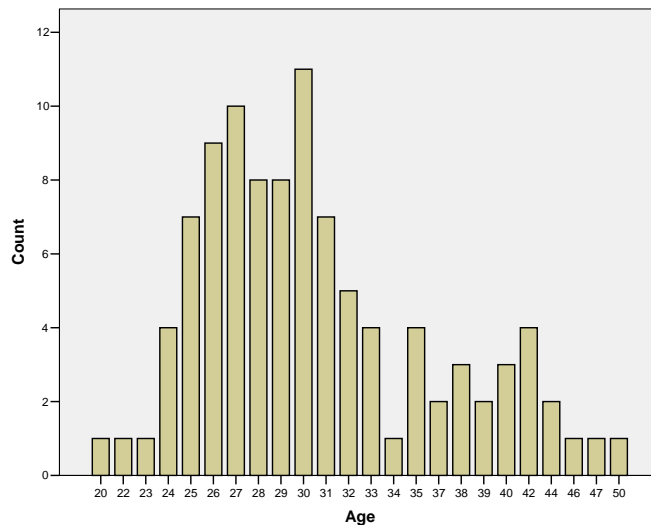
To a certain extent the issue of 'low' uptake of ALAFA medical services has been addressed by the above analysis. However, there is clearly more to this issue than record keeping. In the remainder of this chapter the other factors motivating or de-motivating uptake are discussed in detail. However, first we begin by presenting a brief profile of the workers who participated in this stage of the research.

### 6.3 Background of VCT Users

#### Gender and age

The vast majority of participants (93%) were women, which is in-keeping with the female dominated profile of the workforce. The ages of participants ranged from 20 to 50 years, with the majority falling between 25 and 35 years, as is apparent from the figure below:

Figure 7: Age distribution of interviewees



#### Knowledge of services

When asked how they had learned about the VCT services on offer at Precious Garments through ALAFA, the following responses were given in the table below. As the question allowed for multiple responses the table gives both the 'percent of responses' (distribution of all responses) and the 'percent of cases' (showing the percentage of interviewees who gave a particular answer). As can be seen, the factory Supervisors are playing a key role in making workers aware of the VCT services, with 42% of respondents mentioning this as a source of knowledge. Likewise, the VCT Counsellors and Co-workers are very active in this regard. By contrast, the Unions are not playing a significant role and relatively few workers became aware of the VCT services through poster (11%) or notices (9%).

**Table 5: How users learned of the VCT services**

Source of knowledge	N	% of responses	% of cases
Poster	11	7.1%	11.0%
Notice	9	5.8%	9.0%
Training	7	4.5%	7.0%
Peer educator	14	9.0%	14.0%
Counsellor	36	23.2%	36.0%
Co-worker	33	21.3%	33.0%
Supervisor	42	27.1%	42.0%
Union	2	1.3%	2.0%
Others who tested	1	0.6%	1.0%
<b>Total</b>	<b>155</b>	<b>100.0%</b>	<b>155.0%</b>

**Text Box 9: Record keeping and monitoring uptake of services**

Supervisors and counsellors are playing a critical role in making workers aware of VCT services. The Unions need to be encouraged to do more in this regard.

**Fears of testing**

The interviews with VCT users confirm earlier findings that fear of testing was a deterrent for many. In all, 42% said they had been fearful to test before coming forward. The reasons given also support earlier analysis, as seen in the table below:

**Table 6: What users feared before testing**

Fears of Testing	N	% of responses	% of cases
Depression/Shock/Stress	30	42.3%	71.4%
Death/Suicide	7	9.9%	16.7%
Incurable disease	3	4.2%	7.1%
Fear of status being exposed by fellow worker	11	15.5%	26.2%
Fear of status being exposed by a counsellor	2	2.8%	4.8%
Loss of reputation/dignity	2	2.8%	4.8%
Fear being despised/isolated	5	7.0%	11.9%
Fear of abandonment	2	2.8%	4.8%
Fear of work discrimination	3	4.2%	7.1%
Fear of being fired	3	4.2%	7.1%
Fear of having been infected when nursing relative	1	1.4%	2.4%
Had an accident	1	1.4%	2.4%
Fear of knowing my status	1	1.4%	2.4%
<b>Total</b>	<b>71</b>	<b>100.0%</b>	<b>169.0%</b>

The overwhelming fear that VCT users experienced before testing was that they would respond to a positive result by falling into a depression or suffering a shock (71% of cases). Some feared that they might even be tempted to commit suicide (17%).

Significantly, fewer than 5% of interviewees fear that the counsellors would disclose their status, putting the FGDs (where this seemed to be a serious problem) into perspective.

Exploring this further, the reasons for their eventual acceptance to test at the PG clinic, the interviewees were asked: “What feelings or thoughts made you decide to take a test at the PG clinic?” As can be seen from the table below, in over half the cases (58%), respondents said they just really wanted to know their status as they were tired of living with uncertainty. Almost half (47%) decided to test because they felt unwell or because they had lost weight (8%). Interestingly, the third most common reason for testing was being ‘motivated by someone living with HIV’ (17%).

**Table 7: What motivated VCT users to test**

Motivating factors to test	N	% of responses	% of cases
Felt ill	47	28.7%	47.0%
Motivated by someone living with HIV	17	10.4%	17.0%
Wanted to know my status	58	35.4%	58.0%
People died not knowing their status	9	5.5%	9.0%
Suspicious of partner's status	9	5.5%	9.0%
Don't want to (re) infect ill person	1	.6%	1.0%
Want to know what I am treating if ill	5	3.0%	5.0%
Raped	2	1.2%	2.0%
Pregnant	1	.6%	1.0%
Weight loss	8	4.9%	8.0%
Wanted to test	1	.6%	1.0%
Brother passed away	3	1.8%	3.0%
Proximity of services	2	1.2%	2.0%
Peer pressure	1	.6%	1.0%
<b>Total</b>	<b>164</b>	<b>100.0%</b>	<b>164.0%</b>

When the users were asked specifically why it was that they used the VCT services at Precious Garments rather than else they gave the following responses:

**Table 8: What motivated use of workplace VCT services**

Motivating Factors	N	% of response	% of cases
Proximity of services	90	67.7%	90.9%
Friendly staff	12	9.0%	12.1%
Trustworthy staff	3	2.3%	3.0%
Readily available staff	7	5.3%	7.1%
Wanted to get treatment	6	4.5%	6.1%
Trust accuracy of tests	1	.8%	1.0%
Benefits from ALAFA	12	9.0%	12.1%
Other	2	1.6%	2.0%
<b>Total</b>	<b>133</b>	<b>100.0%</b>	<b>134.3%</b>

The results affirm the critical importance of proximity. In over 90% of cases this was the reason why the factory services were used rather than others. Two other important factors can be noted: friendly staff (12%) and the broader benefits of registering with ALAFA (12%). By promoting these aspects ALAFA should be able to further increase the uptake of VCT services.

#### 6.4 Satisfaction with the Precious Garments Clinic

All users were asked if they were satisfied with the services they received at the clinic: 98% declared that they were. The only concerns raised had to do with ‘lack of equipment’ (possibly a reference to the absence of X-ray equipment) and that ‘services were not immediately available’. None of the respondents used the opportunity to question the confidentiality of staff, suggesting that concerns about this raised during the FGDs could have been exaggerated.

## 6.5 VCT Users' Reactions to Test Results

Earlier we noted that this stage of the research was designed to focus on VCT users who had obtained a positive result (to explore why they did, or did not, subsequently visit an ALAFA-listed doctor). As the status of interviewees was not known to the research team, a simple question ('How did you feel when you got your results') was asked as a mechanism for interviewees to volunteer their status. From this, the following results were obtained:

**Table 9: VCT users' reactions to getting test results**

Reaction	Percent
Relieved to be negative	25%
Shocked/worried to be positive	34%
Although positive, relieved to know status	41%
<b>Total</b>	<b>100%</b>

All interviewees were then asked to explain, in their own words, the reasons for their reaction. These open-ended explanations were recorded in each questionnaire. Following this, the 25 interviewees who reported a negative result were thanked for their contribution and released. The 75 who said they tested positive were invited to continue the interview. All accepted and the interviews continued.<sup>33</sup>

Although the question about interviewees' reaction to their results was originally intended to serve simply as a screening device, it generated unexpected and revealing results which are described in some detail below.

### 'Shock'

Given the discussion in Chapter 4, it is not surprising that about one third of those who got a positive result were shocked or worried, to the point of fearing they would die:

*"I was shocked. My head didn't feel well, my heart was sad as I was so worried about my problem."*

*"I was scared people would laugh at me and that I would die."*

*"I was afraid. I thought only of death."*

*"I was afraid of dying and leaving my baby alone."*

*"I was so worried. I went to the doctor and he found my blood pressure had gone very high."*

*"I was afraid that people would see I am positive and make fun of me".*

*"I was worried about what my husband would say when he heard."*

*"I was so worried I stopped eat and then I went to the church to see the priest."*

### 'Acceptance'

The second category of responses belongs to those who found they were able to accept their new status. The reasons they give for this reaction are particularly interesting because they can be used to formulate messages for other to test:

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<sup>33</sup> It will be recalled that the sample (done by ALAFA) intentionally included a higher proportion of positive people than is actually the case in the workforce to ensure adequate number of the analysis of the key questions addressed in this chapter.



*“I accepted because I know I am not alone in having the disease.”*

*“I accepted my result because I know this virus is living among us (i.e. is reality we all have to deal with).”*

*“I accepted immediately, because I believe this is a disease that can kill if a person refuses to accept that they have it.”*

*“I took it as a disease that is no different from others, so I accepted.”*

*“I accepted because disease is something that exists. It is not the beginning or end of life.”*

*“The test was well done so I accepted the results.”*

*“I accepted because now I know can get better.”*

#### **Text Box 10: Promote acceptance**

The key message to emerge from VCT users’ reactions are: “You are not alone. Accept your status and join us in living positively.”

#### **‘Relief’**

What came as more of a surprise was how many interviewees were actually *relieved* to learn of their positive results. When asked to explain their reactions the reasons for this relief become apparent, as can be seen from extracts below.

*“I was relieved, because I then knew what I must do to protect myself so I can live a long life.”*

*“I was relieved because although my result was positive my CD4 count was still high.”*

*“I was relieved because before I didn’t understand why I was sick and not getting better.”*

*“I used to get sick very often that is why I was relieved to know my status.”*

*“I was relieved because I had observed that I was sick, so I was satisfied to know the reason.”*

#### **Text Box 11: It can be a relief to know your status**

VCT users are frequently relieved to know their status, even when it is positive. It is reassuring to know what you are living with; with this knowledge you can tackle any problems you might face and plan a health life. This critical message needs to be incorporated into ALAFA materials and campaigns.

In open-ended conversation it emerged that a few interviewees were using the Precious Garments clinic to confirm test results obtained elsewhere. They were either relieved to find that the results were the same, or shocked when they were found to be different. When different results were obtained there was a tendency to question the validity of the Precious Garments’ clinic tests. Overall, it would appear that there is a need for further awareness raising/training on the issue of the windows period and the need for repeated testing.

## 6.6 The Question of Registration

### 6.6.1 The extent of registration

It will be recalled that one of the three research questions was: “Why do people who come for VCT and who get a positive result not register for treatment?” To determine this, all 75 HIV positive interviewees were asked the following question:

“When you were informed that you had a positive result were you offered the chance to register with the ALAFA programme?”

All but 3 of the 75 (or 2%) recalled being invited to register with the ALAFA programme. When the remaining 72 were asked if they accepted the invitation all but three did so (i.e. 6 out of 75 were not registered). One of those who did not accept to register after being offered the chance indicated said this was because she was ‘afraid of the doctor’. The other two did not give a clear reason.

When all interviewees were asked specifically: “What advice regarding health services did the counsellor give you when informing you of your results?”, 85% recalled being advised to see an ALAFA registered doctor so they could access ARVs. Other types of advice (mentioned by between 2% and 9% of respondents) include: use condoms; eat well; stay healthy; keep good hygiene; don’t share toothbrushes and (in one case) chose between ALAFA doctor and the Sankatana centre.

Overall, it would seem that the positive VCT users are being provided with sound advice and are, above all, being encouraged to see the ALAFA-registered doctors.

*These results suggest that initial concerns (dating back to September 2006) about positive VCT users not registering with ALAFA were somewhat misplaced. Currently, non-registration is not a major issue. This was confirmed during open ended discussion with the ALAFA Counsellor (who have not encountered resistance to registration) and with the VCT users themselves.*

#### Text Box 12: Monitoring registration

The vast majority of VCT users are registered with ALAFA. Nevertheless, refusal to register - for whatever reason - would be an important indicator of any emerging negative perceptions towards the programme. For this reason a systematic record should be kept of the percentage of VCT users who refuse to register, and the reasons for this.

### 6.6.2 Threats to registration with ALAFA: Fear of exposure

In the course of the interviews one issue emerged that may threaten VCT users willingness to register, and this is fear of having one’s status exposed through participation in ALAFA activities. During the interviews with VCT users, two respondents indicated that did not appreciate being called out of the lines by ALAFA counsellors because they feared this would raise suspicions about their status. Although this concern was raised by very few participants it was immediately recognised to be valid, given the earlier interviews where such fear were raised as a serious deterrent to testing (see 4.4.3).

As a result of the concerns raised, the interviews were suspended and a series of meetings were held with ALAFA management and with all key role players at Precious Garments.<sup>34</sup> These discussion involved brainstorming a way forward, not just for the completion of the interviews but for the broader problem of *how ALAFA should communicate with its positive VCT users without exposing*

<sup>34</sup> Francinah Motekase (Peer Educator), ‘Mamakalo Mohapi (Peer Counsellor), Marianne Mafike (?), Nthabiseng Mohapi (Nurse), Palesa Mokhatla (IRC) and two VCT users.

*their status.* Although these discussions did not form part of the Consultant's terms of reference they are recorded here in full as the dilemma presented is a serious one for the programme.

### **The Existing Approach**

Departments that usually call out employees from the factory lines are the clinic staff, peer educators and counsellors, the HR/accounts, the Inspection team (Precious Garments Buyers/clients) and Industrial Relationship Committee (IRC). In order for anyone of these to have access to the employee, the employee's Line Supervisor must be approached to request the release of the employee at a certain time. The Inspection team is the only party that can approach the employee directly, without the supervisor's permission. However, this does not happen often as these inspections are carried out only twice a year.

### **Alternative approaches**

Different ideas were put forward for discussion, including the following from the VCT users and the Sechaba research team:

**VCT Users' ideas:** Two VCT Users who were asked to give their opinion on alternative approaches. One suggested that maybe a different person, other than the counsellors, can do the 'calling'. The other felt that counsellors should have a list of those who did not want to be called out so that they are left out in AIDS related activities

**Research team's suggestions:** The research team suggested that maybe writing notes and getting them delivered to employees in the lines (requesting that they come to the clinic at a particular time) or possibly 'posting' these to employees' lockers might be an alternative. The team also suggested that the 10 o'clock break could be used to inform VCT users of upcoming events where their participation would be needed and would then ask them to suggest times that would suit them.

### **Discussion on alternative approaches**

The peer educators and counsellors felt that there really is no other way to access people other than what they already are doing, i.e. to approach a supervisor and ask for permission to talk to the person *as the supervisor is the only authorised person to give this permission as they supervise work and are supposed to manage production.*

Other options were discussed and the following points were made:

- Use a neutral person as a messenger. It was pointed out that this would have to be a different person every time because the person would soon be associated with acting as a messenger for the clinic.
- Use other departments such as IRC, Accounts or Inspections. If other departments were to be involved the status of the VCT users could be compromised by sharing information with a third party. The use of inspectors was dismissed as an option because they only visit the factor twice a year.
- Use notes posted to workers' lockers. Just over two thirds of VCT users (69%) have access to a locker that could, potentially, be used to transmit messages. The flaws in this idea are that one would still need to find a way of reaching the one third that do not have a locker and that the lockers by workers so there is no guarantee that the information posted would remain confidential.
- Use the 10am tea break. The immediate concern with this idea was that not all HIV positive VTC users make use of the extra break that they are entitled to (data gathered in the interviews show that only 48% do). It was argued that for the break to become an effective channel of communication greater uptake of this privilege would be need. The best way to achieve this might be to provide an incentive (such as soup or tea), but this may not be acceptable to management because of the costs.

- Make participation mandatory. Some of the stakeholder who participated in the discussions felt that it should be mandatory for all who test at ALAFA to be notified that they will have to participate in all matters related to workplace HIV and AIDS programme. Others felt that this would simply act as a deterrent to testing.
- Warn all those who register with ALAFA that they may get called out to participate in ALAFA activities and give them the right to decline. This could involve including a clause in the ALAFA briefing card that is read to VCT users and maintaining a clear record of who has accepted and who has declined (see Section 6.2 for more on record keeping).

Those who participated in the discussion felt that there was no easy solution to the problem. Most argued that positive VCT users just need to ‘learn to live with their status’ and be educated about HIV and how to accept themselves.

Some felt that if there were incentives (nutrition boosters/food/medication) for those who tested positive this would motivate them to be more open about their status and would encourage others test and be open. They argued that by creating an open attitude to one’s status the problem of calling VCT users out from their lines could be overcome. An example was given of a programme initiated by one of the ALAFA doctors. This involved providing a herbal mixture (for some 2 weeks) for HIV positive patients who were prepared to be open about their status. The response is reported to have been overwhelming with many people openly declaring the status to become involved.

### Conclusion:

- ✓ There does not appear to be any easy way to bring VCT users out of their work lines on the factory floor.
- ✓ This is a long term issue that needs to be given careful thought. Different approaches may need to be tried over time.
- ✓ It is important to give VCT users the option of not participating in any exercises (such as interviews) that might require them to be called from their lines.
- ✓ It was agreed that, with regards to the research exercise, as three quarters of the sample have already been interviewed and as only very few VCT users (2) raised any objections, the exercise should be completed with as much discretion as possible being used in calling those in the sample from their lines.<sup>35</sup>

### Text Box 13: Minimising the threat of exposure

Most VCT users do not object to participating in ALAFA activities. However, a fear of such activities exposing their status is a deterrent to some. If such fears were to spread this could result in greater refusals to test or register for the programme. ALAFA needs to experiment with different ways of communicating with workers, such as passing notes through supervisors. All factories should be encouraged to establish systems of ‘pigeon holes’ or similar where individual workers can receive (and deliver) messages. If this is not feasible, at least the supervisors should have pigeon holes through which the programme (and others like management and the unions) could communicate to workers.

## 6.7 Users Pre-test Expectations

When asked: “What benefits did you expect to get from registering with the ALAFA project?”, the most common response from VCT users was “to access health monitoring services” (by a doctor). This

<sup>35</sup> Following this the interviews continued with no further concerns being raised.

was mentioned by 80% of interviewees as a pre-test expectation, and is obviously a very critical factor in motivating them to test and register with ALAFA. Followed closely by this, at 64% of cases, was the expectation of access to medicines (usually implying access to ARVs). The next substantial expectation was counselling (at 40% of cases). The only other substantial expectation was for the extra 10am break privileges, but mentioned by only 16% of interviews. A full list of expectation is given in the table below:

**Table 10: What VCT users expected from registering with ALAFA**

Expectation	N	% of response	% of cases
Counselling	28	17.9%	40.0%
Access to medicines (ARVs)	45	28.8%	64.3%
Access to health monitoring (CD4 counts, etc)	56	35.9%	80.0%
Extra 10am break privileges	11	7.1%	15.7%
Sick leave benefits	4	2.6%	5.7%
Participation in training/workshops	1	.6%	1.4%
Food donation	4	2.6%	5.7%
Consultation paid by ALAFA	1	.6%	1.4%
Check-ups	1	.6%	1.4%
Nothing	4	2.6%	5.7%
Other	1	.6%	1.4%
<b>Total</b>	<b>156</b>	<b>100.0%</b>	<b>222.9%</b>

From the above, it would seem that VCT users clearly have a good sense of what ALAFA has to offer and are not being misled by false expectations (for example, only 4 persons mentioned ‘food donations’ as an expectation).

## 6.8 Use of ALAFA-registered doctors

To investigate people’s users responses to the advice given, interviewees were asked: “Did you make use of any health service following your results and counselling with ALAFA?”. The responses show that 65 of the 75 positive VCT users (87%) did seek health care following their tests. Most of these followed the Counsellors’ advice to see an ALAFA-registered doctor for health monitoring and or ARVs. The distribution of the health-seeking actions taken is shown in the table below.

**Table 11: Use of health services after testing**

Action	N	% of responses	% of cases
Saw ALAFA doctor for health monitoring	58	53.2%	81.7%
Saw ALAFA doctor for ARVs	31	28.4%	43.7%
Saw other service provider for health monitoring	6	5.5%	8.4%
Saw other service provider for ARVs	4	3.7%	5.6%
No action	10	9.2%	14.0%
<b>Total</b>	<b>109</b>	<b>100.0%</b>	<b>153.4%</b>

As some interviewees said they took more than one action, such as seeing and ALAFA doctor for health monitoring and for ARVs, the number of cases in the table exceeds the number of those taking an action by 40 (i.e. 65 users vs.105 actions). All of those who were receiving ARVs also reported undergoing health monitoring (including CD4 counts).

The vast majority of these using the ALAFA-registered doctors were fully satisfied with the services provided: 82% said the staff were “friendly”; 88% said the “service was good” and a further 20% added that they “felt well cared for”. A number of users mentioned, anecdotally, that they had been impressed when they had been offered tea on arrival. Only a small minority (7%) said that the “staff were not welcoming”.

Further evidence of the high level of satisfaction with ALAFA-registered doctors comes from the fact that 79% of those who had been to an ALAFA doctor said they recommended the service to others on their return.

#### Text Box 14: Use of ALAFA-registered doctors

At the start of the study, ALAFA management were concerned about what appeared to be relatively low uptake of the medical services offered by the programme in relation to the number of people testing positive. One year later, as the study draws to a close the situation appears to have changed with four out of five registered VCT users *who are still working at the factory* reporting use of an ALAFA-registered doctor. Nevertheless, for the reasons given in Text Box 12, this is an indicator that should be constantly monitored.

### 6.9 Other Motivating Factors

It was thought that positive VCT users might have been motivated to use ALAFA medical services because of the other benefits offered. For this reason interviewees were asked to indicate what non-medical benefits they had made use of. As can be seen, other benefits are a factor, but even the most common (benefiting from an extra break) is enjoyed by less than half of those entitled to it.

Table 12: Non-medical benefits enjoyed by positive VCT users

Benefits	N	% of responses	% of cases
Extra break (10am)	30	32.3%	48.4%
Medical assistance when ill	26	28.0%	41.9%
Seeing a Counsellor at any time	13	14.0%	21.0%
Full pay even if absent from work	12	12.9%	19.4%
None	11	11.8%	17.7%
Gifts	1	1.1%	1.6%
<b>Total</b>	<b>93</b>	<b>100.0%</b>	<b>150.0%</b>

Although the 10am break appears to be appreciated, it is somewhat controversial among the positive VCT users who are part of the programme. This is for two reasons. The first is that some of the users don't see the point of an extra break if one has nothing to eat:

*Although we are given a 10am break, we have nothing to eat at this time. If only ALAFA could help us with food that would be good. We need to live. This is the most important because the medicines won't work if you are hungry. We work, but we run out of money. I am the only one who works in my household, and I come from out of town which costs me M300 per month. My money does not last, so I cannot afford to buy food to eat at 10am.*

(Woman, 30 yrs)

The other reason for relatively low uptake of the 10am break is fear of exposure (discussed in some detail in Chapter 4). A number of interviews made it clear that they did not go for the break because they felt this would make their status known to fellow workers.

## 6.10 Use of non-ALAFA Medical Services

As seen in Table 12 above, the use of non-ALAFA medical services is limited. Only 5 out of the 65 positive VCT users who sought treatment went elsewhere for health services. The other service providers mentioned include: Sankatana, Dr Osman, Mabote Clinic and 'Masabateng' (7<sup>th</sup> Day Adventist clinic or Maloti hospital). The main reasons for using other service providers included: the person was already seeing a particular doctor before getting work at Precious Garments; the person needed to see a specialist for other reasons; the service provider is close to the person's home. The satisfaction levels with these other providers was also generally quite high.

The following case study illustrates a number of the points made above.

### Case Study. 'Me Ma 'x', aged 24.

*I have been sick, very sick, for about 4 years. One day I was called by a counsellor and I explained that I have been sick but I don't know what it was. She encouraged me to go for testing to see what the cause might be. She did not force me. I agreed that she should come and get me (from the line) so I could for testing.*

*I had a test and I found that I was positive. I was afraid of testing, because I was afraid that people would laugh at me. I was afraid someone would tell my boss and they would talk about me, and point to me, but I was so unwell I decided to test.*

*When I got my results I was afraid, but I accepted because I realised this is my life. I realise that you can have HIV even without bad behaviour. It is like any other disease.*

*I was given a list of doctors to chose from and material to read. I was advised by the counsellor to have safe sex. I was given a card and told to go to the doctor. I was told the doctor would examine me. I was given the choice of selecting from a list. No mention was made of other service providers.*

*Dr M's services were very good. I was given tea, but without sugar. How will we get better without sugar? I am just joking we were grateful for the welcome. He examines you very well, and asks where the problems are. I have heavy bleeding, that is my problem. So I was happy with his examination. I expect to improve my health by going to a doctor. I have suggested to others that they should go. When I went to the doctor I was given pills called 'A' some thing... But they are finished, and I have not been back.*

*I was offered the chance to take an extra break at 10am, but I did not go because I was afraid that as soon as I went for food at 10am everyone would know my status. ALAFA must continue its good work. But what we need is Powermix. We are hungry. Too keep well I must eat well, when there is a chance. I must keep warm, avoid the cold. I use a lot of garlic at home. It keeps me well and prevents me getting hungry. I mix it with papa and moroho, it boosts the immune system.*

## 6.11 Reasons for not Taking Action

There were 10 VTC users interviewed who obtained a positive result *but did not see an ALAFA-list doctor*. The reasons for this are shown in table below:

**Table 13: Reasons for Not Taking Action**

Reason for taking no action	N	% of responses	% of cases
Feel well	6	42.9%	60.0%
Couldn't get time off	1	7.1%	10.0%
Don't want to lose pay	2	14.3%	20.0%
Don't believe in the results	2	14.3%	20.0%
Left health book (bukana) at home	1	7.1%	10.0%
Not clear about procedures	1	7.1%	10.0%
No reason	1	7.1%	10.0%
<b>Total</b>	<b>14</b>	<b>100.0%</b>	<b>140.0%</b>

*Note: 4 interviewees gave more than one response.*

The most common reason came from the six users who said they did not take action because they “feel well”. In other words, for them, going to a doctor is something you do when you feel sick or have clear symptoms of illness. You don’t waste time and money to see a doctor when you feel fine. Even with the small number of cases studies it is apparent that this is the key reason for those obtaining a positive result not seeing a doctor.

During the round one interviews a few other reasons who given, including:

- ✓ Don't want to be seen taking special break
- ✓ Don't want to be called out
- ✓ Don't want to be seen at a place associated with HIV
- ✓ Doctors surgery too far away
- ✓ Don't believe in the results
- ✓ Got lost looking for doctor
- ✓ Husband destroyed card
- ✓ Prefers self-treatment

### **Text Box 15: Promoting ‘preventive maintenance’**

Some HIV positive workers are not getting to see doctors because they think they can't get time off or might lose pay. ALAFA, the unions and factory management need to work together to combat this perception. However, more significantly, the perception that feeling healthy means there is no need to see a doctor must be tackled.

The key message should be: “Feeling healthy? Now is a good time to see the doctor”. The concept of preventive maintenance of the human body needs to be deeply instilled in the minds of all workers.

In short, ALAFA should focus its efforts on those who take no action because they “feel well”, as this perception runs the risk of people seeking assistance when it is really too late.

## **6.12 Use of Other Products for Treatment**

ALAFA management expressed concerns that some positive workers at Precious Garments may be forgoing the opportunity of proper health care because they are reliant on alternative treatments of different kinds. To explore this issue, interviewees were asked: “What are the ways in which you prevent yourself getting ill if you are HIV positive?” The responses indicate that most positive VCT users (74%) are doing ‘nothing’ in particular. However, close to 10% said they were using ‘Sesotho medicines’ or using ‘good nutrition’. No mention was made of Herbal Life products which are were



being promoted around the factory at some point. In open ended interviews, a number of workers indicated that they simply could not afford such products.

**Table 14: Additional measures taken to keep healthy**

	N	% of responses	% of cases
Nothing	46	63.0%	74.2%
Cleanliness	2	2.7%	3.2%
Good nutrition	7	9.6%	11.3%
Condoms	5	6.8%	8.1%
Sesotho medicine	6	8.2%	9.7%
Booster from store	1	1.4%	1.6%
Smoking	1	1.4%	1.6%
Green tea	1	1.4%	1.6%
Dress well	1	1.4%	1.6%
Garlic	1	1.4%	1.6%
See doctor promptly	1	1.4%	1.6%
Medicine from chemist	1	1.4%	1.6%
<b>Total</b>	<b>73</b>	<b>100.0%</b>	<b>117.7%</b>

### 6.13 VCT Users' Suggestions

Before the interview was concluded, the positive VCT users were given an opportunity to make their own recommendations for improving the ALAFA programme. This was designed in an open-ended manner so that the interviewees could discuss any issue of concern. Below a summary is given of concerns and suggestions raised. Where appropriate the workers' suggestions are discussed further in the final chapter of the report.

#### 6.13.1 Being called from the line

As noted earlier, a number of VCT users expressed a concern that their status is being exposed by the ALAFA counsellors calling them from their lines (on the factory floor) for ALAFA-related activities (counselling, training sessions, interviews, etc). They urged the Programme to find another way to communicate with them that would not result in their status being exposed. They also asked that the supervisors should be emerged not to hurry them, as being called out can be very stressful if it is made to appear as an emergency.

#### 6.13.2 Expanding services

There is a real appreciation of being able to receive workplace services. So much so, that a number of suggestions were made as to how these could be improved. For example, one worker suggested that the clinic should also be able to test for TB, and another asked if an X-ray machine could not be obtained. A more realistic suggestion was that the clinic should have a special sick bay that can be used for those who get ill at work to rest and recover.

#### 6.13.3 Improving access to doctors

Access to the ALAFA-registered doctors is also valued, but interviewees pointed out that they sometimes need to see the doctor between their scheduled monitoring or ARV visits (for opportunistic diseases or other problems). When this happens they are charged M85 for doctor's fees. Their plea was to be charged not more than the usual M10, regardless of the number of times they see the doctor. In short, they do not want their visits to the doctors to be restricted and would like ALAFA to subsidise all visits.

A closely related suggestion has to do with the need to see specialists. A few interviewees recommended that ALAFA should cover the costs of eye doctors (or other specialists) who need to be

consulted from time to time. They also asked that the transport costs of getting to Queen Elizabeth II Hospital (for additional tests not available at the ALAFA doctors) should be covered.

#### **6.13.4 Follow-up visits**

Many workers live on their own and, apparently, there have been cases of workers falling ill and dying without anyone being aware of their plight. A suggestion was made that ALAFA should put in place a follow-up mechanism that would enable counsellors (or any designated person) to pay home visits to those positive VCT users who suddenly disappear from work.

#### **6.13.5 Food Aid and immune boosters**

The most frequently suggestion was that positive VCT users should be given some sort of food aid by the ALAFA programme. The arguments made in favour of this were that:

- ✓ Workers salaries are very low and by the time they have paid for transport, school fees and rent they do not have enough left to purchase food for the whole month.
- ✓ It is difficult to work when you have not eaten enough.
- ✓ The 10am break is of little use if you have no food to eat.
- ✓ ARVs need to be taken with food.
- ✓ ARVs increase one's hunger.
- ✓ Food is given by other programmes, like Sankatana.
- ✓ Immune boosters should be provided for those who are not yet taking ARVs.

#### **6.13.6 Work conditions**

A number of suggestions had to do with work conditions. The most frequent one was that those registered with ALAFA should get full payment went on sick leave, *even when this exceeds the current allowance of 12 days*. Other suggested that measures should be taken to reduce the workload of those who are sick, such as assigning tasks that do not require long periods of standing.

#### **6.13.7 Access to medical services once work contract ends**

Interviewees strongly recommended that measures should be found to maintain access to medical services, even after their contracts end (without any specific limit).

#### **6.13.8 Information Dissemination**

A final suggestion that emerges from these open-ended interviews is for ALAFA to increase information dissemination so that more workers are made aware of how the programme operates.

### **6.14 Section Conclusions**

The overall conclusion to be drawn from the above findings is that the system is generally working well.

- ✓ The vast majority of positive VCT users (85%) recall being encouraged to see an ALAFA-registered doctor by their counsellors.
- ✓ 87% of positive VCT users sought health care after testing.
- ✓ 82% of positive VCT users saw an ALAFA doctor of health monitoring.
- ✓ Satisfaction levels are very high.
- ✓ Only 13% of positive VCT users are not seeking treatment, with 'feeling well' being the chief reason.
- ✓ Use of alternative remedies and measures is limited.

Returning to the two key research question discussed at the start of the chapter the following can be reiterated:

- ✓ Why do people who come for VCT and who get a positive result not register for treatment?

- *12 months after this concern was first raised (Sept 2006-Sept 2007) this is no longer appears to be a serious issue. 96% of VCT users were encouraged to register and virtually all of them did so.*
- ✓ Why do people who register not always go for treatment?
  - *The chief reason is that 23% of those registered no longer work at the factory and have, effectively, been lost to the programme. A further 13% have not sought treatment, primarily because they 'feel well'. A smaller number (about 10% of those who sought treatment) used other service providers, primary for reasons of past use or convenience.*

## 7 Gender Issues

The study was not set up to look into gender issues in any detail. This chapter, therefore, makes only a few passing observations that may be of value to the ALAFA programme.

The first observation is that the factories are largely a world of women, where men, who make up around 10% of the workforce, are very much in the minority and easily overlooked. Although this issue only emerged once, it is apparent that there are concerns about the lack of ‘man-friendly’ services at the factory. In one of the women’s FGDs several women said that, from their observations, men are generally reluctant to test because most service providers are female and most users are women.

Men’s reluctance to use female dominated health centres is certainly supported by studies of men’s use of health centres in Lesotho. For example, in 16 FGDs conducted with men in the *Poverty Mapping Exercise* (Sechaba, 2000) a number of reasons for male under-utilization emerged:

- Many men were reluctant to take STIs to health centres where they knew there were only female nurses attending, especially in cases where the nurses were young.
- They felt they would get greater ‘privacy’ if they were examined by a male nurse and said they could not explain the ‘male illnesses’ to female workers.
- Men would like to see traditional healers being trained in modern methods, as many feel more comfortable seeing a traditional healer than a nurse.
- They were not happy that so many health facilities had foreign doctors who could not understand what they were saying.
- A few resented the health centres as they blamed the contraceptives provided to their wives at the centres as being a cause of STIs.
- Examination rooms do not offer adequate privacy (staff may enter when they like).
- A few indicated that patient confidentiality is not maintained.
- Many complained that nurses did not take the time to listen to their problems.

This study has not been able to explore the attitudes of male factory workers, but it can be assumed that some of the concerns expressed above will apply to men in the workplace.

### Text Box 16: Gender balance

Men are often embarrassed to use female dominated facilities. ALAFA should encourage men’s use of VCT services by making male counsellors available, at least on a part-time basis (possible by having men’s health days).

The interviews made it clear that the men themselves are far from blameless. A number of interviews said men’s apparent underutilization of health services lies more in their macho perspective. Instead of seeking help when needed, they see illness as a sign of failed manhood, and therefore they only test when they really do not have much of a choice (and most often that decision is made by the carer).

In the FGDs, some women were adamant that “most males are still in denial about the existence of HIV and AIDS”, as well as “their vulnerability to infection” and that this makes them reluctant to test. They accused men of denying the problem, blaming and abandoning their female partners and punishing them by withdrawing the “benefits” that the woman got from the relationship.

In the follow-up interviews the point was made that men are often just fatalistic:

**Q:** *Last week’s discussion indicated that men are afraid to test. What exactly do you think makes men fear to take an HIV test?*

**A:** *Such people often say they do not care whether they live or die. I have heard men saying “if I live, I live...if I die, I die”. It sounds like they just don’t care. If they feel healthy, they don’t believe they can have HIV.*

**Q:** *Do you mean that they don't want to change their lifestyle?*

**A:** *I think so.*  
(Married man, 36 yrs)

Others thought the men were just being stubborn:

**Q:** *From last week discussions, men are said to be reluctant to test. Why are men so reluctant or afraid to test?*

**A:** *Because they are stubborn or should I say they're in denial? I really don't know but I'm aware that here at work you will see many women attending trainings and workshops on HIV/AIDS and only few men will attend.*  
(Married woman, 41 yrs)

#### **Text Box 17: Combating macho-fatalism**

Men have different perspectives of illness and treatment. ALAFA needs to keep these in mind in its programme and use men to target men in the promotion of VCT services.

## 8 Summary and Conclusions

### The context

The ALAFA project is promoting the use of VCT services in the Lesotho garment sector in the midst of a devastating pandemic. Lesotho's high HIV infection rates are responsible for nearly 25,000 deaths per annum, placing a massive burden on those who remain behind. One factor driving the pandemic is that many of those most at risk do not know their status and are apparently reluctant to take an HIV test. In the garment factors HIV prevalence is over 40%, well above the national average, presenting a serious threat to the industry.

### Reasons for the Study

The Precious Garments apparel factory in Maseru was the first to benefit from ALAFA's efforts, which include on-site VCT services and access to off-site ARV treatment via eight private doctors. Although nearly 500 people had used the VCT services by the end of September 2006, there were concerns that far fewer than expected had completed the expected process of registration and treatment. To better understand the reasons for this the study investigated the factors promoting and impeding use of VCT and related services provided by ALAFA.

### Key findings from a Literature Review

A literature review found very few documents locally or internationally dealing specifically with barriers to the uptake of VCT. However, from those available a number of key points emerge that were affirmed by the research conducted at Precious Garments:

1. Workers live on minimal wages and find it extremely difficult to satisfy the many demands placed on their income by their dependents. This can result in high levels of stress and a sense of living on precarious lives. Many interviewees said that they are reluctant to test because they fear a positive result will create more stress than they can manage.
2. The literature suggests that high levels of stigmatisation will undermine VCT use. The current study confirmed that workers fear being stigmatised and that there are repeated examples of this taking place on the factory floor. It is also found that fear of stigmatisation is a serious constraint to VCT use.
3. Stigmatisation would not be so feared if confidentiality could be maintained. A study by ILO in Lesotho suggests that fear of confidentiality being breached is a factor constraining use of workplace VCT services. The current study confirms this, but goes on to point out that it is very difficult to offer those who tested positive workplace benefits (such as extra tea breaks) without exposing them.
4. Other key findings from the literature that concur with the findings from the current study are: believing that a positive VCT test will lead to societal rejection is a critical barrier to VCT; that VCT services are likely to be under-utilised if perceived threats outweigh perceived benefits; and that many HIV positive workers wait too long to be tested and seek treatment resulting in a rapid demise that is often associated with the test itself.

### Use of mixed methods

The study built on the findings of the literature review and developed a mix of qualitative and quantitative methods to explore the key research questions. The release of data from a related ALAFA Seroprevalence and KAP survey of over 2,500 workers in eight factors provided opportunities to compare and 'triangulate' the findings.

### Higher than average percent testing

The findings show that workers at Precious Garments are far more likely to have tested than those in other factories, with over 68% of the former having had at least one test, compared to 41% of the latter. However, only 25% of the Precious Garments workers had used the on site facility, with the remainder (43%) having used a facility elsewhere. A key factor for the use of off-site facilities is fear of exposure.

### **Fear as a deterrent to testing**

Fear of one's own response to a positive result, and of those at home and at the workplace, is the key factor constraining VCT use. The immediate fear is that one may not be able to cope psychologically with the news of a positive result, and that the shock may be so great that it would itself cause a rapid demise. This fear is related to an extremely negative perception of AIDS as a 'killer disease' and with the already-high levels of stress workers experience in their daily lives. *Workers feel that they are already living on a knife's edge and fear a positive test result would push them into an abyss from which they would never escape. Ironically, workers who do not test ultimately die, because of their fear of dying.*

➤ **AIDS should be portrayed as a 'normal disease' requiring regular check-ups**

For this reasons it is recommended that less emphasis should be placed on AIDS being a "killer disease" associated with "bad behaviour". Campaigns should encourage people to think of it as any other disease that needs regular "check-ups" (i.e. testing) as well as addressing the on-going prevention efforts. *See key messages in Text Box 6.*

### **Fears of work place disclosure**

The study found that fears of workplace disclosure, and the subsequent reactions of those at work, are a major barrier to testing. Workers worried that such disclosure would result in them being stigmatised and ridiculed at various levels. The sources of potential disclosure of status include counsellors (through professional error or malicious intent), supervisors and, very significantly, fellow workers. Well-intentioned measures, such as the extra 10am break, can be negatively perceived as workers associate these with the HIV-positive group.

➤ **Maintain 'Zero tolerance' for confidentiality being breached: maintain existing counsellors.**

With regard to the counsellors, ALAFA will need to consider the strengths and weaknesses of the different options presented. As related results show that very few of those who actually took at test fear any breach of confidentiality has taken place, the Consultants recommend the existing counsellors should be maintained, with an alternative external VCT option being provided on a regular basis (Option 4, Text Box 2). With regard to supervisors, there must be no compromise. Any breach of confidentiality should be taken very seriously, with demotion or dismissal as a punishment.

➤ **Don't give co-workers any opportunity to expose others**

It is apparent that workers discuss each others HIV status, and that anyone suspected of being positive runs the risk of being ridiculed. Workers are likely to use any 'evidence' of a positive result as weapon against each other in disputes. Such 'evidence' includes ALAFA registration cards, ALAFA invitations to workshops or meetings and extra 10am tea-break privileges. To avoid these it is recommended that:

- ✓ Every effort should be made to maintain the multi-purpose character of the PG clinic. Those attending for VCT purposes should never be given any document to take back to the lines that might become a source of gossip.
- ✓ Stigmatisation is real, common and hurtful. It is a serious barrier to VCT use and must be combated through a multi-pronged and prolonged campaign.
- ✓ People's fear of not being able to cope with the news of being positive must be tackled head-on in a vigorous campaign using the messages to emerge from this study.

### **Factors that motivate testing**

With regard to those who have tested, it was found that they are motivated to test by a mix of negative factors (feeling sick, fearing exposure, seeing others die) and positive ones (company policy, advised by doctors, encouraged by training, setting an example, good service delivery). The project will have little control over some of the factors influencing the decision to test, but there are other factors which are certainly well within the project's area of influence, including training and policy development.

➤ **Keep policies alive and make them well-known**

Policies easily die. Unless they are frequently revisited they become outdated and stale. Precious Garments has done well to develop a policy but it needs to be made better known. Where it is known, the policy does encourage people to test, and so does training. These aspects of the programme must be kept alive, as much by the workers themselves as by management. Workers should actively participate in discussing policy options and training ideas. Knowledge of the policy should be passed to those on the factory floor through varying the medium as frequently as possible: sometimes posters, sometimes drama, sometimes a leaflet, sometimes invited speakers (Mundy, 2006).

**Keeping track and measuring success**

One reason why the proportion of positive VCT users going on to see an ALAFA doctor is lower than expected has to do with record keeping. It appears that a significant proportion of those who registered with ALAFA (on receiving a positive result) have not been to an ALAFA doctor *simply because they no longer work at Precious Garments*.

➤ **ALAFA needs to maintain an up-to-date record of its VCT users.**

This can only really be achieved with a computer record and frequent communications with the Precious Garments' Human Resources Department. (See Text Box 8).

**Reactions to test**

A large proportion of those who tested positive at the Precious Garment on-site services found they were actually relieved, *despite getting a positive result*. VCT users were relieved to know their status, even when it was positive. They found it reassuring to know what they were living with. Others who tested positive found they were able to accept their status by appreciating that they were not alone to live with a disease already in their midst.

➤ **Use key messages emerging from people's reported reactions to test results and incorporate these into ALAFA materials and campaigns.**

**Registration with ALAFA**

A very high proportion of HIV-positive VCT users (95.5%) registered with ALAFA, following the advice and encouragement of the counsellors.

➤ **Systematic monitoring** of registration should be established to serve as an indicator of any emerging negative perceptions towards the programme.

**Threats to registration: exposure through being 'called out'**

Two VCT users sampled for interview raised concerns that ALAFA activities which required them to be called out of their lines risked exposing them. This concern resulted in the temporary suspension of interviews while meetings were held to discuss the immediate and broader issue of how to maintain contact with positive VCT users without exposing their status.

➤ **This is a long term issue that needs to be given careful thought. VCT users need to be informed of their right to decline participation from the start.**  
ALAFA needs to experiment with different ways of communicating with workers, such as passing notes through supervisors. All factories should be encouraged to establish systems of 'pigeon holes' or similar where individual workers can receive (and deliver) messages (See Text Box 13).

**Use of ALAFA-registered doctors**

87% of VCT users *still working at the factory* sought medical health after testing positive, and 82% of those saw an ALAFA-registered doctor. Those using ALAFA doctors were fully satisfied with the services provided.

➤ **The proportion of positive VCT users going to ALAFA doctors must be monitored based on accurate Human Resources Data and an upto date list of VCT users.**



### **Reasons for not seeing an ALAFA doctor**

Some of those who tested positive at the factory did not go to see doctors because they think they can't get time off or might lose pay. However, by far the most common reason for not seeing a doctor was that the workers still "felt well" after testing.

- **ALAFA, the unions and factory management need to work together to combat this perception.**
- **The perception that feeling healthy means there is no need to see a doctor must be tackled head on.**

The key message should be: "Feeling healthy? Now is a good time to see the doctor". The concept of 'preventive maintenance' of the human body needs to be deeply instilled in the minds of all workers.

### **VCT users' suggestions**

Users have offered a number of suggestions for improving the ALAFA programme (see Section 6.13) which should be given careful consideration.

- **Make use of VCT Users suggestions.**

### **Encouraging men**

The gender aspects of the project should be kept in mind. Men are often embarrassed to use female dominated facilities. ALAFA should encourage men's use of VCT services by making male counsellors available, at least on a part-time basis (possible by having men's health days). Men have different perspectives of illness and treatment. ALAFA needs to keep these in mind in its programme and use men to target men in the promotion of VCT services.

## Annex 1: The Revised Approach

### Revised Approach to Study of Uptake of VCT and ARV Services at the Precious Garments Factor

#### Background

Following the submission of Sechaba Consultants' proposal for the above study, a literature review and interview guides were prepared and two meetings were held with ALAFA. The interview guides were reviewed and at the most recent meeting the Consultants were asked to revise their method to make it more focused on the key research questions. This paper proposes a new approach that is clearly linked to the critical questions.

#### Approach

##### Issue: Constraints to the uptake of VCT services

**Key Question 1:** Why do people not test?

**Target groups:** General workers

**Methods:** 6 Focus Groups, with 20 open-ended follow-up interviews, self-completed questionnaires to general workforce.

#### Focus Group Discussions

Take-up of the VCT services offered in the work place is far from universal. A large proportion of workers do not go for testing. The literature review provides some of the likely reasons for this, but to better understand workers' perceptions and reasons for not testing Focus Group Discussions will be held with workers.

The FGDs will be designed to explore any significant gender and age differences in people's attitudes towards testing. They will be organised in the following way:

- 1 FGD of younger men (under 30)
- 1 FGD of older men (over 30)
- 2 FGDs of younger women (under 30)
- 2 FGDs of older men (over 30)

The FGDs will be managed by one facilitator and one note taker. There will be between 8 and 10 people in each group.

A 'card sorting' method will be used in the FGDs. In essence this will consist of the following steps:

1. A brief introduction is made to the group. The facilitator will say something similar to:
  - Thanks for participating. We are from Sechaba Consultants and we are doing a study to better understand your views and experiences regarding HIV/AIDS and related services, especially counselling, testing and treatment.
  - Everything you say will be taken as confidential, so we don't need to know your name.
  - We would like to use a tape recorder but please be reassured that nothing of what you say will find its way back to management or any other party, so feel free to be open and honest. The tape will remain in the hands of Sechaba and will be deleted once our research is complete.
  - We are going to begin with a kind of a game that will require you to do some writing. If you have any difficulties in writing just raise your hand and one of the facilitators will help.

Note: This introduction assumes that participants have already been informed of the exercise and have consented to participate in the FGDs.

2. Blank cards are distributed to members of the group together with a marker.
3. The group is then given the following instructions by the facilitator:
  - Please take a few minutes to reflect quietly on your own about why some people are reluctant, or refuse, to go for voluntary counselling and testing for HIV/AIDS.
  - Taking the marker please write simply and clearly one reason per blank card. If you need help please indicate.
  - There is no limit, so just write as many cards as you have ideas, or reasons for reluctance or refusal to use VCT services.
  - Remember there is no such thing as a 'right' or a 'wrong' answer.
  - Don't put your name on the cards. When you have finished we are going to put them on the table and mix them all up so we won't know which card came from which person.
  - All the cards we put down can be taking as belonging to all of us in the group, there is no need to say which ones you wrote.
4. The cards are then collected from participants, mixed and then spread out on the table facing upwards. The facilitator will then say something along the following lines for each stage in the sorting and ranking.

### **Checking/clarifying**

- Let us first check that we all understand what is written on each card. Where it is not clear you can help to rephrase or rewrite it.
- (She will then read each card checking it is clear and getting the group to reword or clarify where needed.)

### **Grouping and elimination of duplicates**

- Thank you. I would now like you to help me group the cards.
- If any are more or less the same can we agree which one to keep.
- Let us look at which ones can be put together because they are somehow similar or relate in some way to each other.

### **Discussion of groups**

- Let us look at the cards in each group and talk about why we think each card has been included.
- What does it tell us about people's reluctance to go for VCT?
- How important is this reason compared to others in the group?
- How 'true' to life is this reason (going through the cards)? Is this a problem that many people face or just a few?
- Is the problem specific to the workplace? Or how does it compare with outside the workplace?
- Can anyone give us some examples of how the problem may have impacted on themselves or someone they know well?

**Note:** The above is basically repeated for each group of cards. This will probably result in some cards being moved to new groups, which is fine.

### **Ranking of groups**

- Could we now look at all the groups we have created (not the individual cards). In your opinion, which of these is the most important group, in terms of people not wanting to go for VCT? Why?
- What is the next most important (do this for up to 3 groups depending on time).

### **Relating findings to the work place**

There is no problem if the group discusses the cards in a general way. However, it is important to get the participants to focus on the workplace issues at some point. If the facilitator feels workplace issues have not been adequately covered then the following questions could be used as prompts:

- Looking at the issues we have discussed, what policies or activities does this factory have that make it make it difficult for people to go for VCT?
  - What does it do to make it easy?
  - What recommendations do you have for the company to overcome the problems we have discussed at the workplace?
5. Closure. At this stage the facilitator will thank all the participants and release them, noting that some may be requested at a later stage to be interviewed individually.
  6. All the cards will be collected in their groups, and sealed in envelopes to be kept by the recorder.
  7. Prompting. The literature review and the pre-testing of the above approach (outside the factory) indicates that the sort of reasons for not going for testing that are likely to emerge during the card sort exercise include:
    - Fear that it will result in exposure of status.
    - Fear that if status is known it will result in discrimination (“how will people treat me?”)
    - Concerns that if one falls ill and one’s status is known nobody will be prepared to take care for you (“nobody will want to touch me”).
    - Fear that a positive result will result in depression and a rapid demise (“if I know I will die quickly”) and that children will be left alone.
    - Lack of knowledge of available services.
    - Time and cost barriers.
    - Uncertainty about the outcomes of a positive test result (“will I get treatment, or care and support”).
    - Lack of trust in the service provider.

As the exercise unfolds, this list will certainly grow. At the end of each card sorting exercise, if certain reasons in the list have not been mentioned, the facilitator can prompt, saying something like: “We have heard from others that x or y are reasons for not going. How do you, as a group, feel about this? How important are these reasons compared to what we have discussed?”

## Follow-up Interviews

As noted earlier, after the first FGDs have been completed follow-up interviews will begin with around 20 of the FGD participants. The objective of these in-depth interviews will be as follows:

1. Verify, in a one-on-one confidential setting, some of the issues that emerged during the FGD.
2. Go into more detail to explore particular points raised during the FGD.
3. Seek actual examples of how constraints to accessing VCT or going for testing have been experienced.

No interview guide has been prepared as the questions will emerge from an analysis of the FGD results. Before these follow-up interviews begin a guide will be prepared and sent to ALAFA for comment.

## Self-completed questionnaires

The first research question (why people don’t go for testing) will also be explored through a structured – *but very simple* – questionnaire aimed at the entire work force. The objective is to quantify, in a statistically meaningful way, the *key issues* that emerge from the FGDs and follow-up interviews. Some questions on workplace policy and the ALAFA project will be included, but most will be about why people do not go for VCT. The actual questions will only be formulated once the first two activities described above have been completed.

As there is considerable uncertainty about the extent to which workers will be able to complete the questionnaire there will be at least two rounds of pre-testing before the questionnaire is finalised. The use of a raffle to encourage participation (as per the original proposal) will be maintained. The essential difference is that this activity now comes after the FGDs and follow-up interviews, not before.

## **Issue: Constraints to registration and seeking treatment**

**Key Question 2:** Why do people who come for VCT and who get a positive result not register for treatment?

**Key Question 3:** Why do people who register not always go for treatment?

**Target groups:** People who have come for testing

**Methods:** Semi-structured interviews.

A proportion of those who do come forward for testing do not register for treatment once they are told they are HIV+. The key objective of this exercise is to find out why. For reasons of confidentiality the interviewees will be sampled from a list of all those who have come forward for testing. A two-staged approach will then be used to identify those who are HIV+ (in a willing and confidential manner) for further questioning. These stages are described below:

### **Stage 1: Semi-structured interviews for all VCT participants**

During this stage, a simple questionnaire will be used that focuses on the factors which *did* motivate people to come forward for testing. In other words, it will explore how people managed to overcome all the fears or constraints that were identified in the first stage of research. For this reason the exact question to be used will depend, to a large extent, on the results of the FGDs and follow-up interviews. However, it can be anticipated that the key questions are likely to be:

- How did you learn about the VCT services?
- What aspects attracted you?
- What concerns did you have before coming for testing?
- How did you overcome these concerns?
- Are you satisfied with the way the service has been provided?
- What suggestions do have for improving?
- Did you encourage others to come?

These questions, which will be of some value to the research effort in their own right, will then lead to a key question that will determine whether or not the interview continues. This question, to be finalized after the first rounds, will be along the lines of:

- Once you got your results did you take any action?

If the person indicates there was no need for action because the result was negative, the interview will end with the usual thanks. If the person indicates, voluntarily, that they got a positive result but have yet to do anything or that they are positive and have registered for treatment then the interview will continue *if they are willing*. At this point they will be fully assured of confidentiality.

### **Stage 2: Open-ended interviews of those who tested positive**

Those who pass-on to the next stage will be made up of two categories:

1. Those who tested positive and took no action at all (i.e. did not register with ALAFA).
2. Those who registered but have yet to seek treatment (ARVs) from any of the registered ALAFA doctors).

So little is known about the factors that inhibit the next stages of action (or inaction), following a positive test result, that it would not be wise to develop a structured questionnaire. For this reason, a very open-ended approach will be used. However, it can be anticipated that key questions for those who took no action might include:

- Once you learnt of your results what went through your mind?
- Did the counsellor give you a full understanding of your options?
- Did you feel you could discuss issues fully and confidentially with him/her?
- Did you have anyone else you could discuss with?
- What were your reasons for not taking any action?
- If you intend to take action at a future point what could help you to do so?

For the second category (those who registered but have not been to see a doctor), the likely questions (in addition to the first four above) will include:

- You mentioned that you registered, but have not been to see a doctor, can you explain why?
- Besides the reason given are there constraints in terms of money or time off work (if not mentioned)?
- Have you had any negative feedback from those you know who have gone?
- Can you suggest how these constraints could be overcome?

## **Analysis**

As noted in the original proposal, this will involve the use of NUD\*ST for open-ended interviews and SPSS for structured ones.

## Annex 2: Examples of Worksheets

	Group 1 - Women under 30 years	Concise translation	Category	Sub category
<b>1</b>	<b>Ba ts'aba/Fear</b>			
	<b>Ba ts'aba ho testa mali hobane ba ile ba ts'osoa haholo ka eona</b>			
1.1.1	<i>People are afraid to test because they are very afraid of AIDS; It was initially introduced as a very bad disease for one to have</i>	Because they were made to greatly fear AIDS	Fear of HIV/AIDS	Fear of disease
	<b>Ba ts'aba ho testa hobane e hlaha ka mokhoa oa thobalano; Batho ba nahana hore ke matekatse</b>			
1.1.2	<i>People are afraid to test because AIDS is supposed to be transmitted through sex therefore people will see them as very promiscuous people to have contracted the disease</i>	Because HIV is sexually transmitted people will think you are a prostitute	Reputation	Community perceptions of positive people
	<b>Ho ile ha tuma hore ea bolaea</b>			
1.1.3	<i>AIDS is known to kill; therefore people do not want to test lest they get a positive result and therefore know that their death is near</i>	Because HIV kills	Fear of HIV/AIDS	Fear of dying
	<b>HIV ha e fole</b>			
1.1.4	<i>HIV in incurable</i>	Because HIV is incurable	Fear of HIV/AIDS	Fear of not healing
	<b>Ba tla qabana le molekane</b>			
1.1.5	<i>People are afraid to test because a positive test result will result in the spouse knowing their status and lead to possible abandonment by the spouse/partner</i>	Your spouse will abandon you	Fear of conflict	Fear of conflict/abandonment
	<b>Ho hobosoa</b>	<b>To be exposed shamefully</b>	<b>Exposure</b>	
	<b>Ho khesoa joale ho tliša ho se be hantle (motho o ba depressed)</b>			
1.2.1	<i>Others knowing one's status brings about depression</i>	Being despised will make you depressed	Being despised	Depression caused by being despised
	<b>Ho khesoa ho tliša lefu la pelo</b>			
1.2.2	<i>Others knowing one's status brings about heart disease/stroke</i>	Being despised will give you heart diseases	Being despised	Illness caused by being despised
	<b>Motho o nahana ho ipolaea</b>			
1.2.3	<i>A positive result brings thoughts of suicide/killing one's self</i>	You will think of killing yourself	Fear of suicide	Psychological inability to accept positive result
	<b>Phetoho ea bophelo</b>			
1.2.4	<i>Knowing &amp; being HIV positive demands a change of lifestyle(Implication : Being HIV+ will force one to adopt a more healthier, less risky lifestyle in terms of managing the HIV+ status</i>	You are unwilling or unable to accept a lifestyle change	Lifestyle change	Unwilling or unable to accept a lifestyle change
	<b>Motho o se a kheseha</b>			
1.2.5	<i>A positive test result makes one a lesser person; people do not regard you the same way they used to; you have kind of lost value in their eyes</i>	People will despise you	Fear of being despised (general)	Being seen differently
	<b>Ho tla thoe motho oa kula empa a ikutloa hantle</b>			
1.2.6	<i>People are not going for a test because they are afraid that they will be told they are ill even if though they still know &amp; still feel healthy</i>	You don't want to be told you are sick when you still feel well	Knowing you ill, when feeling well	Psychological inability to accept positive result
	<b>Batho ba se ba mots'aba</b>			
1.2.7	<i>A positive test result will make other people fear the person; make them fear interacting with them because they are afraid they might contract HIV from them</i>	People will fear you	Fear of isolation	Fear of rejection by others
	<b>Batho ba tla ba tsoafa</b>			
1.2.8	<i>People will not want to interact with them anymore/people will no longer like them and interact with them because they would have HIV which to some extent is a disease that is frowned upon</i>	People will ostracize you	Fear of isolation	Fear of rejection by others

### Annex 3: Example of Follow-up Interview

Sex: Female  
Age: 38  
Educ: Form 1  
Marital status: widow  
Occupation: IRC  
Dependents: 2 children/8 & 15  
                  Mother, sister in Law  
                  Orphans 7 & 10 years  
The latter 2 are in the village. She stays in Maseru with her 2 children.

**Q:** Do you ever talk about AIDS with your group of friends?

**A:** Yes, we do.

**Q:** What do you exactly talk about? Do you ever consider yourselves at risk of infection?

**A:** Yes we do. We talk about how easy it can be to get infected as it not only gets transmitted through sexual contact. For instance, as we travel by taxis, and they normally get into accidents, we can easily get infected either through wounds or by trying to help someone near you as there will be no time to think about using gloves or protecting yourself in any way.

**Q:** Is that the only way you think you may be at risk?

**A:** Well, the other thing is that we have *linyatsi* (lovers) to try to supplement our meagre salary. Some of the boyfriends refuse to use condoms

**Q:** Why do they refuse to use condoms? Don't they care about getting infected?

**A:** Some people still do not think about AIDS. *Ha ba tsotelle; ba re "Na kea itjolla ha ke tl'o hloloa ke monate oo ke o utloang.* (Trans: They don't care they say they are not going to compromise the pleasure they get. They basically do not want to change their lifestyle. They would only test when they are ill.)

**Q:** So how do you and your friends protect yourselves from the risk of infection in this case?

**A:** As much as possible we use condoms

**Q:** Do you insist on condom use yourself

**A:** Yes.

**Q:** How about your friends?

**A:** They try, but some boyfriends, especially if they are steady, refuse to use them

**Q:** So how else do people protect themselves?

**A:** Such as when they go to a traditional healer, they get their own blades. We also try to use gloves when helping someone with a wound. We actually try to use all the recommended methods of preventing another person's blood coming into contact with our own bare hands or wounds.

**Q:** In this circumstance/situation you just described with boyfriends; have you tested yourself?

**A:** No, I have not.

**Q:** Do you think there are any benefits at all in knowing one's status?

**A:** Yes, there are benefits – such that one can be able to rear one's own children (*ho phelisa bana*).

**Q:** How about disadvantages?

**A:** If I know my status, I will die quickly. I will succumb to opportunistic infections and die. I am not sure if I will actually be able to cope with a positive result (*Nke ke ka tseba ho ikamohela*)

**Q:** What would make it difficult to accept the result? Some people have said they do not trust Precious counsellors. Is that the case with you too?



**A:** No. It's not that I do not trust them; I do trust them. Some people don't because they think if they get a positive result; the counsellors will laugh at them. But this is only their thinking, it has never happened. Even the management is supportive of people who have HIV.

**Q:** There is a lot of talk about being afraid to have one's status known here at Precious. People say they are afraid others will laugh at them. Do you know or have you heard of someone who stigmatised someone with HIV?

**A:** Yes. There was this girl whose friend was HIV+; but later the friendship went sour and she started talking about the friend; they eventually had a fight about the issue and the friend was taken for disciplinary action.

**Q:** Generally, people are quite afraid of having HIV. What are people doing about not acquiring the disease & safeguarding their loved ones?

**A:** They use condoms

**Q:** How do you know this?

**A:** Every Friday condoms are put in the toilets and people take them home, especially men. Well, what I do not know is whether they actually use them; but I know that they do take them from the toilets

**Q:** Let's talk about the men. From what you have observed, do men generally test for HIV?

**A:** Most people that test are women. Very few men test. They say they don't believe AIDS exist.

**Q:** Really? Is it true that men abandon their partners once they test positive? Have you seen this happen? Why is this so?

**A:** I know of a neighbour, we stayed in the same '*malaene*'. She tested here at work and when she told her husband that she was HIV + the husband left her. My co-worker also told me another story where the husband abandoned the family. They have not heard from him ever since.

**Q:** Let's talk about the HIV policy here at work. Is there any HIV/AIDS policy in your workplace? Some document that talks about how Precious will treat an employee with HIV/AIDS? If yes, what does the policy contain?

**A:** I think so. I think I have heard something like that.

**Q:** Please explain.

**A:** I heard about this policy through a friend/co-worker who is on the HIV/AIDS committee and also from an HIV+ co-worker who was part of the group working on the policy. She has since died. Actually I think those who actually have tested positive would know for sure.

**Q:** I think this is important and should be known by everybody. How can others be made to know?

**A:** Through the shop stewards – the shop stewards usually disseminate information to workers through their meetings. Precious should also organise meetings or workshops for workers.

Interviewer: Thank you for your time and your answers...

Interviewee: Kea leboha .....END.

**ALAFA- PRECIOUS GARMENTS SURVEY, Sechaba Consultants, May 2007**

Tšoea likarabo tsohle tsa hau lethathamong la likarabo leo u le filoeng. Ha u qetile ho araba lipotso, tabola nomoro e pampiring ea hau u ipolokele eona; mohlomong u tla ba mohloli ha ho fanoa ka limpho papaling ea phupe ka lefe e tla latela kamora ho mona.

**1. ALAFA ke eng, e etsa eng?** *Tšoea tsohle tseo u li tsebang.*

- Ha ke tsebe → **E ea ho potso ea 2**
- Tlhahlobo le tlhabollo ka kokoana-hloko ea AIDS (HIV)
- Ho rupela methaka (Peer educators)
- E fana ka meriana ho phekola kokoana-hloko ea AIDS (HIV)
- E etsa lingoliloeng tse kang lipostara le litsebiso
- ke ntho ea boithabiso

**2. Na u ka re bolella hore uena u bona mosebetsi oa ALAFA o le joang?** *Tšoea karobo e le 'ngoe.*

- Ha ke tsebe → **E ea ho potso ea 3**
- E etsa mosebetsi o motle/o khabane
- E hloka ho lokisoa
- E sebelisoa ho fumana chelete

**3. Na u se kile ua sebelisa tlilini ea feme 'me e ne e le sebakeng sa eng?** *Tšoea libaka tsohle tseo u se u kileng oa fumana thuso ka tsona.*

- Ha ke so e sebelise ho hang → **E ea ho potso ea 4**
- Thuso ea pele
- Sefuba/flu/hlooho
- Mafu a likobo
- Mafu a mang
- Tlhabollo ka kokoana-hloko ea AIDS (HIV)
- Tlhahlobo ea kokoana-hloko ea AIDS (HIV)

***Phethola leqephe....***

**4. U se u kile oa etsa tlhahlobo ea kokoana-hloko ea AIDS (HIV) ho kae? Tšoea libaka tsohle moo u ileng oa testa teng.**

- Ha ke s' o ho hlahlobe ho hang → **E ea ho potso ea 6**
  
  - Tlilinking ea 'muso
  - Ngakeng ea poraefete
  - PSI (New Start)
  - Tlilinking ena ea precious
  - Tlilinking ea feme e 'ngoe
- } → **E ea ho potso ea 5**

**5. Haeba u se u kile oa hlahlobela kokoana-hloko ea AIDS (HIV), ke eng e ileng ea o qholotsa ho tseba boemo ba hau?**

*Haeba u se u kile oa testa, khetha likarabo tse tharo tse hlahosang maikutlo a hau.*

- En e ka khothatsoa ke leano la feme
- En e ke kula
- En e ke ts'aba/ts'ohile hore e sebe ke fumane ts'oaetso
- En e ka khothaletsoa ke motho ea phelang le ts'oaetso
- Ke bone batho ba bangata ba e shoa en e tsebe boemo ba bona/ se ba bolaeang
- En e ka khothaletsoa ke ngaka
- En e ka khothatsoa ke thupelo eo ke ileng ka e fumana
- En e ka lakatsa ho ba mohlala (ho basebetsi 'moho)
- Re ile ra ea re le sehlopha

**6. Haeba ha u s' o etse hlahlobo mabaka a hau ke afe?**

*Khetha bonyane likarabo tse tharo.*

- Ha ke kholoe hore AIDS ke ntho e teng.
- Ha ke etse thobalano, kahoo ha ke hloke ho etsa litlhahlobo.
- 'Na joaloka motho oa monna, ha ke rate ho hlahlojoa ke basali.
- Ha ke tšepe batho ba sebetsang tlilinking, ba tloha ba bolella ba bang ka boemo ba ka.
- Ha ke na ho tseba ho amohela ha ke na le tšoaetso.
- Ke tšaba hore ke tla shoa/ke tla ipolaea ha nka tseba boemo ba ka.
- Ke tla tšoha hoo ebile ke utloang eka nka ba le lefu la pelo.
- Molekane oa ka o tla ntlhala/o tla nkotla.
- Ha lelapa la ka le ka tseba boemo ba ka ke ba ntlhokomela.
- Ha ba motseng ba ka tseba boemo ba ka, ba tla nahana hore ke boits'oaro bo bobo
- Ha batsebetsi 'moho ba tseba boemo ba ka, ba tla nkhesa le ho nqoea
- Ha batsebetsi 'moho ba, ba tla nqosa ka hore ke letekatse/seotsoa
- Ha bookameli bo ka tseba boemo ba ka boemo ba ka, ke tla lelekoa mosebetsing.

Re leboha tšehetso ea hau