

The role and experiences of people living with HIV in the context of Swaziland's *MaxART* programme

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Photo by Adriaan Backer.

The Swaziland Network of People Living with HIV (SWANNEPHA) took the lead in a study to document experiences and perspectives of people living with HIV across a range of areas that affect their lives. Using a global framework called Positive Health, Dignity and Prevention,¹ SWANNEPHA adapted a questionnaire that had been developed and piloted in Bolivia, Tanzania and Vietnam. Positive Health, Dignity and Prevention is the new name for a revised concept of HIV prevention for and by people living with HIV, formerly known as 'positive prevention'.

The Positive Health, Dignity and Prevention questionnaire explores areas that affect the lives of people living with HIV in various areas. They include empowering people living with HIV, health promotion and access, gender equality, human rights, prevention of new infections, sexual and reproductive health and rights, social and economic support, and measuring impact. This article shares findings from the initial baseline survey, and lessons learnt from the study.

With technical support on research design and analysis from the Global Network of People Living with HIV (GNP+), the Population Council and the Clinton Health Access Initiative (CHAI), SWANNEPHA conducted a baseline survey between December 2011 and February 2012 in the four regions of Swaziland.

The survey is part of a programme led by the Swaziland Ministry of Health, coordinated by STOP AIDS NOW! (SAN!) and CHAI, and funded by the Dutch Postcode Lottery. The survey recorded baseline measurements of the experiences of people living with HIV at the start of the *MaxART* programme and offers important data to support human rights monitoring amidst a significant scale-up of HIV testing, care, and treatment services in Swaziland. Maximising ART for Better Health and Zero New HIV Infections (*MaxART*), is a three-year (2011-2014) programme. *MaxART* takes a multi-faceted approach, strengthening the ability of health facilities to provide high-

quality HIV services to all in need while simultaneously engaging the broader Swazi community to identify solutions to problems, become actors of change, and play a proactive role in accessing these services. Additionally, within the programme, Swaziland is embarking on a Treatment as Prevention (TasP) pilot study to evaluate the feasibility, acceptability, outcomes and scalability of Swaziland's government-managed health system providing treatment earlier (i.e. sooner in the clinical progression) for individuals who are living with HIV.

Involving people living with HIV

Involving people living with HIV in all the areas that affect their lives is widely recognised as best practice. It is articulated by the principle of the Greater Involvement of People Living with HIV (GIPA).² In 1994, 42 countries signed the Paris Declaration, formally recognising the call for the active and meaningful involvement of people living with HIV in the HIV response.³ Such involvement in the design, implementation, monitoring and evaluation of programmes ensures that programmes are grounded in the realities of those they are intended to benefit, their families and communities.

Networks of people living with HIV are engaged in the *MaxART* programme at country level (SWANNEPHA) and at global level (GNP+). One of the activities led by people living with

HIV in the programme is a study to document their experiences and perspectives in areas that affect their lives.

At country level, SWANNEPHA developed and submitted a protocol for ethical approval.⁴ The network later organised a three-day training course for data collectors. The training involved thorough review and adaptation of the questionnaire to fit the Swazi context, and a discussion about principles of research and training in the use of personal digital assistants (PDAs). SWANNEPHA members collected data. Ten people living with HIV from the four regions of Swaziland were trained in community-based research. The data collectors reported that it was an empowering process, which enhanced their research and technical skills.

Partnerships and data collection

SWANNEPHA and GNP+ collaborated with the Population Council and CHAI in the research. SWANNEPHA, GNP+ and the Population Council trained data collectors and supervised the adaptation of the questionnaire while CHAI ensured that the methodology and the research questions addressed evidence gaps. The networks also received support from other *MaxART* partners – National Emergency Council on HIV and AIDS (NERCHA), STOP AIDS NOW! (SAN!), Southern Africa HIV and AIDS Information Dissemination Service (SAfAIDS), the University of Amsterdam (UvA) and the South African Centre for Epidemiological Modelling and Analysis (SACEMA) – in reviewing the protocol for ethical approval, reviewing the questionnaire, training data collectors on the use of the PDAs and analysing the data.

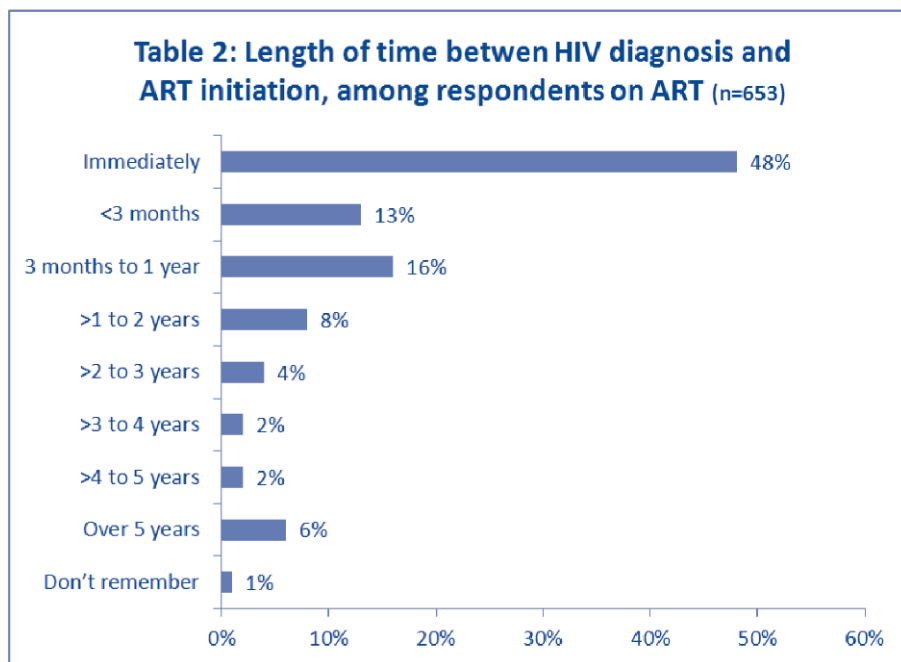
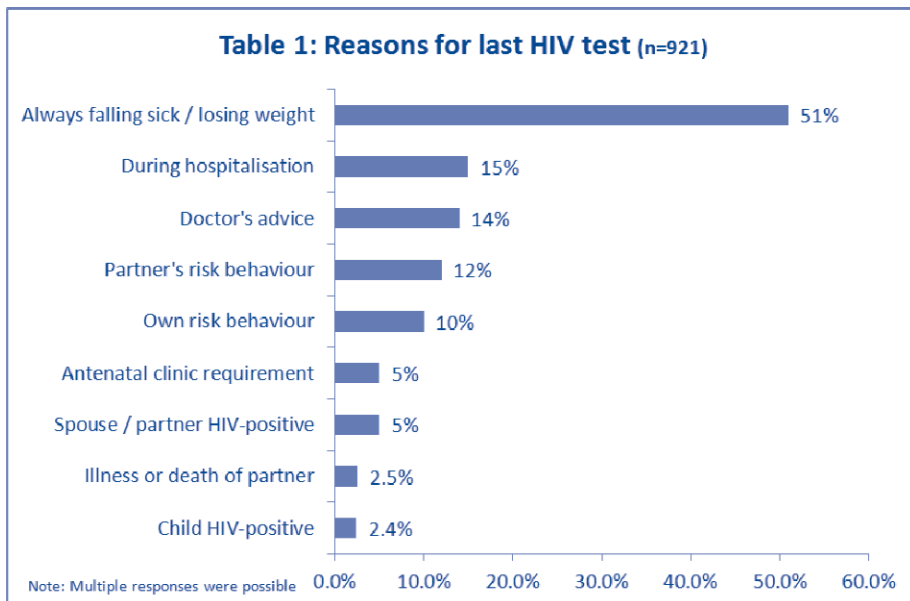
The study involved 921 people living with HIV across the country. Participants were approached through 100 support groups and 22 health facilities. Data collectors carried

out face-to-face interviews using PDAs. Participants included men (30%) and women (70%), individuals on ART (71%) and pre-ART (19%), from the four regions of Swaziland, in both rural (92%) and urban (8%) areas.

Findings

A wealth of information was gathered, including:

- Sixty-eight per cent of respondents reported having been diagnosed with HIV within the past five years. Eighty-one per cent had not tested regularly prior to their diagnosis, and 52 per cent had only had one HIV test over their lifetime. Testing venues were government health facilities (62%), voluntary counselling and testing (VCT)/New Start sites (27%), private health facilities (7%), outreach/mobile testing (4%), and home-based (0.4%). Sixty-one per cent of respondents reported making the decision themselves to go for an HIV test (client-initiated), while 39 per cent reported that the test was offered by a health provider (provider-initiated). The main reason for HIV testing was sickness and losing weight (51%), followed by admission to hospital and doctor's advice (Table 1).



- Ninety-six per cent of respondents indicated having ever had their CD4 count taken; CD4 count measures the strength of the immune system in the blood, and the test is used to monitor the clinical progression of individuals living with HIV before and during treatment. Among respondents who had not had their CD4 count taken (n=38), the main reasons were: no services available, not thinking it was necessary, not knowing about CD4 count tests, and not affording transport to the health facility. Among respondents who had their CD4 count taken, 98 per cent received the results. Among those who did not receive the results (n=17), the main reasons were: not going to collect the results because of fear/reluctance, not affording transport to return to the health facility, the health facility lost the results / there was a problem with the machine, and lack of time/too busy to return to the health facility.

- Among respondents on pre-ART (n=172), 33 per cent were enrolled into pre-ART on the same day as they were diagnosed with HIV; 21 per cent were enrolled within a week, 24 per cent within a month, and 22 per cent were enrolled more than a month later. Among

respondents not enrolled in pre-ART (n=94), the main reasons were: not having had time to attend (34%), not having been offered it (29%), not being aware of it (19%), having a high CD4 count (12%), and unwillingness, mainly because they did not feel sick (6%).

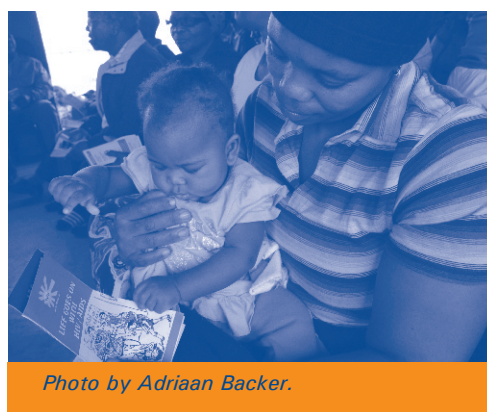


Photo by Adriaan Backer.

- Among respondents on ART (n=653), 48 per cent of people living with HIV reported having started ART immediately after their diagnosis (Table 2). This suggests they presented late to the health facility and needed to start ART straightaway.⁵

- The majority of respondents received ART services from government facilities (77%). Mission health facilities accounted for 13% of facilities followed by NGO-owned (6%); industrial-owned (1.4%) and private practitioners (1.3%). The main types of health providers usually seen for regular ART services were nurses (cited by 96% of respondents), followed by doctors (43%), expert clients (39%) and peer counsellors (7%).

- Twenty-eight per cent of respondents (both on ART and pre-ART), thought it was difficult for some people to take treatment. Among those who said it was difficult to take treatment (n=183), 85 per cent felt that stigma and discrimination, namely being seen at a healthcare facility, were barriers to taking treatment. Other barriers included lack of food (39%) and lack of family support (20%) (Table 3).

- Among respondents on ART, 25 per cent reported having ever omitted to take their ARVs. Among these (n=165), the main reasons for not taking their ARVs were having forgotten (69%), forgetting the ARVs at home or work (29%), and the patient running out of stock (6%). In terms of support, 90 per cent of respondents on ART rated the support received from facility-based expert-clients as excellent (72%) or adequate (18%).

- Among all respondents, 60 per cent reported having a treatment supporter, i.e. a friend/family/colleague who supports the individual in receiving his/her pre-ART or ART services; 13 per cent had a treatment supporter but were not supported, and 27 per cent had no treatment supporter. The main reasons (n=234) for not having a treatment supporter were: not knowing what it was (27%), not needing or not wanting one (21%), not knowing who to choose (17%), not being asked to choose one (14%), and the treatment supporter having relocated (9%).

- Disclosure remains a critical issue in Swaziland with a significant number of respondents expressing concern that their partner would leave them (18%) or their family would abandon them (16%) if they were to disclose their HIV status (Table 4). Most were concerned about the impact that disclosure would have on their personal relationships. However, most participants in the study felt

they would get support (67%) if they were to disclose their HIV status.

- In the last 12 months, 14 per cent of respondents reported experiencing some incidence of discrimination. Of the 14 per cent (127 individuals), 33 per cent experienced discrimination within a social/community gathering, followed by 31 per cent from family and 13 per cent from a sexual partner or within a relationship (Table 5). The findings indicate the importance of addressing stigma and discrimination at community level, within homes and in community spaces.

- Among individuals who experienced some form of discrimination, the majority (40%) said they did not do anything to respond to their experience of discrimination (Table 6). Further analysis is required to understand whether individuals would want to be supported to respond, and if so, how they could be supported.

Lessons learnt

SWANNEPHA has demonstrated that they can lead research to document and highlight the realities of people living with HIV. Undertaking research on Positive Health, Dignity and Prevention has enabled the network of people living with HIV in Swaziland to methodically and systematically gather information on the experiences of people living with HIV.

Engaging networks of people living with HIV in programmes, such as *MaxART*, is critical to the HIV response. Global frameworks, such as the Strategic Investment Framework and the Global Fund's

Table 3: In your opinion, what are the main reasons why it is difficult for some people to continue taking their ARVs? (n=183)

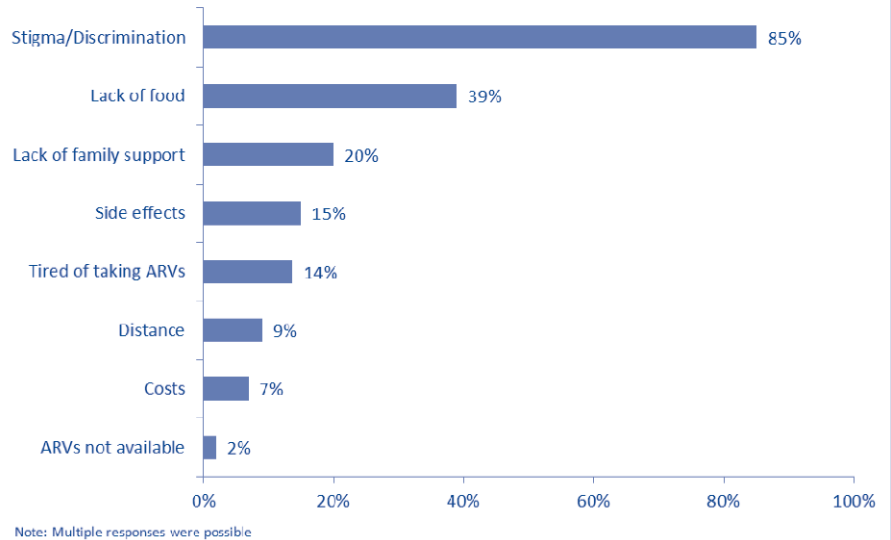
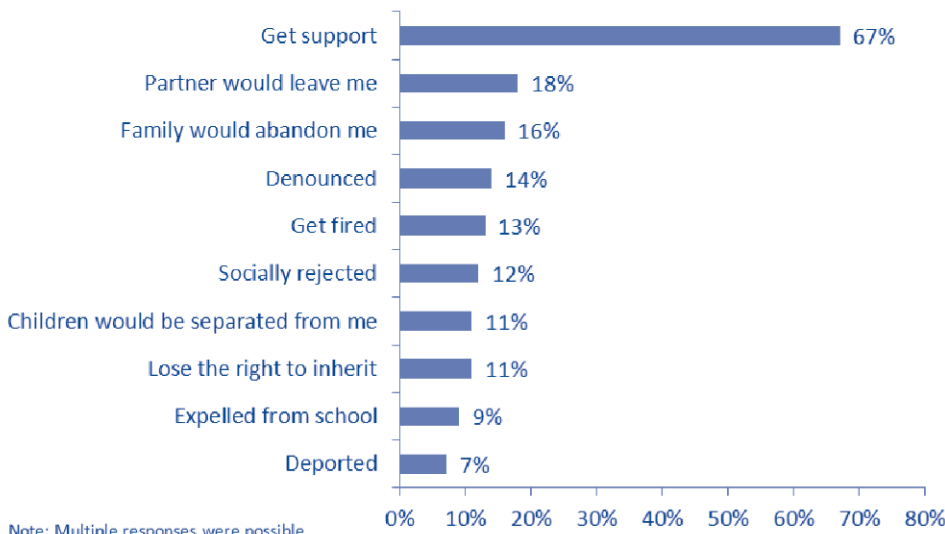


Table 4: What do you think would happen if you disclosed your HIV status? (n=618 to 795)



Lessons learnt

- Undertaking research on Positive Health, Dignity and Prevention has enabled the network of people living with HIV in Swaziland to methodically and systematically gather information on the experiences of people living with HIV.
- Understanding the stigma and discrimination experienced by people living with HIV, their access to services and their socio-economic context is key to identifying and promoting approaches and interventions that work for them.
- Programmes such as *MaxART* are an opportunity to bring together multiple stakeholders and perspectives and to identify concrete ways of partnering and strengthening one another's work to improve the lives of individuals and to strengthen the possibility for HIV prevention.



Photo courtesy of SWANNEPHA

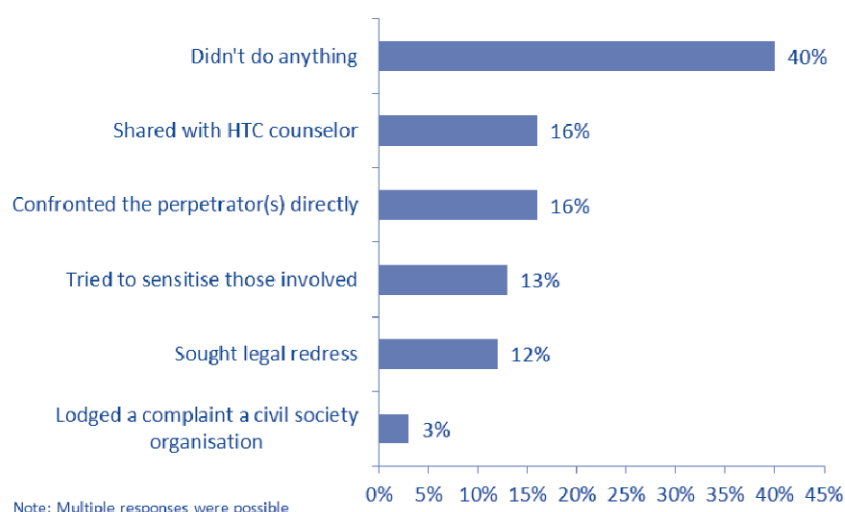
Community Systems Strengthening framework are recognising the role of communities in identifying solutions and driving action to support people living with HIV and prevent new HIV infections. These programmes are an opportunity to bring together multiple stakeholders and perspectives and to identify concrete ways in which to partner and strengthen one another's work towards one end - to improve the lives of individuals and to strengthen the possibility for HIV prevention.

In Swaziland, the findings from the survey will inform the development and direction of the *MaxART* programme, including project interventions such as community mobilisation for HIV testing, treatment support, nurse-initiated ART and improved linkages and retention. Partners in the national HIV response

Table 5: In the last 12 months, in what areas of life would you say you have experienced the most discrimination because of your HIV status (n=127)



Table 6: What action did you take to respond to this discrimination? (n=127)



have welcomed data about the experiences of, and barriers to, testing and accessing HIV services. The data are also critical for sustained evidence-based advocacy and government accountability in Swaziland, and is enabling SWANNEPHA to inform both the country's national action plan on stigma and discrimination, as well as the national plan for Positive Health, Dignity and Prevention.

The data are also used by GNP+ at global level in advocacy for the health and rights of people living with HIV. Understanding the stigma and discrimination experienced by people living with HIV, their access to services and their socio-economic context is key to identifying and promoting approaches and interventions that work for individuals living with HIV and that enable them to support their partners and communities in knowing their HIV status, accessing necessary services and leading healthy lives.

The study will be repeated in the third year of the MaxART programme to measure and document the extent to which the continued scale-up in HIV testing and treatment services has impacted on the lives of people living with HIV in Swaziland. ■

References:

1 GNP+, UNAIDS. 2011. *Policy Framework: Positive Health, Dignity and Prevention*. Amsterdam, GNP+. http://www.gnpplus.net/images/stories/PHDP/PHDP_ENG_V4ia_2.pdf

2 UNAIDS. *Greater Involvement of People Living with HIV Policy Brief*. http://data.unaids.org/pub/BriefingNote/2007/jc1299_policy_brief_gipa.pdf

3 *The Paris Declaration, 1994*. http://data.unaids.org/pub/externaldocument/2007/theparisdeclaration_en.pdf

Endnotes:

4 *Title of the protocol: Documenting the experiences of people living with HIV in Swaziland in terms of Positive Health, Dignity, and Prevention in the context of national scale-up of HIV testing, care and treatment (October 2011)*

5 *In Swaziland, the ART guidelines follow the WHO recommendation of starting treatment at a CD4 count of 350 cells/μL or below. Based on a retrospective study by the Ministry of Health of individuals who initiated ART between 2004 and 2009 in Swaziland, the median CD4 count was 130 among adults (aged 15 years and above), and 75.5% of individuals initiated ART with a CD4 count of less than 200 cells/μL.*

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