

**HIV testing and disclosure in women attending
prevention, treatment and care clinics at
Katutura hospital, Windhoek, Namibia**

A PRA PROJECT REPORT



**University of Namibia
with Training and Research Support Centre**



**In the Regional network for equity in health in east
and southern Africa (EQUINET)**

March 2009

With support from SIDA (Sweden)

TABLE OF CONTENTS

Executive Summary.....	3
1. Introduction.....	5
1.1 Testing, counselling and disclosure in pregnant women	5
2. Methods	8
3. Implementation and findings	10
3.1 Initial meetings and baseline questionnaires: Initial views on testing and disclosure.....	10
3.2 PRA process: exploring the perceptions of women about testing and disclosure.....	15
4. Developing and reviewing actions on testing and disclosure.....	23
4.1 Developing actions.....	23
4.2 Implementing actions.....	24
4.3 Progress review.....	24
4.4 Comparison of the baseline and follow up questionnaire	25
5. Reflections, lessons learned and next steps.....	28
5.1 Lessons learned on primary health care oriented responses to AIDS ..	28
5.2 Lessons learned on participatory methods.....	29
5.3 Way forward	30
References.....	31

This report has been produced within the programme on participatory research and action (PRA) for people centred health systems co-ordinated by TARSC and IHI in EQUINET. It is part of a growing mentored network of PRA work and experience in east and southern Africa, aimed at strengthening people centred health systems and people's empowerment in health.

Cite this publication as: Hofnie-//Hoëbes K, Kakororo O.M, Jankowsky V, Shilongo N, Callard B, Paulus D, Kaim B, Loewenson R (2009) 'HIV testing and disclosure in women attending prevention, treatment and care clinics at Katutura hospital, Windhoek, Namibia UNAM, TARSC, An *EQUINET PRA project report*. EQUINET: Harare.

Executive Summary

Routine HIV Testing and Counseling (RHTC) is a crucial entry point for expanding HIV prevention to a significant population and preventing transmission to children. Knowing one's HIV status could assist women to make an informed decision on future pregnancy. This is more effective if their partners know their HIV status, and are equally counseled on HIV prevention and care. However, HIV infection has been stigmatised globally. Those infected and affected have felt victimised, guilty, ashamed and hopeless. This makes disclosure of one's sero-positive status to a partner difficult.

This study explored the challenges experienced by HIV infected pregnant women and the coping strategies used by those who disclose or do not disclose, to inform community and health workers roles in supporting pregnant women around disclosure. It was implemented by University of Namibia (UNAM) within an EQUINET programme that aimed to explore dimensions of (and impediments to delivery of) Primary Health Care responses to HIV and AIDS. The programme, was co-ordinated by Training and Research Support Centre (TARSC) in co-operation with Ifakara Health Institute, REACH Trust Malawi and the Global Network of People Living with HIV and AIDS (GNPP+) to draw learning across diverse settings in east and southern Africa on Primary Health Care responses to AIDS.

The Namibia study used participatory methods to

- explore pregnant women's perceptions of and address barriers to and promote uptake of counseling and testing and partner disclosure of HIV status.
- create awareness in and communication between male and female partners and adult relatives of sero-positive women on the barriers/fears related to HIV/AIDS and to disclosing positive status
- explore information provided to pregnant women at the PMTCT and CDC clinics on VCT and disclosure and empower health workers to provide information and communicate effectively with clients on VCT and disclosure.
- strengthen PRA capacities and skills in five nursing students, to support VCT and disclosure in HIV-positive women.

The work was implemented at Katutura state hospital, an intermediate hospital in Windhoek, at the Centre for Disease Control, antenatal care and PMTCT services within the hospital complex. The work was done with a small sample due to the criteria of voluntary participation and follow through of a more intensive longitudinal participatory process with the women. While the limit of small numbers is recognized, the study nevertheless identifies through qualitative evidence some key issues affecting disclosure, and the study gives some evidence of the processes needed to support it. A baseline checklist was given to twenty women with and without HIV and four health workers at ANC and PMTCT services. This was followed by a participatory reflection and action process with this group (excluding six women who delivered in the period) to identify experiences and barriers around testing and disclosure, and to identify and implement priority actions to overcome barriers. A review of progress markers and repeat of the baseline questionnaire was used to observe whether there were changes in perceptions and practices as a result of the process.

The women testing negative were found to have higher levels of disclosure of their results to their partners than those testing positive, the latter fearing negative reactions. Those women that had disclosed did so to close family members, and relatively soon after being told themselves. Disclosure was more likely for stable than casual partners. When the positive

women did disclose, contrary to their fear of blame, they reported receiving support from their partners. Protection of others and accessing treatment were the main reasons given for persuading them to disclose their positive HIV status to their partners. Provision by health workers of information to support positive prevention, or the promotion of health and prevention in people with HIV can reinforce this motivation.

Even while RHTC may be available, and people may be aware of it, this study confirms other local evidence that the women who most need them may not use these services, may not disclose and may receive weak support after disclosure, due to a range of psycho-social factors relating to fears of negative responses like rejection and blame, and of dying. Gender imbalances play a role as women fear being excluded by men, who control their economic security. At the same time, as the study indicates, men may already know their status but also not tell the women.

This undermines both prevention and treatment. These factors may be heightened when health workers, who know the information on testing and disclosure, are not able to communicate with women due to language and time barriers, as found in this study, or due to negative perceptions of the women attending their services.

The intervention highlighted the importance of communication, particularly through approaches that recognise women's perceptions. During the course of the communication intervention in this PRA process, disclosure rose from 60% to 90%. An issue identified but not yet addressed in this study is that of male partners who know their status telling their partners. Acting on the social impediments to testing and disclosure can enhance uptake of services and a PHC oriented response to VCT calls for communication capacities be strengthened in health services. While health workers were able to strengthen their communication in this exercise, the desired shift in communication was limited by language and time barriers. This reinforces the call for expert patient roles, for women in communities to provide more regular support.

The use of participatory methods, while demanding, proved effective even over short time periods to build the empowerment and communication needed to for the changes found. Nursing students proposed that future PRA projects run throughout the year for effective learning and include more students.

PHC responses to AIDS start and end in the community, involving households, networks of affected groups, educational, religious and social institutions and supported by primary care services. The study indicates features of this for testing and counseling:

- Providing high levels of knowledge of services for prevention, testing, health promotion in positive people, partner notification and treatment options to people in the community from an early age onwards
- Creating an enabling social environment encouraging support of PLWHA, openness and reinforcing information on the positive implications of testing and disclosure, including to partners and family members
- Ensuring that testing, counseling and information supporting disclosure, including on positive prevention, is provided at every ANC and PMTCT contact,
- Supporting health worker communication on testing and disclosure with inputs from support groups and expert patients at facilities, and
- Building a health sector response that addresses community as well as health service dimensions of intervention.

1. Introduction

1.1 Testing, counselling and disclosure in pregnant women

In 2006, 19.9% of pregnant women in Namibia were infected with HIV. Without intervention, an estimated third of the approximately 4,200 babies born to those women would have been infected with HIV (MoHSS, 2008a).

Routine HIV Testing and Counseling (RHTC) is a crucial entry point for the interventions that reduce mother-to-child transmission of HIV. RHTC in the antenatal clinic (ANC) setting is different to Voluntary Counseling and Testing (VCT). In VCT, the purpose is for the client to know their HIV sero-status, to receive counseling regarding the results and information about HIV infection and AIDS. In ANC, the pregnant woman seeks health care to improve her health and that of her unborn baby. HIV counseling and testing is thus a necessity for all pregnant women, as part of a routine comprehensive package of care (MoHSS, 2008a). With a high share of women attending ANC and delivering at public facilities, shown in Table 1, RHTC is a means to expanding HIV prevention to a significant population and preventing transmission to children. Knowing one's HIV status could also assist women to make an informed decision on future pregnancy (MoHSS, 2008a). This is more effective if their partners know their HIV status, and are equally counseled on HIV prevention and care.

The extent to which ANC services are being used for HIV testing and counseling is thus of importance for the public health approach to AIDS, as is the extent to which the results are disclosed to partners to support HIV prevention. Supporting routine HIV testing as a part of ANC services is thus an important part of ANC services. Women appear to have a slightly higher rate of HIV testing in Namibia. The Namibia Demographic and Health Survey (NDHS) is cited as showing that more women in Namibia were taking the HIV test and receiving their results than men (51% women and 32% men). The number of women never tested was thus much less (45%) than that of the men (66%) (MoHSS, 2008a). While it is important that women are accessing and accepting to be tested for HIV, it is also important that their male partners are also tested and practice positive prevention. Supporting disclosure between women and their male partners and follow up testing and counseling of male partners is necessary for this.

However, HIV infection has been stigmatised globally. Those infected and affected have felt victimised, guilty, ashamed and hopeless. This makes disclosure of one's sero-positive status to a partner difficult. The decision to disclose involves issues of to whom, when, and how to reveal one's status to others (Sowell et al, 2003).

Trust plays an important role in this decision. The response to disclosure could be supportive and caring, or abandonment and hostility (Sowell et al, 2003). In Namibia, women disclosing their positive HIV status have been reported to have faced hostility, to have been chased out by partners or mother's in laws and partnerships to have been broken due to anger that one of them was not faithful (Hofnie et al, 1999). People are reported to resist disclosing their HIV status due to fear of: separation, of being labeled a bad person, of breach of confidentiality and of physical abuse. Women are also reported to not want to worry their partners and to have feelings of uncertainty about how partners, among others, would react, among others (Deribe et al, 2008; Brou et al, 2007).

Table 1: National antenatal care and delivery statistics

Place of antenatal care	Percentage
Urban	
Public Health facility	84
Private Health facility	15
Home	1
Rural	
Public Health facility	95
Private Health facility	2
Home	2
ANC care provider	
Urban	
Nurse/Midwife	69
Doctor	27
TBA	0.4
Rural	
Nurse/Midwife	86
Doctor	7
TBA	1
ANC assistance from health Professional	
Nurse/Midwife	79
Doctor	16
TBA/Other	1
No one	4
Any skilled provider	95
Place of delivery	
Urban	
Public facility	85
Private facility	9
At home	6
Rural	
Public facility	70
Private facility	2
At home	28
Assistance during delivery	
Nurse/Midwife	63
Doctor	19
TBA	7
Relative/Other	11
No one	1

Source: MoHSS (2008a)

These factors deter infected people from disclosing. However health services can also facilitate or deter disclosure. In one study in Namibia, HIV positive women who did not disclose their status were found to have not received supportive counseling on how to disclose by the health workers. These women had many questions to ask and issues to discuss around their HIV positive status, but did not tell anybody, and obtained little supportive counseling from health workers (Hofnie, 2003).

Even if health workers do not provide supportive counseling, family members could be a source of support, if there was an acceptable platform of sharing information of positive status with relatives. Such disclosure could help people living with HIV (PLWHIV) to:

accept their HIV-positive status; reduce the stress of coping alone; access the care and support that they need; protect themselves and others; and reduce the stigma, discrimination and denial that surrounds AIDS (Sowell et al, 2003; Health 24, 2000-2008). RHTC services thus need to provide support for disclosure to family members and partners and support for coping with negative reactions. Health systems need to incorporate these dimensions on the basis of evidence of the perceptions of and problems faced by pregnant women.

Against this background, this study explored the challenges experienced by HIV infected pregnant women and the coping strategies used by those who disclose or do not disclose, to inform community and health workers roles in supporting pregnant women around disclosure.

At University of Namibia (UNAM) we felt that participatory reflection and action (PRA) approaches could be used to achieve these goals. The work was implemented within a Regional Network for Equity in Health (EQUINET) programme that aimed to explore dimensions of (and impediments to delivery of) Primary Health Care responses to HIV and AIDS. The programme, co-ordinated by Training and Research Support Centre (TARSC) in co-operation with Ifakara Health Institute, REACH Trust Malawi and the Global Network of People Living with HIV and AIDS (GNPP+) provided training on participatory reflection and action (PRA) methods and supported their integration in primary health care and primary care level health services for prevention, treatment and care for HIV and AIDS. This study is one of a multicountry programme aimed at synthesising learning across diverse settings in east and southern Africa on Primary Health Care responses to HIV and AIDS.

In the Namibia study we aimed to use PRA methods to

- explore pregnant women's perceptions of and address barriers to and promote uptake of Voluntary Counseling and Testing (VCT) and partner disclosure of HIV status.
- create awareness in and communication between male and female partners and adult relatives of seropositive women on the barriers/fears related to HIV/AIDS and to disclosing positive status
- explore information provided to pregnant women at the PMTCT and CDC clinics on VCT and disclosure and empower health workers to provide information and communicate effectively with clients on VCT and disclosure.
- strengthen PRA capacities and skills in five nursing students, to support VCT and disclosure in HIV-positive women.

We implemented this work at Katutura state hospital, one of the three intermediate hospitals that forms a bridge between district health services and the more costly specialised health care offered at the national hospital in Namibia. According to the National Sentinel Serosurvey, the HIV prevalence rate in the study area of Katutura hospital increased from 4.0% in 1992 to 21.7% in 2008 (MoHSS, 2008a; MoHSS, 2008b). The adult HIV prevalence rate in the study area was 17.0% (MoHSS, 2008b) , while the national adult HIV prevalence rate was 21.7% (MoHSS, 2008b).

Between January and June 2008, there were 1 918 deliveries at Katutura hospital, of which 327 were to HIV positive women who were enrolled in the programme for

Prevention of Mother to Child Transmission (PTMCT). The hospital provides services for health promotion, prevention and HIV treatment for communities in Windhoek.

We implemented the work at selected sites, including public sector and Centre for Disease Control (CDC) services for antenatal care (ANC) and PMTCT within the Katutura hospital complex. Katutura ANC clinic provides routine information on PMTCT and VCT, usually to groups of women, together with normal ANC health talks. Those women that opt for testing are referred to the PMTCT programme for individual pre-test counseling and testing. After post-test counseling, those who tested positive are screened for appropriate follow-up as well as for anti-retroviral therapy. At ANC, mothers are encouraged to bring their partners for antenatal talks, although this was reported by hospital personnel to have had slow uptake to date, with only about 8% of women attending ANC having their partners visiting services. Prior to this work, staff at the hospital noted to the study team that they felt this low uptake of partners of services to be a missed opportunity.

All pregnant mothers that test positive are enrolled with PMTCT and consequently with Centre for Disease Control (CDC) for follow-up and treatment by the six registered nurses and eight counselors. HIV positive women at these services are informed by health workers about the importance of partner and close relative notification. The women are entirely responsible for disclosing to their partners, and while health workers can provide information, they have no control over whether this is done or not.

We included third year UNAM nursing students in the work. These students are not trained in participatory approaches, as this is not covered in their curriculum. We hoped that the use of the participatory approaches would provide them with useful learning experiences.

We also hoped that using PRA approaches would enable us to share learning between pregnant women and health workers about VCT at Katutura and the barriers to disclosure by HIV positive women, especially to male partners and adult relatives. The PRA approach allowed us to learn not only about the barriers. From experiences of implementing measures, we sought to explore and strengthen health worker responses, health worker knowledge of the guidelines for HIV-status disclosure and communication with HIV-positive women on the VCT and disclosure at PMTCT and CDC. We also aimed for the students in the research team to improve their knowledge on VCT and HIV disclosure and their confidence to use PRA approaches.

2. Methods

The research used a mix of qualitative and quantitative methods. The participants in this study were: mothers who attended antenatal care clinic, those who attended the PMTCT services offered by CDC; health workers who worked at above mentioned sites; and third year nursing students. The PRA work was facilitated by a person who was trained in PRA work.

The facilitator held familiarisation meetings with the health workers in-charge of Katutura ANC, PMTCT and CDC services in Windhoek, prior to the commencement of the work. An existing training agreement between UNAM and Ministry of Health and Social Services covered permission for this work as part of a UNAM training activity. The

facilitator also briefed and obtained support from the Chief Nurse Manager and the maternity section of the hospital. Individual permissions were sought and granted from clients after the purpose of the PRA work was explained to them. The whole exercise was based on voluntary participation, and only those who volunteered were included throughout.

After the familiarisation meetings, mobilisation and selection of participants began.

We initially intended to randomly select 30 women from the daily booking of 40-50 women attending the ANC clinic attending for their first visit. With a qualitative and participatory longitudinal process, we aimed for smaller numbers of participants in more intensive and inclusive processes, to give women time to contribute individually, and to collectively validate their individual experiences through the participatory methods. The methods involve both drawing out of experience and collective validation. A specific day of the ANC clinic was selected for the initial recruitment to allow for regular follow up. The study design involved review and follow up meetings with these women prior to delivery. It was understood that some women would dropout during the course of the PRA work, due to return travel to rural areas or the demands of nursing a newborn baby.

However the sample selection faced greater challenges than anticipated. On the day of the selection of sample, only 46 women in total attended ANC for the first visit. Participation in the study was voluntary and only ten ANC mothers volunteered to participate. All of them tested negative for HIV. Before the second meeting, although their expected dates suggested otherwise, six of these delivered and were not available for the PRA work, leaving us with only four women from the ANC services participating throughout the process. To give us an understanding of the different views and experience of women with HIV, we purposively included, again through voluntary participation, a further group of ten mothers who tested positive.

Four health workers (of 7 nurses and 11 counsellors) working with pregnant women at the PMTCT and CDC services were also included in the study. The numbers were limited by understaffing and the health workers' workloads. Six students initially volunteered from those allocated during the month of the study (August 2008) to Katutura maternity section. One of the six students dropped out due to their workload.

While these samples sizes were small (14 pregnant women, 4 health workers and 5 nursing students) this was a qualitative study not intended to provide in depth understanding of the phenomenon under investigation. As a qualitative study it seeks to discover meaning and identify multiple realities through more intensive focus on limited samples, (Polit & Beck, 2004; Streubert & Carpenter, 1995). While the limit of small numbers is recognized, the qualitative evidence is able to point to key issues affecting disclosure, and evidence of the processes needed to support disclosure. At the same time limitations of the data are acknowledged: The frequencies were too small for quantitative data analysis and the small numbers may introduce bias, even in the qualitative work, particularly as subjects volunteered. Those who volunteer may have more positive attitudes towards testing and disclosure. We also acknowledge that the factors identified are relevant to the area serviced by Katutura hospital, although where relevant we cite consistency with other studies that suggests possibilities for wider generalisation.

A range of participatory methods were used such as baseline checklists, focus group discussions, role play, scoring and raking, problem tree and “but why” exercises, story codes and spider diagrams. The PRA process sought to develop a collective understanding why people do and don't volunteer for testing; to explore the implications of disclosing/not disclosing their status and the coping strategies used. The role of partners, health workers and family members was also explored. The process was also used for the mothers, health workers and students to develop an action plan and markers of progress on what they can each do and what they can do together over the next three months to increase uptake of VCT and improve disclosure and the response to it in the community.

Plans for action were defined and implemented. Progress markers were jointly developed by all the stakeholders (mothers, health workers and UNAM PRA team). These markers were monitored midway, after the action plans were implemented and at the end of the PRA work.

A baseline checklist was given to all three groups (ANC and PMTCT mothers and health workers) on key parameters being explored in the work at the beginning of the PRA work. These checklists were repeated at the end to observe whether there were changes in their views and perceptions as a result of the PRA process.

The full programme was implemented between August 2008 and end January 2009. Dr Käthe Hofnie-//Hoëbes, University of Namibia, led the research team with third year nursing students of the same University namely: Ms Kakororo, O, Ms. Jankowsky, V, Ms Shilongo, N, Ms Callard, B, and Ms Paulus, D, with design input, mentoring review input and support for report preparation from Dr Rene Loewenson and Barbara Kaim (TARSC).

3. Implementation and findings

The findings are presented below on the process:

- The initial recruitment meetings and baseline test for all groups,
- The PRA process;
- The actions implemented and
- The follow up questionnaires.

In the next section we provide reflection on the lessons learned and the way forward.

3.1 Initial meetings and baseline questionnaires: Initial views on testing and disclosure

Initial recruitment meetings were held to explain purpose of the PRA work and elicit voluntary participation in the PRA process. The baseline questionnaire was then administered.

The women in the ANC group:

The questionnaire with the women in the ANC sample was implemented over two meetings, with 10 respondents for the initial set of questions and four in the second due to the six women who delivered between rounds. The split in the questionnaire was unavoidable due to logistic reasons. The results are shown in Tables 2a and 2b.

Awareness of testing was high in this group, as was reported intention to be tested, importance of disclosure and intention to disclose. The women reported that they would primarily be tested to know their own health status and protect themselves. This is similar to findings in other studies in Namibia (Hofnie et al 1999). The health workers and media were the main sources of information on VCT and disclosure, with the woman's mother the first person to be informed of the positive HIV status (See Table 2a). This is also similar to other studies reporting a preference to disclose to parents, before disclosing to partners or husband (Sowell et al 2003).

Table 2a: HIV negative women's at ANC baseline questionnaire results, part 1

Attitude Assessment	Pre-test	Results
Q1. Have you ever heard of HIV voluntary counseling and testing?	Yes No	100% (n=10) 0%
Q2. If yes, where did you hear?	1. Friend 2. Media 3. Health workers 4. Other (Specify... <i>Aunt</i>)	10% (n=1) 50% (n=5) 60% (n=6) 10% (n=1)
Q3. Will you one day volunteer for counseling and testing?	Yes No Don't know	100% (n=10) 0% 0%
Q4. If yes, why?	1. To know my HIV-status 2. To protect others 3. To access treatment 4. Other (Please specify... <i>(To protect myself)</i>)	70% (n=7) 20% (n=2) 10% (n=1) 60% (n=6)
Q5. Have you ever heard of importance of HIV status disclosure?	Yes No	100% (n=10) 0%
Q6. If yes, where did you hear?	1. Friend 2. Media 3. Health workers 4. Other (Please specify...)	20% (n=2) 30% (n=3) 50% (n=5) 0%
Q7. Will you one day disclose your status if you are tested positive?	Yes No	100% (n=10) 0%
Q8. If yes, Why?	1. To get treatment 2. To have somebody to talk to when I am not feeling well 3. To protect others 4. Other (Please specify... <i>For my own health</i>)	40% (n=4) 10% (n=1) 10% (n=1) 50% (n=5)
Q9. Do whom will you disclose your HIV positive status first?	1. Mother 2. Partner/Husband 3. Other (Please specify relationship...)	60% (n=6) 40% (n=4) 0%

Table 2b: HIV negative women's at ANC baseline questionnaire results, part 2

Attitude Assessment	Pre-test	Results
Q1. What information was given to you by health workers on the benefits of testing?	1. Protection of baby 2. Accessing treatment 3. Change of risky behaviour 4. Protect others 5. Other (Please specify...)	100% (n=4) 50% (n=2) 50% (n=2) 0% 0%
Q2. Have you had counseling and testing for HIV?	Yes No	100% (n=4) 0%
Q3. How was the result?	Negative Positive	100% (n=4) 0%
Q4. Do you think it's important to tell your partner/Husband?	Yes No	100% (n=4) 0%
Q5. Did you tell your partner/Husband?	Yes No	100% (n=4) 0%

Q6. If yes, why? (Positive results)	1. For him to support me 2. For him to go for HIV test 3. For us to protect each other from new infection 4. Other (Please specify)...	N/A
Q7. If no, why not? (Positive results)	1. He will be angry 2. He will chase me away 3. I don't know how it will affect my relationships with my partner/husband 4. Other (Please specify)...	N/A
Q8. In case of negative results, why did you tell him?	1. To know that we are still healthy 2. To remain faithful to each other 3. Other (Please specify)...	0% 50% (n=2) 50% (n=2)
Q9. In the event of negative test results, how did he react?	1. Relief 2. Happy 3. Other (Please specify)...	0% 50% (n=2) 50% (n=2)
Q10. In the event of positive test results, how did he react?	1. Angry 2. Blaming 3. Understanding 4. Other (Please specify)...	N/A
Q11. Have you tell any person other than your partner/Husband?	Yes No	75% (n=3) 25% (n=1)
Q12. If yes, Who did you tell?	1. Mother 2. Elder sister 3. Trusted friend 4. Other (Please specify)...	50% (n=2) 50% (n=2) 0% 0%

All participating women were counseled and all tested negative as they had anticipated earlier. These women all informed their male partners and or adult relatives of their negative test results, as has been found in other studies with negative results (Brou et al 2007). Protection of baby was the major reason for HIV testing, and some reported that they disclosed negative HIV results to their partners to remain faithful to each other and for re-assurance of couple's negative status. They reported partners to either be not surprised or happy by the negative test results.

The women at the PTMCT clinic

The results of the baseline questionnaire for the HIV positive women at the PMTCT clinic are shown in Table 3.

Nearly all (90%) of the women in this group had heard of HIV counseling and testing with a similar distribution of sources as in the ANC womens group. Although all of the mothers in this group acknowledged the importance of partner notification, only 60% reported having disclosed their positive HIV status to their partners. The main reason for disclosing their positive status was for the partner to go for HIV testing (See Table 3). This group differs from the HIV negative mothers in this respect, as the latter all disclosed their results to their partners.

Various reactions were received when positive status was disclosed, with a relatively even distribution of blaming of women as the source of the problem, initial denial followed by later support, and cutting contact with the women. Blaming, separation and disbelief of wives' positive test results were also reported in other studies (Brou et al 2007; Deribe et al 2008).

In this study, 30% of the women's partners knew that they were positive and were already on treatment, but had not told their partners until the women attended ANC and discovered for themselves. In all the above cases no violence was reported. Contrary to

this, it was reported in another study that one fourth of all mothers experience violence, rejection and abandonment after disclosing positive status (Sowell et al 2003). Of those 40% who did not disclose their positive status, 30% were concerned about how disclosure would affect their current relationships. This concern regarding the effect on the relationships has also been found in other studies (Brou et al 2007).

Table 3: Results of baseline questionnaire for women attending PMTCT programme

Attitude Assessment	Pre-test	Results
Q2. Have you heard about HIV counseling and testing?	Yes No	90% (n=9) 10% (n=1)
Q3. If yes, where did you hear?	1. Friend 2. Media 3. Health workers 4. Other (Please specify)...	10% (n=1) 50% (n=5) 70% (n=7) 0%
Q1. What information was given to you by health workers on the benefits of testing?	1. Protection of baby 2. Accessing treatment 3. Change of risky behaviour 4. Protect others 5. Other (Please specify... To know health status Infant feeding	70% (n=7) 40% (n=4) 20% (n=2) 30% (n=3) 20% (n=2) 10% (n=1)
Q4. Do you think it's important to tell your partner/Husband?	Yes No	100% (n=10) 0%
Q5. Did you tell your partner/Husband?	Yes No	60% (n=6) 40% (n=4)
Q6. If yes, Why?	1. For him to support me 2. For him to go for HIV test 3. For us to use condoms 4. Other (Please specify)...	10% (n=1) 50% (n=5) 40% (n=4) 0%
Q7. How did he react?	1. Angry 2. Blaming 3. Understanding 4. Knew already and was not surprised 5. Other (Please specify)... First in denial, but supports me later Never calling since then Never visiting since then, just sent the baby's name	10% (n=1) 20% (n=2) 30% (n=3) 30% (n=3) 20% (n=2) 10% (n=1) 10% (n=1)
Q8. If no, why not?	1. He will be angry 2. He will chase me away 3. I don't know how it will affect my relationship with my partner/Husband. 4. Other (Please specify)... Nobody to tell, we are separated and I do not see any need	0% 0% 30% (n=3) 10% (n=1)
Q9. Have you told any person other than your partner/Husband?	Yes No	70% (n=7) 30% (n=3)
Q10. If yes, who did you tell?	1. Mother 2. Elder sister 3. Trusted friend 4. Other (Please specify)... Elder brother	20% (n=2) 20% (n=2) 0% 30% (n=3)
Q11. Why did you tell that person?	1. To support me 2. To have somebody to talk to when sad 3. Other (Please specify)... For him to know	30% (n=3) 30% (n=3) 30% (n=3)

The health workers

A small sample of four health workers were given the baseline questionnaire and their results are shown in Table 4.

Table 4: Results of baseline questionnaire for Health workers

Attitude Assessment	Pre-test	Results
Q1. Are you confident to talk to pregnant women about VCT?	Yes No	100% (n=4) 0%
Q2. If yes, to which extent?	1. 20% 2. 40% 3. 60% 4. 80% 5. Other (Please specify)...	25% (n=1) 0% (n=0) 25% (n=1) 50% (n=2) 0%
Q3. Are you confident to talk to pregnant women about disclosure?	Yes No	100% (n=4) 0%
Q4. If yes, to which extent?	1. 20% 2. 40% 3. 60% 4. 80% 5. Other (Please specify)	25% (n=1) 25% (n=1) 0% 50% (n=2) 0%
Q5. What are your barriers in effective communication regarding VCT?	1. Language 2. Shortage of time due to workload 3. Mobility of clients	50% (n=2) 25% (n=1) 25% (n=1)
Q6. What are your barriers in effective communication regarding issues of disclosure	1. Lack of partner participation 2. Lack of real understanding of disclosure 3. Lack of confidence in communicating issues of disclosure	50% (n=2) 25% (n=1) 25% (n=1)
Q7. What do the guidelines for pre-test Counseling provide for?	1. HIV transmission 2. Routine Counseling and Testing 3. Baby care and immunizations 4. Impact of HIV and pregnancy 5. Other (Please specify)...	100% (n=4) 100% (n=4) 75% (n=3) 50% (n=2) 0%
Q8. What do the guidelines for pre-test Counseling provide for in the event of positive results	1. Healthy for mother 2. Review meaning of test results 3. Give time and space to express emotions 4. Review risk reduction 5. Other (Please specify)...	100% (n=4) 100% (n=4) 100% (n=4) 100% (n=4) 25% (n=1)
Q9. What do the guidelines for post-test Counseling provide for in the event of negative results?	1. Discuss risks of couple discordancy 2. Give time and space to express emotions 3. Revisit the window period 4. Schedule the next visit 5. Other (Please specify)...	100% (n=4) 100% (n=4) 75% (n=3) 50% (n=2) 25% (n=1)
Q10. What do the guidelines for HIV disclosure provide	1. Prepare for negative reaction 2. Identify sources of support 3. Other (Specify)...	100% (n=4) 100% (n=4) 25% (n=1)
Q11. Why is it important that mother disclose her positive status	1. To accept her status 2. For reduction of stigma 3. Help her to negotiate safer sex 4. Help to access support 5. Other (Specify)...	100% (n=4) 100% (n=4) 100% (n=4) 100% (n=4) 25% (n=1)
	Preparation of HAART assessment For family planning Feeding options For saving the baby	25% (n=1) 50% (n=2) 25% (n=1) 25% (n=1)

All participating health workers indicated that they were generally confident with talking to pregnant women on VCT and disclosure, although with some lack of confidence around aspects of these issues (see Table 4). Language was pointed out as the main barrier to discussion of testing, while absence of partners was the main barrier to communication on disclosure. The majority of the mothers do not speak the official

national language, leaving some health workers handicapped and putting pressure on others able to speak the language to assist. The health workers appear to be relatively well versed in the guidelines on testing, counseling and disclosure volunteering themselves the issues, shown in Table 4. They also noted a number of reasons for disclosure, including to accept their status, to reduce stigma; to negotiate safer sex, to access support and for a range of public health and health care reasons (including assessment for treatment, family planning, feeding options and HIV prevention for the baby).

These baseline results indicate that while awareness of testing and disclosure is high, and while health workers are generally aware of the guidelines for implementing testing, counselling and supporting disclosure, there are perceived barriers in implementing this:

- For positive mothers, in negative and unsupportive responses from their partners
- For health workers in accessing partners and communicating in local languages.

3.2 PRA process: exploring the perceptions of women about testing and disclosure

HIV negative women at ANC services

The women who were HIV negative at the ANC clinic were gathered for a meeting using PRA methods to explore the issue further. After an introduction of the process simulated case studies were used to stimulate the discussion on uptake and responses to counseling and testing. . One of these is shown below with the discussion:

Case 1: Why do some people volunteer for testing and others not?

Anna-Marie is pregnant and visits ANC for the first time. Routine ANC health talks were given to her, and at the end also importance of Voluntary Counseling and Testing was explained to her and she was encouraged to consider this. Let us talk about what was probably going on in this woman’s mind regarding this new information on VCT.

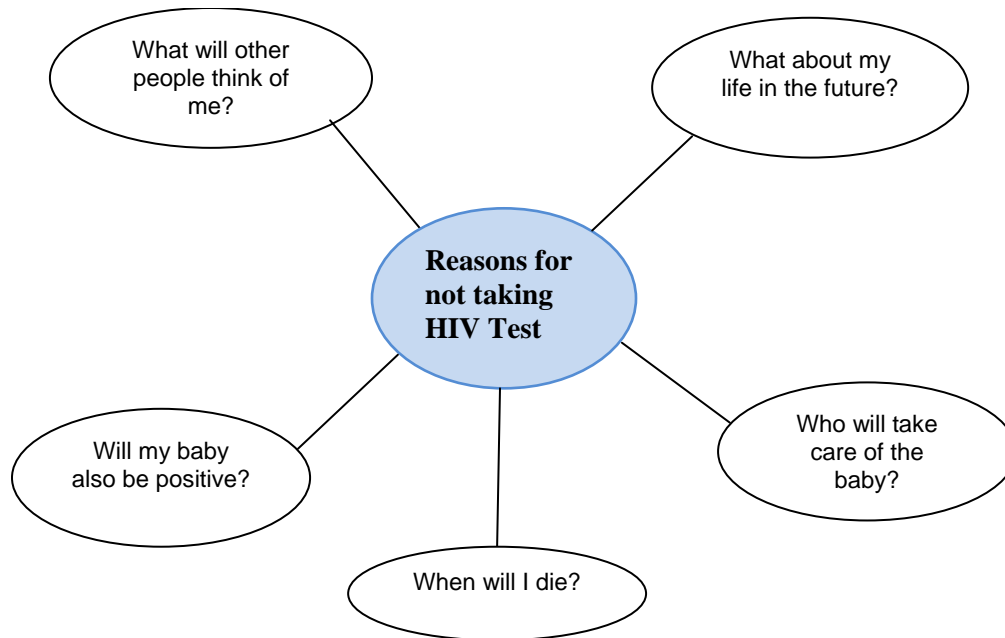
The mothers unanimously agreed that this woman will not agree to testing, as it is her first time for ANC and HIV testing, and as she trust herself and not her partner.

The case was used to probe reasons for not testing for HIV. A spider diagram was used for women to collectively explore the reasons for not taking the HIV test, and the fears and issues raised are shown in Figure 1 overleaf. These reasons were ranked and scored by women collectively, after discussing amongst themselves and ranking by consensus. (See Table 5).

Table 5: Ranking of reasons for not taking test

Reasons for not taking HIV test	Ranking
What will other people think of me?	1
When will I die?	2
What about my life in the future	3
Who will take care of the baby?	4
Will my baby also be positive?	5

Figure 1: Spider Diagram showing reasons for not taking HIV test



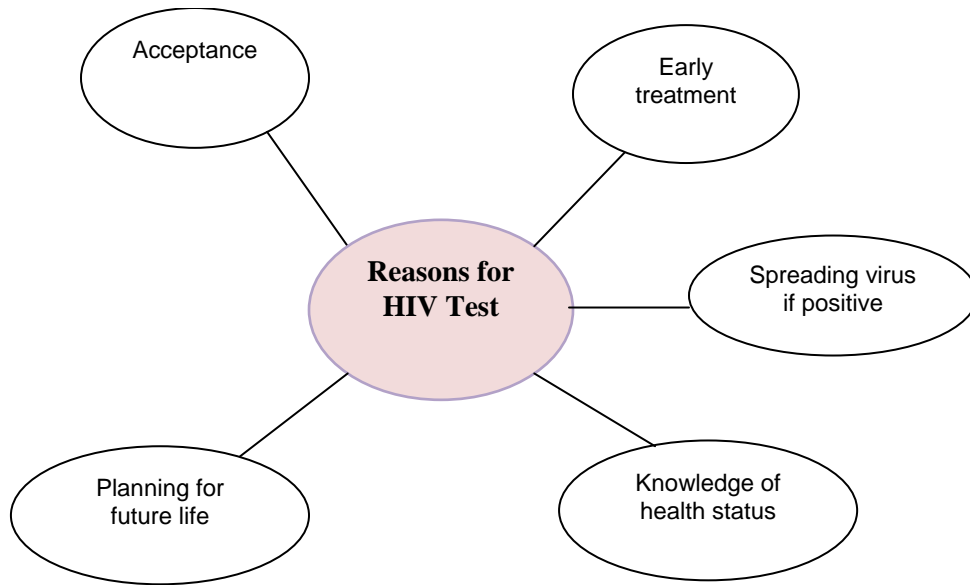
Fear of discrimination by people with AIDS and continuous negative thoughts of death, when tested HIV positive, were rated as the main reasons why mothers are reluctant to take HIV test. Discrimination leads to isolation and isolation to hopelessness (Hofnie, 1997). This leads to people preferring not to know their HIV status. Knowledge of positive HIV status has in other studies been reported as a ‘dark cloud’ hanging over one’s head, and compared to a ‘death penalty’ (Hofnie, 1997).

The top ranked factor deterring testing was further explored, using a “Problem tree”, method to explore the underlying causes for the fear “*what will other people think of me*”. The issues raised are shown below:

- Why worry about others opinions?
 - *People will think that mother slept around*
- Why would the people think she slept around?
 - *Because she has contracted the virus*
 - *Sex is the root cause of HIV infection*
- What can happen if she has contracted the virus?
 - *They will think she will infected them*
- What will happen if they think so?
 - *Friends will leave her*
- What will happen if friends leave her?
 - *She will feel isolated and hopeless*

In contrast, a similar process was used to explore reasons for **having** an HIV test. The results are shown in Figure 2 .

Figure 2: Spider Diagram showing reasons for taking HIV test



Of these, planning for future life was ranked as the strongest reason for testing (see Table 6). It has also been found from other studies that people report the need to know their health status to plan whether they could get married and get children, or whether they could study further or not, if positive (Hofnie (1997)

Table 6: Ranking of reasons for testing

Reasons for testing	Ranking
Planning for future life	1
Knowledge of health status	2
Early treatment	3
Acceptance	4
Spreading virus if positive	5

Case 2: Disclosure to male partner and or adult relative

Anna-Marie eventually decides on HIV testing and tests positive. Post-test counseling was done, including the importance of partner notification or and disclosing her status to adult relative for support.

The ANC women were in agreement that it was not easy to tell their partner, but that the woman will tell a “trusted friend” after she accepted the results. According to the mothers, the woman will not first believe the first test results and will go for the second and third tests, before she will believe and disclose to somebody. Other studies support the finding that disclosure remained difficult for women (Sowell et al, (2003).

The women reported discrimination and blaming as the main barriers to disclosure of HIV infection to male partners. Fear of separation, fear of discrimination and blame for

unfaithfulness have been found in other studies to be the main reasons for non-disclosure (Deribe et al, 2008; Brou et al, 2007).

In contrast, the women reported that they would tell partners to demand explanation; to access treatment for both; to protect others; to prevent re-infection; to change sexual behaviour; and to foster open relationship after this mistake. Similar results linked to self protection and protection of others were reported by Hofnie (1997). Of these, protection of others was rated as the most important reason for telling their status to their partner.

Table 7: Ranking of reasons for telling positive status to partner

Reasons for telling positive status to partner	Ranking
To protect others	1
To access treatment	2
To change sexual behavior	3
To prevent re-infection	4
To foster open relationship	5
To demand explanation	6

The baseline questionnaire indicated knowledge of health status and self-protection to be major reasons for HIV testing. In the discussions the women attending ANC indicated the importance of protecting others as a prioritized reason for disclosing positive HIV status. It is interesting that women shift perception from 'self-protection' to 'protecting others' in relation to disclosure. This selflessness and desire to protect others after testing HIV positive was reported by earlier studies in Namibia (Hofnie, 1997).

In a third meeting the process was used to explore more deeply the coping strategies used by mothers who disclose their positive status, as well as by others who choose not to disclose their positive status. The UNAM PRA team prepared a role play to stimulate the discussion, illustrating the challenges in coping that are experienced by pregnant women who tested positive and who did not disclose their status to significant others and the difference in coping when they do disclose their positive status. The role play was followed by a facilitated group discussion.

Description of the role play

A married woman goes to ANC. Voluntary Counseling and Testing was explained to her and she tests positive. After being given her results, she weeps a lot. Her main concern was what other people would think of her. She talks to herself that other people may think that she was sleeping around. She also wonders how she will tell her husband. She blames her husband for the positive results. The woman cannot eat or communicate with others and is obviously stressed.

After some 6 months, she decides to tell her 'mother'. She doesn't find it easy to disclose her positive status and is hesitant, but after a while, she breaks the news.



A disappointed mother after her daughters disclosure



Mother embraces her daughter

Her mother reacts very negatively. Initially, it is a great disappointment for the mother, as she is her only daughter. The mother accuses her daughter of sleeping around and therefore contracted the deadly virus. The mother repeatedly asks her whether the baby has also AIDS. The woman explains to her that she does not have the disease (AIDS) at this stage, but only the HIV virus. She also explains to her mother that the counselor told her that the baby has still high chance not to get the virus, as many babies are born without the virus, even if the mother has the virus. Furthermore, the woman explains that she was told by the counselor that she has still long life ahead of her, if she adheres to

positive living principles. The Mother asks the woman whether she has informed Peter, her husband. She replies that she did not inform him, and the woman urges her mother not to tell anybody. After a while, the mother embraces her daughter and weeps over her shoulder and promises that she will not share this with anyone. A significant relief is noticeable on the young woman's face, after she discloses her status to her mother..

In the discussion the women observed that similar scenarios happen in their community. They indicated that the woman was stressed out before disclosure, because she kept her status as a secret, alone. After disclosure, the woman had relief from stress, because she found a trusted friend in her mother. They indicated some negative effects of non-disclosure such as: that a person could be broken down psychologically, could easily commit suicide, her condition could deteriorate, and death could occur due to lack of medical care and support.

According to these mothers who all tested negative, **social security** was the main reason why women are reluctant to disclose their positive HIV status to male partners:

"Sometimes, it is only men who are working. That's why women don't want to tell them. What will happen if he chases her away? Where will she get money and food?"

"Others (male partners) will be angry and beat you up and say that you brought the disease"

Women participants

Physical violence by a male partner, after disclosing mother's positive HIV status has been reported (Deribe et al, 2008) However, it was less commonly reported in this study than the fear of separation, which was indicated as the main reason for non-disclosure.

The women acknowledged that disclosure was not easy and that people are different and use different coping mechanisms. They suggested that women who test positive have a 'trusted friend', someone who will listen, to whom mothers could empty their hearts when stressed. They felt that women need to give greater priority to their own needs, and not mind too much what others think of them. Some felt religious faith to support this position, a belief referred to in other studies (Sowell et al 2003). AIDS was

perceived to be a worldwide problem, and it was felt that women who do not disclose need to think about the future life, including to prolong life.

The discussions indicated the range of social barriers to testing and disclosure. On the one hand women fear what others will think of them, while on the other if they take some control and test and disclose they do so because they are thinking of others. The social context for testing and disclosure is this very important to women. Community dialogue on HIV/AIDS is long overdue, to enable women to see AIDS in broader perspective and to provide a more supportive social environment.

Women living with HIV at PMTCT services

The meeting with the ten women living with HIV at the PMTCT services was used for a focus group discussion on the issues affecting disclosure:

Information given to PMTCT mothers by health workers was noted to include: exclusive breastfeeding for 4 months; use of condoms; no alcohol use; taking of medication at right time; eating of healthy food and hygiene of mother and baby. The women did not volunteer the issue of disclosure, but after probing they reported that all of them were informed about disclosure on the very first day. It thus appears that health workers are covering the issues in the counseling manual, but perhaps not reinforcing these by raising issues such as disclosure on each encounter.

Disclosure to male partners The main reason for disclosing positive status to a male partner was reported to be due to the possibility that the woman may then negotiate condom use. Sowell et al (2003), found similar findings that disclosure was needed to prepare male partners, in case they insist on sexual intercourse without a condom. Two mothers raised that their partners left them after disclosing their positive HIV status. Similar findings were reported by Brou et al (2007).

Disclosure to female partners The women were asked to what extent their male partners disclose their positive status to them. This question was raised due to information gathered from the baseline questionnaire. It appears that male partners wait until mothers are tested positive and when told, confirm the knowledge of their own positive status. Two mothers share their experiences as following:

"I got sick, before tested positive and suggest for HIV test, but he (partner) refused and told me not to go. I insisted and take the test that was positive. But I already suspect something, when he prohibit me to go for testing that he probably knew something about his status, but did not disclose it to me". Another comment was:

"My boyfriend knew that he was positive, since he was on treatment, but he did not tell me. I have seen some tablets he was taking, but he never informed me about those tablets. The day when I came back from the clinic and told him that I was tested for HIV and my test was positive, he calmly said that he was already on treatment".

Of interest this lack of disclosure by men contrasts with findings reported by Sowell et al (2003) which reported that women have greater difficulty disclosing their HIV status to partners than men.

Disclosure to relatives Mothers, aunts, uncle, brothers, friends and siblings were reported to have been told, particularly mothers and aunts. Disclosure to relatives, and siblings has been reported in other studies (Sowell et al 2003), but the women at the PMTCT services did not generally support informing children.

"In my opinion, I will not tell my son or daughter. It is not easy; it may affect the child at school, because the child's understanding of HIV/AIDS is poor".

"It all depends on the child's understanding, but importantly the good communication and understanding that exist between you and your children. Therefore, for some of us, it is easy"

Benefits of disclosure The women indicated the value of disclosure, despite the fear of physical violence they indicated previously:

"I don't know how to express that feeling. It feels as if a big thing is taken off your shoulders".

"If you keep this thing to yourself, it is suicidal. I mean it can kill you, or you will also go to the extent of suicide. You will always just think of death. But now, I am feeling like a normal person. I am free of any fear".

The feeling of relief and psychological health due to lower stress levels after disclosure has been reported elsewhere (Sowell et al 2003).

When to disclose? Surprisingly, despite the fears raised, all the women had disclosed their status to their male partners on the day they were told. Early disclosure has also been reported in a previous study among HIV positive women in Windhoek and elsewhere (Hofnie et al, 1999; Deribe et al, 2008), although some women were found to wait until their illness was more advanced (Deribe et al 2008). One woman, separated from her partner, disclosed the same day to her brother. A woman who disclosed to her children indicated that she informed them one month after testing.

Motivating factors for positive living All the women indicated that they accepted their status and are living positively and are strong. They seemed comfortable when discussing issues around their positive status. Some mothers felt that there was no difference between positive and negative person, and that death will come anytime to anybody, whether you are positive or negative. Therefore, they suggested a positive outlook.

"You need to have a positive outlook on life. If positive, does not mean that it is the end of the world. Life is still there and you need to look forward".

Emotional and treatment support, religious belief, acceptance by people around them, and confidence in self were indicated as playing an important role in positive living.

"You need to have confidence in you, so that you may not worry about what other people think or talk about you".

"Now we know there is help (treatment). In the beginning (refers to time treatment was not available), the people were very secretive, and they did not talk about HIV. But things have changed. Another issue is almost every house has someone with this problem (HIV). Therefore, why should you hide?"

The women at the PMTCT services discussed how to motivate those HIV positive women, who do not have positive outlook. They supported the idea of support groups to meet and talk about HIV/AIDS and education of the community. Sowell et al (2003), report that coping focuses on the importance of one's cognitive appraisal of an event and their reaction to it. It appears that the women living with HIV at the PMTCT services had a good understanding of HIV in general, and of positive living in particular. Their perceptions appeared to keep them strong and give them a positive outlook, together with self-esteem and confidence.

The health workers

The meeting with health workers explored the information provided by health workers to mothers at PMTCT and CDC clinics on VCT and disclosure and the challenges experienced by the health workers through focus group discussion.

Health workers indicated that vulnerability, peer pressure and dependency syndrome were major high risk factors among the women. According to the health workers, young people do not listen to the parents, do not want to be under their guidance, and easily move out of parental home and leave a baby with the parents or grand parents”.

“She (woman) will rent a room elsewhere, but cannot afford to pay the rent. Consequently, she will employ three sexual partners: one to pay the rent, other one for the taxi (public transport) and the third one to provide in her daily needs... They do not go to church either. There is an absolute moral decay among this group of mothers... This is a different breed, a complete new strain of the society which is out on material gain only and bothers with nothing else”

This situation they felt to be harmful as prevention starts at **home**. By the time the women reach the health services, it is too late, and social change was felt to be needed. For example the health workers felt that education on AIDS should start at **pre-primary level** and that the HIV and AIDS education in **school curricula** should be strengthened. They also pointed to the reach of churches to young people and the need for music to not block young people in listening to messages on AIDS.

“The other problem is music of the day. There are messages on radios and many more adverts out in the community on these issues (HIV/AIDS). But who listens?. The young people are just listening to the music of kwaito, kizomba, hip-hop, kwasa – kwasa”.

They reflected on the difficulties they faced in VCT and disclosure at **health facility**:

“Disclosure is a very complicated one. The mothers have many problems. They are nomads. They do not have fixed address, no fixed sexual partners. Due to the moral decay, some do not know the father of the baby; sometimes, pregnancy happens from “one night stand” type of sexual relationship. Women are out on survival, and do not some times care as far as their basic needs are been met. To whom should they disclose their positive status then? Sometimes, the women will tell you that they are aware that their partners have relationship with other more than one sexual partner. How do they disclose to such a partner? Young women ran away from parental homes and live alone in the urban or semi-urban areas, thus to whom to they disclose?, mother is far in the north or so. Or some said that they were born in exile and do not have parents, and prefer rather to die of AIDS. They don’t even go to church for religious support, to whom will they disclose? They don’t think to disclose to friends, because friends will spread the news. You will not believe when they are telling you all these things. You are later so crowded by listening to the voices of these women to the extent that you sometimes feel to leave your ‘crowded head’ at work and just take your bag and go home”

This perception of the women by health workers is rather negative. They are preoccupied by the problems in reaching the women, and in their disclosing. It is interesting that this contrasts with the rather more positive picture from the interviews with the women at the ANC and PTMCT services, which indicated a higher rate of disclosure and support than the health workers dialogue suggested.

The health workers seemed themselves to be stressed and somewhat demoralized about the women they are treating, with problems lying beyond the reach of the services. It would be important to have a more quantitative assessment of the reality of levels of testing and disclosure at a population level, such as through the demographic and health household surveys.

The health workers also however raised some areas for strengthening. They agreed on the need to re-enforce learning, particularly, risk reduction and proper counseling at each encounter.

“The counseling must not be ‘microwaved’ (microwave means superficial counseling). We are picking up some cases during adherence counseling that sometimes counseling is been ‘microwaved’. I think, this is the area we need to improve on. Wrong information is difficult to erase”

With the diversity of perception across the women and health workers, we finally held a meeting using PRA processes with all three groups together, to take the issues forward to action and review progress.

4. Developing and reviewing actions on testing and disclosure

4.1 Developing actions

A combined meeting of women, health workers and the UNAM PRA team was held to review shared perceptions of priorities and the possible actions around these, and to set goals and progress markers for these actions. The participants discussed the actions that each group could do, and what they could do collectively over the next three months, in order to increase uptake of VCT and improve disclosure and the response to it in the community.

- The action plans of the health workers focused on education and re-education of the mothers on issues around advantages of VCT and disclosure.
- The action plans of the women from the ANC services, after some hesitation on their possible role, focused on communicating the importance of VCT and of sharing HIV results with their relatives and friends.
- The action plans of the women living with HIV from the PMTCT services focused on the issue of disclosure and forming support groups among themselves.
- Across the three groups it was noted that all would be focusing on education and re-education of women on the advantages of VCT and disclosure, as well as on openness around HIV/AIDS.

The process also provided a means to enhance shared planning between the women and their health workers. The group set progress markers of things that they felt they **MUST** achieve after the three months in these areas, and five things they feel they would **LOVE** to achieve, if making progress on their plan. These are shown in Table 8. These were used for review midway and at the end of the process. Further checklists were used to assess the interventions between the health workers and the women attending PMTCT services, such as to evaluate whether the women were counseled at each encounter as agreed by health workers and how open the mothers were to talk about issues of HIV/AIDS etc. Checklists were also used to monitor the knowledge of

health workers on disclosure guidelines, and how comfortable they were, talking to mothers about VCT and disclosure.

4.2 Implementing actions

Actions by participating mothers

The mothers followed up with education through sharing of HIV and AIDS related information and issues. This encouraged openness, giving confidence through exchange of positive experiences within the group. One example of this is of women who were initially reluctant to disclose to family members changing view after hearing positive experiences from other women who had done this. Many of the women disclosed their status to their partners and relatives in the process and the women planned to form a more consistent support group beyond this process to encourage each other, and to later open this group to other HIV positive women. This issue will be followed up as it took longer than the initial time frame set for the study.

Health workers

Counseling on disclosure was not in the past done at each encounter, after the first encounter. In the PRA process, the health workers identified counseling as an important short coming and pledged to improve on it. Implementing this change took time and there was some effort to provide more effective counseling from the health workers at service encounters, although not consistently so.

4.3 Progress review

Through the checklists it appeared that information was given to women at the clinics on risk reduction, on boosting of the immune system through eating and avoidance of smoking and alcohol. However, it seems that significant numbers (60%-40%) did not receive any information at some follow-up visits. Disclosure was not dealt with at each encounter (0%-30%) during midway and final review respectively, contrary to what was agreed upon when progress markers were developed.

Table 8 overleaf shows the progress made, reviewed against the progress markers developed collectively by the team.

There seemed to be a difference between knowledge, intention and practice. The health workers know the disclosure guidelines (knowledge was 70%-100% during midway and final review respectively), and intended to provide information at each encounter. However, only 0%-30% of women indicated that they had received information on disclosure at each encounter.

It appears that the women were comfortable talking about HIV/AIDS (60% by the final review). Notably, while the baseline reported that only 60% of the women disclosed their positive HIV status to their male partners initially, by the final stages of this process, nine mothers (90%) had disclosed.

Table 8: Progress markers for PRA team

MUST TO ACHIEVE MARKERS		Done: (End Oct) Midway	Done: (End Dec) End monitoring
1	80% of participating health workers know disclosure guidelines	Partially achieved	Fully achieved
2	80% of participating PMTCT mothers counseled by health workers at each encounter on disclosure	Not achieved	Partially achieved
3	80% of participating ANC mothers volunteering for VCT and disclose HIV status	Fully achieved	Fully achieved
4	80% of participating HIV positive women have knowledge on disclosure	Partially Achieved	Fully achieved
	50% of participating HIV positive women open to talk about HIV/AIDS	Fully Achieved	Fully achieved
6	40% of participating PMTCT mothers disclosing their HIV positive status to male partner and or an adult relative	Fully Achieved	Fully achieved
WOULD LOVE TO ACHIEVE MARKERS			
1	All participating health workers know disclosure guidelines	Partially achieved	Fully achieved
2	All participating PMTCT mothers counseled by health workers at each encounter on disclosure	Not Achieved	Partially achieved
3	All participating ANC mothers volunteering for VCT	Fully Achieved	Fully achieved
4	All participating HIV positive women have knowledge on disclosure	Fully Achieved	Fully achieved
5	All participating HIV positive women open to talk about HIV/AIDS	Partially Achieved	Partially achieved
6	All participating PMTCT mothers disclosing their HIV positive status to male partner and or an adult relative	Fully Achieved	Fully achieved

Only one mother, who was separated from her boyfriend, did not tell her partner. Studies have shown that women disclose more to main partners than the casual partners. This may be risky to their casual partners, and for themselves increase risk of re-infection, in case their casual partner is HIV positive (Brou et al, 2007; Sowell et al, 2003).

The main reason reported for disclosure was for support (70%-80%). Although the mothers did not receive information on disclosure at each encounter, it appears that considerable number (50%-50%) were now able to tell others about the value of disclosure.

With the women in this intervention, according to the participants and PRA team, most of the progress markers had been achieved, except for the regularity of counseling by health workers and the openness in talking about AIDS. The mothers themselves seem to have made significant changes, although some of the institutional service and environmental factors have been slower to change.

4.4 Comparison of the baseline and follow up questionnaire

Together with the review checklists, post intervention questionnaires were provided to the mothers and health workers on the same issues as they had responded in the baseline at the beginning of the PRA work.

Table 9 shows the comparison of pre and post-test results of baseline questionnaire of The women living with HIV attending the PMTCT services. The results indicate that while overall awareness has not changed, there has been an increase in information flow between health workers and the women, and improved specific information on testing from health workers (See Table 9). Disclosure rates had increased, with a greater focus on support to and protection of the women from disclosure. Interestingly in those who had not originally disclosed Table 9 suggests that there were a greater share of

partners who already knew. Further there had been an increase in the share of women telling others, particularly mothers, primarily to obtain solidarity and support.

Table 9: Baseline and post intervention questionnaire for mothers attending PMTCT programme

Attitude Assessment	Responses	Pre-test	Post-test
Q2. Have you heard about HIV counseling and testing?	Yes No	100% (n=10) 0%	100% (n=10) 0%
Q3. If yes, where did you hear?	1. Friend 2. Media 3. Health workers 4. Other (Please specify)...	10% (n=1) 50% (n=5) 70% (n=7) 0%	10% (n=1) 40% (n=4) 80% (n=8) 0%
Q1. What information was given to you by health workers on the benefits of testing?	1. Protection of baby 2. Accessing treatment 3. Change of risky behaviour 4. Protect others 5. Other (Please specify... To know health status Infant feeding	70% (n=7) 40% (n=4) 20% (n=2) 30% (n=3) 20% (n=2) 10% (n=1)	80% (n=8) 50% (n=5) 70% (n=7) 50% (n=5) 60% (n=6) 40% (n=4)
Q4. Do you think it's important to tell your partner/Husband?	Yes No	100% (n=10) 0%	100% (n=10) 0%
Q5. Did you tell your partner/husband?	Yes No	60% (n=6) 40% (n=4)	90% (n=9) 10% (n=1)
Q6. If yes, Why?	1. For him to support me 2. For him to go for HIV test 3. For us to use condoms 4. Other (Please specify)...	10% (n=1) 50% (n=5) 40% (n=4) 0%	60% (n=6) 70% (n=7) 80% (n=8) 0%
Q7. How did he react?	1. Angry 2. Blaming 3. Understanding 4. Knew already and was not surprised 5. Other (Please specify)... First in denial, but supports me later Never calling since then Never visiting since then, just sent the baby's name	10% (n=1) 20% (n=2) 30% (n=3) 30% (n=3) 20% (n=2) 10% (n=1) 10% (n=1)	10% (n=1) 20% (n=2) 50% (n=2) 50% (n=5) 20% (n=2) 10% (n=1) 10% (n=1)
Q8. If no, why not?	1. He will be angry 2. He will chase me away 3. I don't know how it will affect my relationship with my partner/Husband. 4. Other (Please specify)... Nobody to tell, we are separated and I do not see any need	0% 0% 30% (n=3) 10% (n=1)	0% 0% 30% (n=3) 10% (n=1)
Q9. Have you tell any person other than your partner/husband?	Yes No	70% (n=7) 30% (n=3)	100% (n=10) 0%
Q10. If yes, who did you tell?	1. Mother 2. Elder sister 3. Trusted friend 4. Other (Please specify)... Elder brother	20% (n=2) 20% (n=2) 0% 30% (n=3)	40% (n=4) 20% (n=2) 10% (n=1) 40% (n=4)
Q11. Why did you tell that person?	1. To support me 2. To have somebody to talk to when sad 3. Other (Please specify)... For him to know	30% (n=3) 30% (n=3) 30% (n=3)	60% (n=6) 50% (n=5) 50% (n=5)

A similar post intervention questionnaire was implemented for the health workers. While noting the small numbers, there was a reported increase in confidence around talking about VCT and disclosure, but language continued to be a barrier, and shortage of time became a more pronounced barrier. While knowledge of the basic information did not change substantially, there was an improvement in knowledge of aspects of disclosure and patient support, such as encouraging disclosure or discussing feeding options.

Table 10: Baseline and post intervention questionnaire for health workers

Attitude Assessment	Responses	Results:Pre-test	Results:Post-test
Q1. Are you confident to talk to pregnant women about VCT?	Yes No	100% (n=4) 0%	100% (n=4) 0%
Q2. If yes, to which extent?	1. 20% 2. 40% 3. 60% 4. 80% 5. Other (Please specify)...	25% (n=1) 0% 25% (n=1) 50% (n=2) 0%	0% 0% 50% (n=2) 50% (n=2) 0%
Q3. Are you confident to talk to pregnant women about disclosure?	Yes No	100% (n=4) 0%	100% (n=4) 0%
Q4. If yes, to which extent?	1. 20% 2. 40% 3. 60% 4. 80% 5. Other (Please specify)...	25% (n=1) 25% (n=1) 0% 50% (n=2) 0%	0% 0% 50% (n=2) 50% (n=2) 0%
Q5. What are your barriers in effective communication regarding VCT?	1. Language 2. Shortage of time due to workload 3. Mobility of clients	50% (n=2) 25% (n=1) 25% (n=1)	50% (n=2) 50% (n=2) 0%
Q6. What are your barriers in effective communication regarding issues of disclosure	1. Lack of partner participation 2. Lack of real understanding of disclosure (community) 3. Lack of confidence in communicating issues of disclosure	50% (n=2) 25% (n=1) 25% (n=1)	50% (n=2) 50% (n=2) 0%
Q7. What do the guidelines for pre-test Counseling provide for?	1. HIV transmission 2. Routine Counseling and Testing 3. Baby care and immunizations 4. Impact of HIV and pregnancy 5. Other (Please specify)...	100% (n=4) 100% (n=4) 75% (n=3) 50% (n=2) 0%	100% (n=4) 100% (n=4) 100% (n=4) 75% (n=3) 0%
Q8. What do the guidelines for pre-test Counseling provide for in the event of positive results	1. Healthy for mother 2. Review meaning of test results 3. Give time and space to express emotions 4. Review risk reduction 5. Other (Please specify)...	100% (n=4) 100% (n=4) 100% (n=4) 100% (n=4) 100% (n=4)	100% (n=4) 100% (n=4) 100% (n=4) 100% (n=4) 100% (n=4)
Q9. What do the guidelines for post-test Counseling provide for in the event of negative results?	1. Discuss risks of couple discordancy 2. Give time and space to express emotions 3. Revisit the window period 4. Schedule the next visit 5. Other (Please specify)...	100% (n=4) 100% (n=4) 75% (n=3) 50% (n=2) 25% (n=1)	100% (n=4) 100% (n=4) 100% (n=4) 75% (n=3) 100% (n=4)
Q10. What do the guidelines for HIV disclosure provide	1. Prepare for negative reaction 2. Identify sources of support 3. Other (Specify)...	100% (n=4) 100% (n=4) 25% (n=1)	100% (n=4) 100% (n=4) 75% (n=3)
Q11. Why is it important that mother disclose her positive status	1. To accept her status 2. For reduction of stigma 3. Help her to negotiate safer sex 4. Help to access support 5. Other (Specify)...	100% (n=4) 100% (n=4) 100% (n=4) 100% (n=4) 25% (n=1)	100% (n=4) 100% (n=4) 100% (n=4) 100% (n=4) 50% (n=2)
	Prevention of re-infections Encourage disclosure	25% (n=1) 25% (n=1)	75% (n=3) 75% (n=4)
	Preparation of HAART assessment For family planning Feeding options For saving the baby	25% (n=1) 50% (n=2) 25% (n=1) 25% (n=1)	0% 100% (n=4) 100% (n=4) 100% (n=4)

A post test was not done with the mothers from the ANC services as the numbers were too few, however for the other two groups there appeared to have been a shift in perceptions and practice in the women and in information to be shared for the health workers.

5. Reflections, lessons learned and next steps

5.1 Lessons learned on primary health care oriented responses to AIDS

HIV testing and counseling is a major entry point for prevention and treatment, and disclosure is key to ensuring that this also reaches partners and to widening support for adherence and care. Even while these services may be available, and people may be aware of them, this study confirms that women may not use these services, may not disclose and may receive weak support after disclosure undermining prevention and treatment due to a range of psycho-social factors relating to fears of negative response, and of dying. Humans are social beings, and no one wants to be isolated and discriminated against. Everybody has a sense of belonging. Women fear an isolation that will result in hopelessness. Rejection and blame was a major factor blocking disclosure. Gender imbalances play a role as women fear being excluded by men, who control their economic security. At the same time, as the study indicates, men may already know their status but also not tell the women. These factors may be heightened when health workers, who know the information on testing and disclosure, are not able to communicate with women due to language and time barriers, as found in this study, or due to negative perceptions of the women attending their services.

The women testing negative were found in the baseline assessment in this study to have higher levels of disclosure of their results to their partners than those testing positive, the latter fearing negative reactions. Those women that had disclosed did so to close family members, and relatively soon after being told themselves. Disclosure was more likely for stable than casual partners. When the positive women did disclose, contrary to their fear of blame, they reported receiving support from their partners. Protection of others and accessing treatment were the main reasons given for persuading them to disclose their positive HIV status to their partners. Provision by health workers of information to support positive prevention, or the promotion of health and prevention in people with HIV can reinforce this motivation.

The intervention highlighted the importance of communication, particularly through approaches that recognise women's fears, perceptions and potentials for action. During the course of the communication intervention in this PRA process, even over a short period, disclosure rose from 60% to 90%. Although this was a small sample it signals the potential for communication and social support to enhance disclosure. This was also signaled by the value given by women living with HIV to support networks as an enabling environment for testing and disclosure. Acting on the social impediments to testing and disclosure can thus enhance uptake of services.

A PHC oriented response to VCT and disclosure thus demands that communication capacities be strengthened in health services. While health workers were able to strengthen their communication in this exercise, they were not able to achieve the desired shift in communication, largely due to language and time barriers. This reinforces the need for expert patient roles, with women from the community able to provide repeated information and support dialogue with support groups. Further, the PHC response starts in the community, from the primary school level upwards. HIV positive women have the power to design their own coping strategies, as demonstrated through their positive outlook, and there is potential for support groups to better design

such interventions, especially if they are viewed as part of the health system with links in the chain of treatment and care.

Previous literature reported violence from male partners after disclosure and high level of discrimination from the communities in general. However, it seems that these trends are in the process of changing. This study suggests, as backed by more recent literature cited, that there is greater understanding and support when mothers disclose their positive HIV status. PHC oriented responses can tap and build on this change in the community.

PHC responses to AIDS start and end in the community, involving households, networks of affected groups, educational, religious and social institutions and supported by primary care services. The study indicates some features of this PHC oriented features of testing and counseling services

- Providing high levels of knowledge of services for prevention, testing, health promotion in positive people, partner notification and treatment options to people in the community from an early age onwards
- Creating an enabling social environment encouraging support of PLWHA, openness and reinforcing information on the positive implications of testing and disclosure, including to partners and family members
- Ensuring that testing, counseling and information supporting disclosure, including on positive prevention, is provided at every ANC and PMTCT contact,
- Supporting health worker communication on testing and disclosure with inputs from support groups and expert patients at facilities, and
- Building a health sector response that addresses community as well as health service dimensions of intervention.

5.2 Lessons learned on participatory methods

This was an interesting project, particularly for the nursing students who met face-to-face with the HIV positive mothers. They admitted weak knowledge of the mothers' and community's ability to identify and respond to their own health problems. This perception of nursing students that community members do not know their own health problems has been reported in other work (Hofnie et al, 2006). After discussion with the women at the ANC, the students were asked whether they learned something out of the PRA exercise. There was an overwhelming positive response.

The students were particularly stunned by the mothers' knowledge and openness around the issues of HIV/AIDS.

"It was such an interesting, worthwhile experience to have mothers sharing their opinions freely on the topic that many fear to discuss (HIV/AIDS)... The community has actually more knowledge than us (Health workers). They say exactly, and know what to my surprise I thought they did not know... Surprisingly, all women had a positive outlook on the future... This kind of bravery is what we really want".

Participation in the PRA work and observing how the women were coping under difficult circumstances, helped students to reflect on issues of power and equity in particular and gender relations in general.

“Women are powerful, yes, they are. Unfortunately, we are living in a men dominated society, therefore they (women) tend to live in unpleasant relationships because of the economic conditions... they just need support and love from family members, health care workers, and anyone else...”

The nursing students proposed that future PRA projects run throughout the year for effective learning and include more students.

The mothers were open in sharing their views in the PRA process, which provided good learning experience for us all. The availability of ART appears to have been an incentive for this openness on HIV/AIDS issues. According to the women at PMTCT, people were more secretive during those years where there was no ART in Namibia. Also the fact that more people are infected made it easier to talk about HIV.

“...almost every house has someone with this problem (HIV),.. why should you hide?”

“There is no difference between positive and negative person... The life is still there and you need to look forward...”

The PRA process has value in building the empowerment and communication needed in PHC oriented systems, but it has its challenges. As facilitators of the process, we found the process quite challenging. We needed to keep in touch with the pregnant women with different estimated dates of delivery, their stipulated follow-up ANC visiting dates and needed to plan our PRA work around that around the movement of mothers to rural homes and the timing of the clinics. We encountered various changes in timing and followup. This process set demands that were not always easy to fit into a process that also needed time for peer review and mentoring.

5.3 Way forward

All our progress markers were fully met, except the one of counseling at each encounter. Therefore, UNAM PRA team will continuously work with the health workers on that issue. The facilitator verified that the health workers have very practical guidelines on disclosure, and only need to be encouraged to use it always. The issue of forming support groups among the PMTCT mothers is a good idea that may help them to overcome reluctance on talking about HIV/AIDS issues and may help them in dealing with their language and time constraints. Therefore PRA team will follow-up with them and encourage its establishment and role. .

References

1. Brou H, Djohan G, Becquet R, Leroy V, Ekouevi GA, Viho I, Desgrees-du-Lou A (2007). When do HIV-infected women disclose their HIV status to male partner and why? A study in a PMTCT programme. *PLoS Med.* 4(12):342. at <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=2100145> (accessed 13 January 2009)
2. Deribe K, Woldemichael K, Wondafrash M, Haile A, Amberbir A (2008). Disclosure experience and associated factors among HIV positive men and women clinical service users I southwest Ethiopia. *Biomed Central Public Health.*8:81. At <http://www.biomedcentral.com/1471-2458/8/81> (accessed 13 January 2009)
3. Health 24- (2000-2008). HIV/AIDS,HIV+, what now? Available online:http://www.health24.com/medical/Condition_centres/777-792-814-1767,22202.asp (accessed 13 January 2009)
4. Hofnie K (1997). 'The views of young people on knowing their HIV-status in Windhoek'. Unpublished mimeo, Windhoek.
5. Hofnie K, Bock L, Haihambo C, Neumbo J (2000). 'Feelings of HIV positive mothers towards their HIV positive children'. Unpublished mimeo, Windhoek.
6. Hofnie K (2003). 'How to Counsel Infant feeding Practices in Southern Africa in a time of HIV/AIDS: A collaborative study between South Africa, Swaziland, and Namibia'. Unpublished mimeo, Windhoek.
7. Hofnie K.(2006). *Creating nurse student awareness on community knowledge on health in "Ontevrede" informal settlement, Namibia.* EQUINET PRA Report, EQUINET, Harare <http://www.equinetafrica.org/bibl/equinetpub.ph>
8. Ministry of Health and Social Services (2008a). 'Guidelines for the Prevention of Mother-to- Child Transmission of HIV'. Government of the Republic of Namibia: Windhoek.
9. Ministry of Health and Social Services (2008b). 'Report on the 2008 National HIV Sentinel Survey'. Government of the Republic of Namibia: Windhoek.
10. Ministry of Health and Social Services Windhoek and Macro International (2007). 'National Demographic and Health Survey 2006-7. Government of Namibia Ministry of Health and Social Services Windhoek, Namibia and Macro International Inc. Windhoek Namibia Calverton.
11. Polit DF, Beck CT (2004) *Nursing research: principles and methods.* Seventh edition. Lippincott Williams and Wilkins: Philadelphia.
12. Sowell RL, Seals BF, Phillips KD, Julious C H (2003). Disclosure of HIV infection: how do women decide to tell? *Health Education Research.* 18(1):32-44. <http://her.oxfordjournals.org/cgi/content/full/18/1/32?ck=nck> (accessed 13 January 2009)
13. Streubert HJ and Carpenter DR (1995). *Qualitative research in nursing: advancing the humanistic imperative.* Lippincott: Philadelphia.

Equity in health implies addressing differences in health status that are unnecessary, avoidable and unfair. In southern Africa, these typically relate to disparities across racial groups, rural/urban status, socio-economic status, gender, age and geographical region. EQUINET is primarily concerned with equity motivated interventions that seek to allocate resources preferentially to those with the worst health status (vertical equity). EQUINET seeks to understand and influence the redistribution of social and economic resources for equity oriented interventions, EQUINET also seeks to understand and inform the power and ability people (and social groups) have to make choices over health inputs and their capacity to use these choices towards health.

EQUINET implements work in a number of areas identified as central to health equity in the region:

- Public health impacts of macroeconomic and trade policies
- Poverty, deprivation and health equity and household resources for health
- Health rights as a driving force for health equity
- Health financing and integration of deprivation into health resource allocation
- Public-private mix and subsidies in health systems
- Distribution and migration of health personnel
- Equity oriented health systems responses to HIV/AIDS and treatment access
- Governance and participation in health systems
- Monitoring health equity and supporting evidence led policy

EQUINET is governed by a steering committee involving institutions and individuals co-ordinating theme, country or process work in EQUINET:

R Loewenson, R Pointer, F Machingura TARSC, Zimbabwe; M Chopra MRC, South Africa; I Rusike, CWGH, Zimbabwe; L Gilson, Centre for Health Policy, South Africa; M Kachima, SATUCC; D McIntyre, Health Economics Unit, Cape Town, South Africa; G Mwaluko, M Masaiganah, Tanzania; Martha Kwataine, MHEN Malawi; A Ntuli, Health Systems Trust; S lipinge, University of Namibia; N Mbombo UWC, L London UCT Cape Town, South Africa; A Mabika SEATINI, Zimbabwe; I Makwiza, REACH Trust Malawi; S Mbuyita, Ifakara Tanzania

For further information on EQUINET please contact the secretariat:

Training and Research Support Centre (TARSC)

Box CY2720, Causeway, Harare, Zimbabwe

Tel + 263 4 705108/708835 Fax + 737220

Email: admin@equinetafrica.org

Website: www.equinetafrica.org

Series Editor: R Loewenson