

**Acceptability and accessibility of HIV testing and treatment services in Bembeyi, Bunia, North eastern DR Congo**



**A Participatory Reflection and Action  
(PRA) Project Report**



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With the Regional Network for Equity in Health in East and  
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Through institutions in the region, EQUINET has been involved since 2000 in a range of capacity building activities, from formal modular training in Masters courses, specific skills courses, student grants and mentoring. This report has been produced within the capacity building programme on participatory research and action (PRA) for people centred health systems following training by TARSC and IHI in EQUINET. It is part of a growing mentored network of institutions, including community based organisations, PRA work and experience in east and southern Africa, aimed at strengthening people centred health systems and people's empowerment in health.

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## Executive summary

In the DR Congo, where the national HIV prevalence is around 5%, testing and treatment services are more available in urban than rural areas, despite the latter being more affected by the epidemic. In Bunia and Aru, North eastern DRC, people living with HIV and AIDS (PLWHA) cannot access testing or treatment services unless they travel to Bunia town, some distance away. Discrimination from community members towards PLWHA is further identified as a reason for people not coming for HIV testing, and for discouraging other prevention activities. The Pan African Institute of Community Health (IPASC) used a participatory reflection and action (PRA) approach with the concerned rural communities to examine and act on negative perceptions within the community around HIV testing and treatment, to support improved demand for and uptake of these services, to make more effective use of available resources and services. The specific groups targeted were male and female PLWHA aged 20-49 years, male and female adolescents 15-19 years, community and church leaders and community health workers. All above groups were targeted because of their vulnerability and influence on attitudes towards HIV and AIDS.

The work was implemented within a Regional Network for Equity in Health in east and southern Africa (EQUINET) programme that aimed to build capacities in participatory action research 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 Tanzania, REACH Trust Malawi and the Global Network of People Living with HIV and AIDS (GNPP+).

This study used a mix of PRA and quantitative approaches. A quantitative survey with 80 respondents from the groups noted above was carried out before and after a PRA process that explored causes of stigma and barriers to testing and treatment services, and identified and implemented shared priorities for action on these causes. The implemented action plan was monitored monthly by a local committee, using progress markers of what the community groups felt they (i) must and (ii) would like to achieve. A post intervention questionnaire administered to the same individuals as the baseline survey assessed changes on the proposed outcomes, and an evaluation meeting was held with the PRA team and selected community groups to review the process, assess outcomes through PRA approaches and define next steps.

The baseline survey showed that knowledge of HIV testing and treatment services was low, and that fear, shame and ignorance were identified as the main barriers to using HIV testing services, particularly by community and religious leaders and women.

People were generally perceived not to be open about their HIV status, especially women, and were ambivalent about knowing their HIV status. People did *not* find HIV testing services accessible, especially women and adolescents, and did not know where to go for treatment. There was limited action on these issues and weak dialogue within social groups on HIV testing and ART treatment.

The PRA workshops in Bembeyi involved men, women, community leaders, religious leaders, adolescent boys and adolescent girls and community members. They also identified the barriers to testing as: fear, shame, services not being available and those available lacking resources. Community level barriers (largely stigma) interfaced with service level constraints to diminish testing and treatment coverage. Both users and providers faced barriers. These

related to resources (drugs, transport), while the lack of accessible services was a fundamental deterrent. Leaving treatment to late stages when people are ill made this worse, as people found it difficult to make the long journey at that stage. This raised the argument for early reporting for testing and treatment. Yet the social barriers found discourage this. There were communication and attitudinal barriers on both sides, from both health workers and patients, and a disabling environment in communities with stigma discouraging openness and support.

These identified barriers faced by health workers and community members were prioritised and actions developed to address shared priorities for awareness and sensitization led by communities. Despite recurrent insecurity in the area, the planned activities were implemented, with community leaders (including the church leaders), women representatives, school teachers and youth representatives from each site running sensitisation activities for about 850 people in total. Further, as a result of these discussions, the community decided to address the issue of inaccessibility of services by making a bridge over the river to facilitate transfers to hospital and by setting up a meeting to discuss services with the Bunia district health authorities.

In their own review of progress markers set, the communities assessed that four of the five things people agreed they *must* see happen were completely achieved, and the fifth was in process. On the two things people agreed they would *love* to see happen, the first one was achieved and the second one was achieved for 90 % of the teachers in the area. From a post intervention questionnaire, a quantitative assessment showed that positive changes had been achieved in knowledge about HIV and about testing and treatment services and in willingness to know ones HIV status and to have an HIV test. Significantly, differences across groups have been reduced, and women and adolescents showed marked positive changes. Accessibility, however, still remained a major challenge for that population with the nearest VCT centre about 7 km away and treatment at the referral hospital. There was however a change in the cited barrier to using these services, from fear and shame before the intervention to inaccessibility after. This is a strong indicator that the intervention has reduced stigma. While service factors were not been dealt with in the short time of the intervention, there were some signs in the perceived improvements in social dialogue on treatment and in the stronger presence of mechanisms to deal with the barriers to testing and treatment that the initiative would be sustained to negotiate for these service improvements.

A major lesson learned for Primary Health Care responses to AIDS is thus that communities are able to make significant changes in barriers to testing and treatment if organised to do so, particularly using participatory processes. Community based sensitisers are an important resource in the community and can produce a measurable change in attitudes that discourage early testing and treatment. Information is indeed power and an important entry point to addressing disabling conditions within the community and to building cohesion around addressing wider service problems. PHC interventions for AIDS that do not invest in these dimensions in an empowering way undermine the effective use of other resources and the necessary synergy between communities and health services needed to manage a chronic condition such as AIDS.

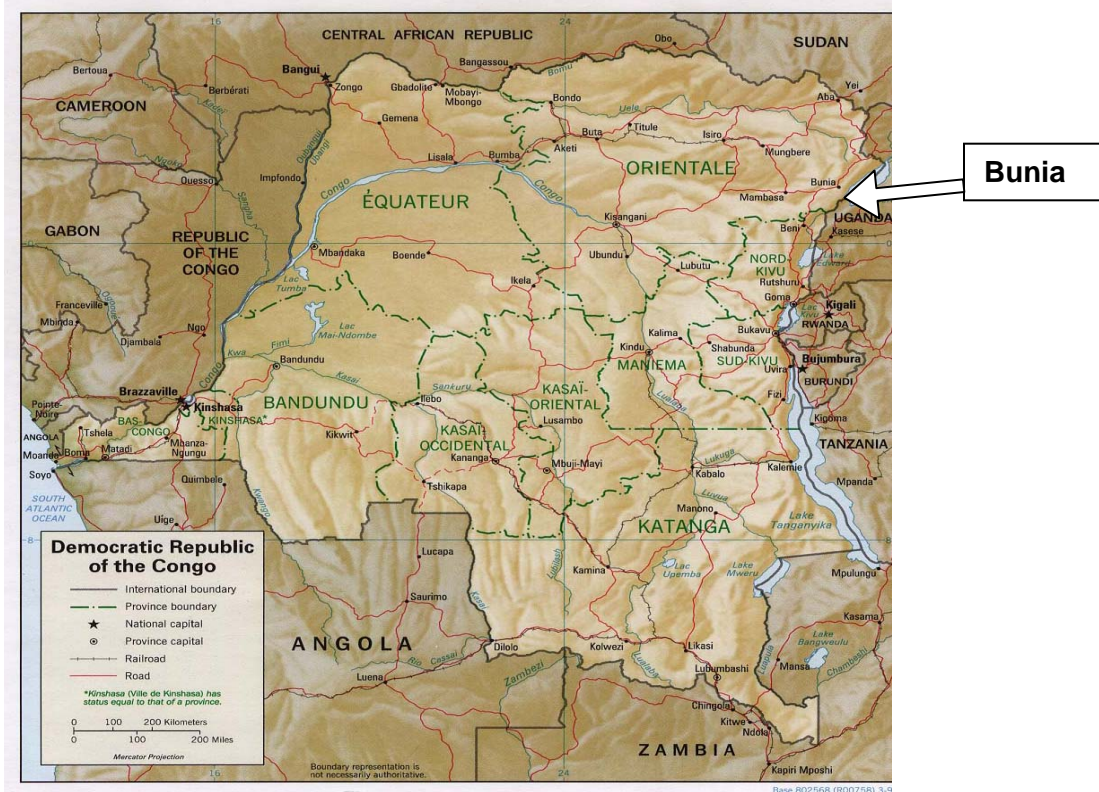
# 1. Introduction

Unlike the situation in many countries where the national HIV and AIDS programmes are more developed, in the DR Congo, where the national HIV prevalence is around 5 %, that programme is still not effectively established (Makwenge, 2008). Services are more available in some urban areas, and rural areas despite being more affected by the epidemic are still unaware of or poorly covered by services. USAID (2008) estimate that 8.6% of People Living with HIV/AIDS (PLWHA) receive ARVs in the whole of DR Congo, with more than 80% of these living in urban areas.

Sustaining coverage of antiretroviral treatment (ART) is a challenge. For instance, in Bas Congo Province in the western part of the country, only thirteen health districts out of 31 are supplied with ARVs (Nekwa, 2008). Still, in these thirteen health districts, the quantity of drugs provided is insufficient to cover those in need. Stock-outs of antiretrovirals (ARVs) are thus a threat to survival for those on treatment and 30 people on ARVs were reported to have died in Bas Congo Province in a recent stock-out (Nekwa, 2008). Access to ART is limited in many provinces of the DR Congo, systems for procurement and supply management of drugs are inadequate, particularly for highly affected rural communities (Office de la Coordination des Affaires Humanitaires, 2009).

Bunia, the focus area of this work is found in the north eastern DR Congo (See Figure 1). It has a population of 300 000 inhabitants (Jacobsson, 2008). Nearly 65% of the population practices agriculture, and the town also has local enterprise.

**Figure 1: Map of DR Congo, showing Bunia town**



Source: Courtesy of the University of Texas Libraries, The University of Texas at Austin.  
[http://www.lib.utexas.edu/maps/africa/congo\\_demrep\\_pol98.jpg](http://www.lib.utexas.edu/maps/africa/congo_demrep_pol98.jpg)

In Bunia and Aru, HIV prevalence rates are respectively estimated at 7.5% and 12% (Programme National de Lutte contre le SIDA, 2008). A separate assessment of blood donors in a Médecins sans Frontières hospital in Bunia found 19% to have tested positive (UNHCR, Programme National Multisectoriel de Lutte contre le SIDA, UNICEF et UNFPA, 2007). The town has a health zone with a general referral hospital and fifteen integrated health centres (Bureau Central de la Zone de Santé de Bunia, 2008). It also has about 18 private for profit clinics, mainly concentrated at the centre of the town. Bembeyi village, found in the eastern part of the town of Bunia, where this work was conducted, has a poorly built health centre with 2 nurses. When patients need to be transferred from the village to the general referral hospital, about 12 kms away, they face a problem with transport as vehicles can not reach the area because of two rivers that have to be crossed for which the bridges are not passable during the rains. Ambulances or transport are thus forced to deviate some distance to where the rivers are passable.

Pan African Institute of Community Health (IPASC) is a Faith based organisation operating locally in the North Eastern DR Congo. The organisation trains community health workers and organises programmes for health. IPASC began its HIV and AIDS programme in 2001, after finding out that one of its students was HIV positive. As there was no support available from government or community, IPASC provided this support so that she would be empowered and be able to support others. IPASC provides Voluntary Counseling and Testing (VCT) services, and uptake has grown from one person coming for VCT every three weeks to four people per day. After VCT, IPASC organises a 300km trip for those who test positive from the town of Aru in the north of Bunia to the neighbouring town of Arua, in Uganda, where a strong treatment programme is found at Arua Hospital. While IPASC provides VCT, it does not itself provide treatment and none of the services in rural DRC do so, hence the need to go to Uganda (Département de VIH/IPASC, 2007). In Bunia, two VCT centres have just been opened, but ART treatment is only available at Bunia Referral General Hospital (Bureau Central de la Zone de Santé de Bunia, 2008). In the absence of prevention and treatment for HIV and AIDS in DRC, especially in the rural context, IPASC is arguably a pioneer in this field.

Some organisations, including churches, have initiated HIV prevention activities, mainly focused on raising community's awareness. These activities are however not continuous, and take place during major HIV and AIDS events, such as 1<sup>st</sup> December. HIV prevention in rural areas of DR Congo has been affected by negative perceptions on AIDS by church leaders.

IPASC has received report of discrimination from community members towards People Living with HIV/AIDS (PLWHA) in Aru. People being taken in the green IPASC vehicle across the Ugandan border for ART are stigmatised. This community attitude is identified as a reason for people not coming for HIV testing, and for discouraging other prevention activities. This is not unique to the area and has stigma undermining prevention and treatment services has been reported in most of the provinces of DR Congo (Makwenge 2008, WHO, UNICEF, UNAIDS 2006).

Given the range of service barriers to prevention and treatment availability and access, we were concerned to explore and address these challenges of stigma associated with HIV testing and treatment services in our area of Bunia and Aru. IPASC thus used a participatory reflection and action (PRA) approach with the concerned rural communities to examine and act on negative perceptions within the community around HIV testing and treatment, to support improved demand for uptake of these services in a remote, poorly served area of DRC. We did this to make more effective use of available resources and services. The specific groups targeted in this work were female PLWHA aged 20-49 years and male

PLWHA aged 20-49 years, male and female adolescents 15-19 years, community leaders (including church leaders) and community health workers. All above groups were targeted because of their vulnerability and influence on attitudes towards HIV and AIDS.

Specifically we sought to

- ♦ identify the nature and reasons for negative perceptions around HIV testing and treatment within the six different community groups specified above and discuss how they can be addressed
- ♦ identify and review the existing services for HIV testing and treatment and within and beyond the study area, and the problems and barriers faced in providing and accessing these services for PLWHA and for service providers
- ♦ facilitate community leaders, PLWHA, health providers and NGOs to identify and take selected actions to address negative perceptions and barriers, to review their progress and identify the wider changes needed to support these community based responses

The work was implemented within a Regional Network for Equity in Health in east and southern Africa (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 Tanzania, 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 health services at primary care level. In each country site involved it has given focus to a specific community level priority on prevention, treatment and care for HIV and AIDS, as a means to synthesise learning across diverse settings and studies in east and southern Africa.

## 2. Methods

This study used a mix of participatory reflection and action (PRA) approaches and quantitative approaches. An intervention design used the spiral modal PRA approach with iterative phases of drawing on and review of experience, identification of problems and of actions to address them (Loewenson et al. 2006).

Following the regional training we set up a local PRA team and work plan, involving the local authorities, community and religious leaders. The team included A Baba who attended the 2008 TARSC-Ifakara PRA training in Bagamoyo, Meso Ulola, an IPASC college alumni living in Bembeyi, Mr. Nengala Azanda, an IPASC College alumni student (Bunia), Mr. Madhira Gregoire, IPASC HIV and AIDS social assistant (from Aru) and Mr. Drikpa David, IPASC librarian (from Aru). They were all identified as part of the team and selected for the work they are doing and their commitment to community level work.

**A PRA skills session** was organised to explain the research programme, to introduce co-facilitators to the methods and review the research proposal and design. We used the session to develop further the different PRA tools, including picture codes to be used in the action research, guided by the EQUINET PRA



Training session in PRA M Ulola, Bunia, August 2008

toolkit (Loewenson et al 2006). The training session was a new experience for the co-facilitators who had not been exposed before to such practical tools at community level. As one of the co-facilitators stated:

*“ These tools look so real and practical at the community level. I wish I knew it before”.*

The study was implemented in the rural community of Bembeyi in Bunia. The quantitative survey (see below) and PRA process involved six groups identified as important targets of prevention and treatment or having an important influence on community attitudes. These were female PLWHA 20-49 years (20 in total), male PLWHA 20-49 years (20 in total), community and religious leaders and community health workers (20 in total), male adolescents 15-19 years (10 in total) and female adolescents 15-19 years (10 in total). The local authority invited different groups in the community, including 216 people from Bembeyi, i.e. 27 women, 35 men, 45 community and religious leaders, 31 health workers, 36 adolescent girls and 42 adolescent boys. From the different groups, the sample for the baseline questionnaire was randomly selected from numbers given to each person present up to the numbers sought for each social group.

**A questionnaire survey** was given at the beginning and end of the PRA work and action programme to assess levels of

- perceptions of HIV testing and treatment within different community groups
- awareness of available services for HIV testing and treatment
- reported access to HIV testing and treatment
- reported barriers to access to HIV testing and treatment
- Reported communication between community leaders, PLWHA, health providers and NGOs on provision and uptake of HIV testing and treatment services

An interviewer administered questionnaire was implemented in end August /September 2008 at the different sites using the addresses of the participants, obtained during the selection. The survey used a likert rating scale (1=low, 5= high) for questions. A post intervention survey on the same parameters with the same people was done after the action programme to assess changes.

**PRA workshops** were held in Bembeyi in a classroom offered by the school headmaster, one of the community leaders. There were twelve community members chosen by the participants from each social group (Men, Women, community leaders, religious leaders, adolescent boys and adolescent girls) by themselves, ten other community members who volunteered to take part as they found the process interesting for their developmental work, two Bunia site co-facilitators and the facilitator, with the latter facilitating the session. The PRA session sought to draw experience, review and identify problems and actions on perceptions on testing and treatment, on available services and on the barriers to provision and uptake of HIV testing and treatment services. The aims of and tools for the steps in the process are summarised in Table 1.

**Table 1: Summary of steps and tools used in the PRA intervention**

Step	Tools
Identifying prevention, treatment and care responses to increased HIV within the Aru and Bunia communities	Market place (with prevention on one flip chart, treatment on another and care on a third) to understand the reasons for use and perceptions Picture codes to initiate the discussion
Identifying HIV testing and treatment services within and beyond the area. <ul style="list-style-type: none"> <li>◆ Health workers on barriers to provision</li> <li>◆ PLWHA and others on barriers to using services</li> </ul>	Community mapping of facilities and resources available for prevention, treatment and care with discussion to identify gaps. Services provided outside the area was also identified.



Problems and barriers in using services and measures to address them	Group discussions on problems and barriers
Identification of community roles, views and actions to address problems <ul style="list-style-type: none"> <li>◆ Priorities for action</li> <li>◆ Actions for these priorities</li> <li>◆ Progress markers for outcomes on these actions</li> </ul>	Ranking and scoring to set priorities Discussions and consensus on actions Setting of 5 progress markers each for “MUST see” outcomes, and “LOVE to see” outcomes within 5 months

In order to follow up the process, a **local committee** was established, including members from different involved groups. That committee was in charge of following the intervention through the process, monitoring the progress and co-ordinating implementation of actions in order to reach the expected change. Regular review meetings were organised in order to follow up the intervention.

The **implemented action plan** was monitored by the local committee on monthly basis in order to assess the progress. The committee set progress markers of what they (i) must achieve and (ii) would like to achieve for the action plan set and use regular meetings to review the progress against the progress markers.

A post intervention questionnaire administered to the same individuals as the baseline survey to assess changes on the proposed outcomes for the work. A final evaluation meeting was held with the PRA team, facilitators and selected community groups to review the process, assess outcomes through PRA approaches and define next steps.

We encountered some potential problems and areas of bias in the work. We worked in numerous languages: English for the design and reporting, French with co-facilitators, and Kiswahili, the language spoken in the area. This meant that we have translated backwards and forwards into the different languages and some losses in content or meaning may have arisen in the process. We tried to control these losses by having a second person checking translations to check meaning was preserved. We faced time constraints and competing commitments. The role of the community leaders in recommending participants to the process enhanced uptake by these groups and of messages around change in attitudes, but could have generated bias in participation. To overcome this we targeted different groups and asked groups in the process to propose persons to be represented in the local committee overseeing the process.

### 3. Findings

#### 3.1. Results of the baseline survey

The findings of the baseline survey indicate that only a third of the study participants (31%) had knowledge of how to ascertain their HIV status (Table 2). Knowledge was greater amongst men and religious leaders, and lower among women and adolescents. This is of concern as these latter groups are the more vulnerable, who possibly have greater need for this information. The majority of study participants (70%) were aware of hospitals and health centres as places offering testing for HIV, but only 21% knew about VCT centres (Table 2). Men and women were more aware of the hospital services than other groups, while they had least knowledge of VCT centres. Adolescents were generally poorly informed on all services. Fifty five percent of the study participants indicated that there is a treatment for HIV and AIDS, with this particularly mentioned by women (80%), adolescents (80%) and community and religious leaders (90%). Nearly all respondents said there were no available treatment facilities (99%). The level of knowledge over all was low, confirming the results of a study by

UNHCR et al. (2007) which found that HIV and AIDS knowledge is poor in most cities and towns in eastern DR Congo.

**Table 2. Knowledge of HIV status and access to treatment in the baseline survey**

	Women N=20 %	Men N=20 %	Community, & religious leaders N=20, %	Adolescent boys, girls N=20 %	Total N=80 %
<b>How can one know about his/her HIV status?</b>					
When they get slim	55	20	35	25	34
By testing the blood	15	40	40	30	31
Don't know	30	40	25	45	35
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>
<b>Where can one know about his/her HIV status?</b>					
Hospitals/Health centres	85	80	50	65	70
VCT Centre	0	15	45	25	21
Don't know	15	5	5	10	9
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>
<b>Is there a treatment for HIV/AIDS?</b>					
Yes	80	50	10	80	55
No	20	50	90	20	45
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>
<b>Are treatment facilities available?</b>					
Yes	5	0	0	0	1
No	95	100	100	100	99
<b>Total</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>

Respondents mentioned that the treatment services were not available in their respective area (Bembeyi, in Bunia), but were aware of treatment services are organised at Bunia Referral Hospital (Bunia site) located outside the study area. The barriers to use of services were thus to these referral level services. Fear and shame (54%) and ignorance (50%) were identified as the main barriers to using HIV testing services, particularly by community and religious leaders (85%) and women (60%) (Table 3).

**Table 3. Barriers faced in using HIV testing services and treatment, baseline survey**

Barriers faced	Women N=20 %	Men N=20 %	Community, & religious leaders N=20 %	Adole- scent boys, girls N=20 %	Total N=80 %
<b>Barriers to using testing services</b>					
Fear and shame	60	20	85	45	54
Stigma	0	0	5	0	1
Inaccessibility	0	0	0	5	1
Ignorance	40	80	55	25	50
Don't know	0	0	0	15	4
<b>Barriers to using treatment services</b>					
Ignorance	75	75	40	40	58
Fear and shame	65	30	65	60	55
Stigma	5	20	10	5	50
Services not available	0	0	20	20	50
Don't know	5	0	0	20	36

Men were more likely to raise ignorance (80%). Ignorance (58%) fear and stigma (55%) were seen to be the main barriers in using treatment facilities located outside the area. While ignorance, fear and shame were more commonly raised by women, and ignorance by men, community and religious leaders more often pointed to fear and shame. Given the role of these leaders as 'opinion makers', this high perception of stigma in this group is a matter for concern.

Most of the respondents (69%) disagreed that people are open about their HIV status in their community. All women disagreed. Few people (15%) felt that their community treat people living with HIV fairly (Table 4).

**Table 4. Perceptions of openness about HIV status and testing**

	Wom en N=20 %	Men N=20 %	Community & religious leaders N=20 %	Adolescent boys and girls N=20 %	Total N=80 %
<b>People in our community are open about their HIV status</b>					
<b>Strongly agree/ agree</b>	0	0	5	0	<b>1</b>
<b>Don't know</b>	0	25	15	0	<b>12</b>
<b>Disagree</b>	100	75	60	65	<b>69</b>
<b>Strongly disagree</b>	0	0	20	35	<b>18</b>
<b>People in my social group are open about their HIV status</b>					
<b>Strongly agree/ agree</b>	0	10	10	0	<b>5</b>
<b>Don't know</b>	0	20	15	0	<b>9</b>
<b>Disagree</b>	100	55	60	60	<b>69</b>
<b>Strongly disagree</b>	0	15	15	40	<b>17</b>
<b>People in our community treat people living with HIV fairly</b>					
<b>Agree</b>	35	10	10	5	15
<b>Don't know</b>	45	40	15	30	33
<b>Disagree</b>	20	40	50	50	40
<b>Strongly disagree</b>	0	10	25	15	12

Not surprisingly therefore there was ambivalence on whether people want to know their HIV status: Only about a third (38%) of participants felt that people in their community were keen to know their HIV status, and the rest did not think so or did not know (Table 5). Of interest a higher number (57%) said that people in their community were keen to have an HIV test, particularly women (70%) and adolescents (55%), possibly indicating their desire to increase availability of services in their area. Most people (45%) felt that people in their community and their social group do not know where to go for HIV test. This lack of knowledge was most commonly reported by adolescents. Further, over half of the participants (54%) stated that people in their community do *not* find HIV testing services easy to access. This was particularly the case for women (85%) and adolescents (80%) (Table 5). It would thus appear that while there is some interest in testing services, people do not know where to access these services and if they do, do not find them accessible.

Most people felt that people in their community do not know where to go for treatment for AIDS, particularly amongst women and adolescents. They also largely felt that people in their community do not find AIDS treatment services easy to access, again with this view more commonly held by adolescents (85%) and women (75%) (Table 5).

**Table 5 Knowledge and perceptions of HIV testing and treatment services**

	Women N=20 %	Men N=20 %	Community & religious leaders N=20 %	Adolescent boys and girls N=20 %	Total N=80 %
<b>People are keen to know their HIV status</b>					
Agree/ strongly agree	30	40	55	30	39
Don't know	35	30	15	40	30
Disagree/ Strongly disagree	35	30	30	30	32
<b>People are keen to have an HIV test</b>					
Strongly agree/ agree	75	55	55	60	62
Don't know	15	35	5	15	17
Disagree/ Strongly disagree	10	10	40	25	21
<b>People in our community know where to go for an HIV test</b>					
Strongly agree/ agree	35	40	24	20	29
Don't know	30	15	16	15	19
Disagree	35	40	35	65	45
Strongly disagree	0	5	25	0	7
<b>People in my social group know where to go for an HIV test</b>					
Agree/ strongly agree	35	30	20	30	28
Don't know	20	25	15	10	17
Disagree/ Strongly disagree	45	45	65	60	55
<b>People in our community find HIV testing services easy to access</b>					
Agree	0	5	10	5	5
Don't know	0	20	30	15	16
Disagree	15	70	50	80	54
Strongly disagree	85	5	10	0	25
<b>People in our community know where to go for treatment for AIDS</b>					
Agree	20	20	20	15	19
Don't know	10	35	5	5	14
Disagree	70	20	50	70	52
Strongly disagree	0	25	25	10	15
<b>People in our community find AIDS treatment services easy to access</b>					
Agree	5	20	10	5	10
Don't know	20	35	10	5	18
Disagree	75	20	50	85	57
Strongly disagree	0	25	30	5	15
<b>PLWHA are given support for their needs in our community</b>					
Agree	5	0	5	5	4
Don't know	35	65	30	20	37
Disagree	55	30	40	45	43
Strongly disagree	5	5	25	30	16
<b>PLWHA in our community understand how to take ART</b>					
Agree	0	0	15	5	4
Don't know	35	30	20	5	23
Disagree	65	60	50	40	54
Strongly disagree	0	10	15	50	19
<b>Health workers communicate well with people on HIV testing and treatment</b>					
Agree	10	5	10	10	9
Don't know	20	30	20	15	21
Disagree	55	55	60	60	58
Strongly disagree	15	10	10	15	12

NB: categories with zero responses not shown (eg strongly agree; categories with small numbers merged with related category)

PLWHA were felt to not know how to take ART, although to a lesser extent. Most respondents felt health workers in their community do not communicate well with people on HIV testing and treatment and that PLWHA are not given support for their needs in their community (Table 5).

Nearly three quarters of respondents did not think that the barriers stopping PLWHA from accessing treatment were being dealt with by health workers and the majority (72%) did not think that there were committees or mechanisms where communities and health workers could discuss testing and treatment services. This signals a relatively high level of dissatisfaction with testing and treatment services, reinforced by the fact that community leaders were generally not felt to be taking action to improve access to HIV testing and AIDS treatment, a view particularly held by women (90%) and adolescents (65%). People also noted that social groups in the area do not meet regularly to discuss HIV testing and ART treatment issues (69%).

**Table 6: Barriers to PLWHA accessing treatment – baseline survey**

	Women N=20 %	Men N=20 %	Community & religious leaders N=20 %	Adolescent boys and girls N=20 %	Total N=80 %
<b>Barriers stopping PLWHA from accessing treatment are being dealt with by health workers</b>					
Agree	5	0	5	0	2
Don't know	15	20	20	15	17
Disagree	75	55	70	85	72
Strongly disagree	5	25	5	0	9
<b>We have committees or mechanisms where communities and health workers discuss testing and treatment services</b>					
Agree	0	0	10	5	4
Don't know	10	5	15	5	9
Disagree	80	90	55	65	72
Strongly disagree	10	5	20	25	15
<b>Community leaders are taking action to improve access to HIV testing and AIDS treatment</b>					
Agree	0	0	5	5	2
Don't know	10	20	15	5	13
Disagree	90	55	45	65	64
Strongly disagree	0	25	35	25	21
<b>People in my social group meet regularly to discuss HIV testing and ART treatment issues</b>					
Agree	0	5	10	0	4
Don't know	10	15	5	15	7
Disagree	85	70	45	75	69
Strongly disagree	5	10	40	15	20

NB: categories with zero responses not shown (eg strongly agree)

It would thus appear that knowledge of and access to testing and treatment services was poorly rated, although there is willingness to be tested. Women and adolescents seem most disadvantaged in this. Treatment services were generally not available but people also noted barriers to use of services of fear and shame and ignorance, with fear and shame particularly noted by community and religious leaders and women. Given the role of leaders as 'opinion makers', a high perception of stigma in this group is a matter for concern. People are this generally not open about their HIV status.

This closed approach has meant that PLWHA lack support. Most respondents felt health workers in their community do not communicate well with people on HIV testing and treatment

and that PLWHA are not given support for their needs in their community. A relatively high level of dissatisfaction with testing and treatment services is felt to be poorly addressed by community leaders, social groups and health workers.

### 3.2 Findings from the PRA meetings

The PRA workshops in Bembeyi involved men, women, community leaders, religious leaders, adolescent boys and adolescent girls and community members. They explored the

- prevention, treatment and care responses to HIV within Aru and Bunia communities
- Available HIV testing and treatment services and the barriers to using or providing them
- Priorities to act on to improve access to prevention, treatment and care and the actions for these priorities

The meetings explored the nature of and reasons for negative perceptions around HIV testing and treatment. Picture codes were used to elicit views on and experiences of the perceptions people have of HIV testing and treatment.

**Figure 2: A picture code used in the PRA meetings**



Source A Baba, Bunia, September 2008

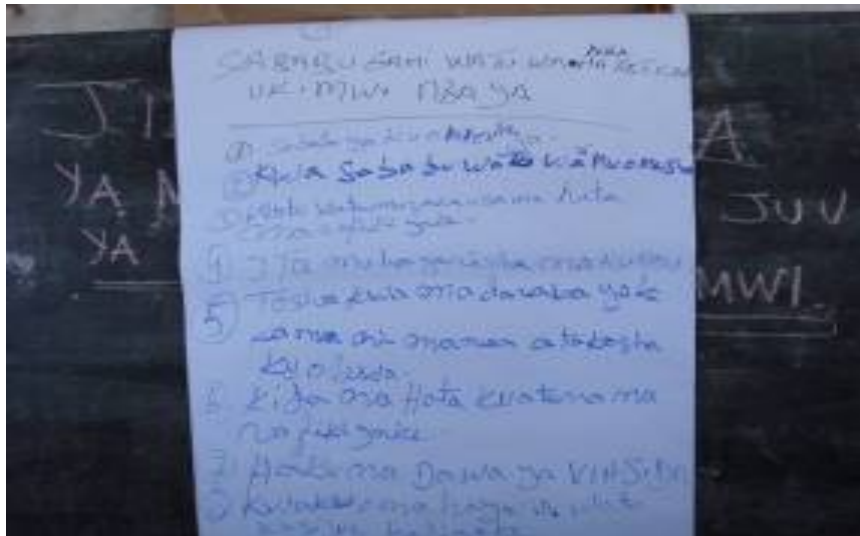
- On the right (1), the picture shows a man coming from VCT centre, and other people are making comments about him
- On the left (2), the picture shows someone leaving the VCT centre and heading towards the treatment centre, with other people observing.

In buzz groups of four people discussed what they saw in the **picture codes**. Their perceptions were large negative, of despondency in those seeking treatment, poor support and stigma from communities and shamefulness associated with HIV infection.

Young boy: *"I see someone who looks so discouraged, from health centre".*  
 Community leader: *"People are pointing at him, thats what makes him sad".*  
 Adolescent boy: *"I see someone going to the hospital".*  
 Community member: *"He really feels shameful being found HIV positive..."*

Concerning what others were feeling about them, participants mentioned:  
*" Other people regret that this man is tested positive, just because maybe he is a relative or an old friend..."*  
*"He feels so hopeless, not knowing what to do"*  
*"He managed to find the courage to go to the hospital"*

**Figure 3: Buzz group feedback on the wall**



Source A Baba, Bunia, September 2008

The views were discussed in plenary, both in terms of what the people visiting the services were feeling, and then what others were feeling about them. There were mainly negative perceptions by either of the groups, with participant comments such as:

*"he really feels shameful being found HIV positive..."*  
*" Other people regret that this man is tested positive, just because maybe he is a relative or an old friend..."*

Through the **market place tool**, participants identified the barriers to testing as: fear, shame, services not available and those available lacking resources. In relation to treatment, the barriers were: shame; not knowing one's HIV status; services not available and difficulties with using services when one is seriously sick. It would thus appear that community level barriers (largely stigma) interface with service level constraints to diminish testing and treatment coverage. The two are linked and the necessity of early testing was recognised by some.

In order to identify HIV testing and treatment services within and outside the area, **Community mapping** was done, within different social groups. In the plenary, all groups recorded that there was no testing facility in the area, nor was there a treatment centre for AIDS. They identified two main centres outside their area: Bunia Cité Referral Health Centre where they organise VCT (7km), and Bunia Referral Main Hospital (12 km) where both VCT and treatment is organised.

Figure 4: Community map done by women



Source A Baba, Bembeyi, Bunia, September 2008

Figure 5: Identifying barriers to services



Source A Baba, Bembeyi, September 2008  
Providers in green, patients in brown

They also reviewed the barriers faced by people in *using* these specific named testing and treatment services, and these were consistent with those raised in the discussions on the picture codes, viz:

- On the community side, fear, shame; ignorance about HIV/AIDS
- In relation to services, services not being available, with a long journey to reach them, and difficulties with making this journey when one is seriously ill

The adolescents group also mentioned the lack of money to go to these services

Health workers discussed the barriers they faced in *providing* the services, including:

- Lack of respect for confidentiality by some health workers
- Lack of work materials and treatment resources
- Misunderstanding between health workers and service users
- No respect of some recommendations given to the services users.

It thus appears that both users and providers face barriers. In part these are related to resources (drugs, transport) and the lack of accessible services is a fundamental deterrent. Leaving treatment to late stages when people are ill makes this worse, as people find it difficult to make the long journey at that stage. So this presents an argument for early reporting for testing and treatment. Yet the social barriers found discourage this. There are communication and attitudinal barriers on both sides, from both health workers and patients, and a disabling environment in communities with stigma discouraging openness by PLWHA or support from communities.

These identified barriers faced by health workers and community members were written on the floor and prioritised through a **ranking and scoring tool**, with each participant given four beans to place a bean next to each issue or barrier they found important and feasible to act on. Thereafter, in a plenary, one of the participants was invited to count the beans put next to each issue in order to find out the issues that participants feel capable of dealing with.



**Figures 6a,b,c,d: Using ranking and scoring to prioritise issues for action**



Source: A Baba, Bembeyi September 2008

The issues ranked highest that people felt could be acted on were

1. Finding out very late that one is HIV positive
2. Fear and shame
3. Ignorance about HIV and AIDS.

*“ Yele njo wa magumu yetu kubwa inye ina elekea ukimwi kwa muji yetu ya Bembeyi”*  
 meaning *“ These are the real problems regarding HIV/AIDS in our area”*

Community leader comments.

These shared priorities were further discussed to identify the actions to be taken, and on these actions two things that people say they must see happen within five months and two things that people say they would love to see happen within five months. These were primarily linked to actions around awareness and sensitization, with community led capacities for sensitizing people seen as necessary to build both awareness and shifts in attitudes.

A three month plan was developed to initiate these activities, shown in Table 7 below.

**Table 7: Action plan made by the study population**

<b>Actions to be taken</b>	<b>October</b>	<b>November</b>	<b>December</b>
Providing trainers to build capacities on HIV and AIDS			
Training of leaders for HIV and AIDS sensitisation activities			
Collecting sensitisation materials			
Sensitisation at <ul style="list-style-type: none"> <li>- the health centre</li> <li>- by the local chiefs in meeting the population</li> <li>- through youth gatherings</li> <li>- at different schools in the area</li> <li>- using audio-visual supports</li> </ul>			

### 3.3 Actions implemented

Due to some threats of insecurity in the area, the planned activities did not start as planned and were delayed to three weeks later in late October. IPASC provided trainers for the rural communities, and trained leaders. Activities were again disrupted in November by instability in the area, and were resumed thereafter.

Different social groups involved in the study wanted specific training for sensitisation. The trainers explored with participants appropriate sensitisation tools and concluded that everyone can implement that sensitisation, not only health workers.

*“Before, we were thinking that sensitisation can only be done by health workers, but we think that we can also sensitise, if we are taught so”* (A youth representative in Bembeji)

The training covered 15 community leaders (including the church leaders), 15 women representatives, 15 school teachers and 20 youth representatives from each site. Different representatives were selected from their own associations to attend the training. The training focused on HIV and AIDS, through the agreed sensitisation methods. These people from the community were responsible for the sensitisation activities in their social groups and communities.

**Figure 7: Training of community and church leaders**



Source: Madhira, Bunia, September 2008

Sensitisation materials were made locally in the area, incorporating the elements and messages that emerged from the PRA meetings and group discussions. The activities, initiated in December 2008 aimed to inform on AIDS, encourage early testing and treatment and discourage stigma.

*“We think that the sensitisation message can just focus on four elements:*

- *HIV/AIDS exists,*
- *How one can be contaminated?,*
- *How one can prevent HIV/AIDS?, How one can know his/her HIV status?*
- *And what one can do if it happens that he/she is tested positive?”* (church leader)

**Figure 8: Sensitisation activities**

**8a: at the health centre**



**8c: through youth gatherings and schools.**



**8b: by the local chiefs during a community meeting**

Source for all: M Ulola, Bunia, September 2008



The process was observed by the PRA team to have led to people feeling it was their responsibility to sensitise their peers. According to the reports provided by different trained groups, the 15 trained community leaders sensitised about 268 inhabitants, the trained women sensitised 189 people, and the teachers talked to about 100 students. Youth representatives communicated with about 287 adolescents. Altogether therefore about 850 people were reached in a month in the process.

As a result of these discussions, the community decided to address the issue of inaccessibility of services. They decided to make a bridge over the river, so that transfers to hospital would not cause a problem during the rains. The construction of the first bridge was finished in early April 2009, and work was underway for the second at time of writing.

Further, to address the availability of services they set up a meeting to discuss the issue with health authorities of Bunia health district. The community is now working with an international organisation to explore how the availability of services can be improved.

### 3.4 Assessment of change

Change was assessed in two ways:

- Firstly, the participants themselves monitored changes against progress markers they had agreed on in the planning and reviewed progress against these markers
- Secondly a follow up questionnaire survey was implemented using the same questions and to the same target group as in the baseline.

The **progress markers** set in planning the actions and the review of achievement of these by January 2009 are shown in Table 8.

**Table 8: Assessment using progress markers**

<b>Five things that people agree they must see happen within 5 months</b>	
<b>Progress marker</b>	<b>Change identified</b>
Local community delegates have been trained in HIV/AIDS by IPASC College students	65 community delegates have been trained in HIV/AIDS, and mainly in sensitisation methods
Sensitisation materials and tools have been prepared and disseminated	Sensitisation materials and tools have been prepared and disseminated to communities
Peer group awareness activities have been implemented	Peer groups have carried out awareness activities, with 28 sessions in total
Visual supports for sensitisation in strategic areas have been provided to the community	Visual materials with the message initiated by the population itself in a monthly meeting have been fixed in the market and main streets.
Awareness has been created on HIV/AIDS among community members	As confirmed in the post intervention survey (see next section), awareness of HIV transmission mechanisms and prevention increased
<b>Things that people agree they would love to see happen</b>	
Community based trainers are in place	65 community based trainers are in place
All school teachers are well informed about HIV/AIDS	18 out of 20 school teachers in the area are well informed about HIV/AIDS, from the training organised

Monthly meetings were organised with the PRA team to monitor the changes in the community against the progress markers. At the beginning, particularly in the first PRA team meeting, the tool used for review of Progress Markers seemed very challenging. The local committee found it strange, not knowing exactly how it could reflect performance. But, it was another opportunity for all of us to learn from what we were doing. By the last meeting

organised in January 2009, the PRA team and about ten more people interested in the whole process of the intervention had used the progress markers as a tool to review progress, and assessed change against the outcomes people agreed they must see happen and the things that they agreed they would love to see happen.

Four of the five things people agreed they *must* see happen were completely achieved, and the fifth was in process. On the two things people agreed they would *love* to see happen, the first one was achieved and the second one was achieved for 90 % of the teachers in the area. The review of the progress markers provided a concrete means to encourage and focus the team as they progressed, and to show gains for the efforts made. The changes indicate the potential for a shift in knowledge and attitudes in the community.

The **post intervention questionnaire** gave more quantitative information on whether that shift had taken place, comparing against the baseline survey. It was given to the same 80 participants to whom the baseline questionnaire was administered.

**Table 9. Pre and post intervention knowledge of and openness on HIV status**

	Women N=20 %		Men N=20 %		Community and religious leaders N=20 %		Adolescent boys and girls N=20 %		Total N=80 %	
	Pre	Post	Pre	post	Pre	post	Pre	Post	Pre	post
<b>How can one know about his/her HIV status?</b>										
When they get slim	55	18	20	10	35	8	5	4	34	10
By testing the blood	15	82	40	90	40	92	30	96	31	90
Don't know	30	0	40	0	25	0	45	0	35	0
<b>Where can one know about his/her HIV status?</b>										
Hospitals, clinics	85	26	80	22	50	25	65	19	70	23
VCT centre	0	71	15	75	45	73	25	81	21	75
Don't know	15	3	5	3	5	2	10	0	9	2
<b>People in our community are open about their HIV status</b>										
Strongly agree	43	4	41	2	40	2	40	1	41	2
Agree	40	8	39	12	38	4	42	9	40	8
Don't know	0	7	8	1	10	4	10	1	7	3
Disagree	7	80	10	83	8	90	4	85	7	85
Strongly disagree	10	1	2	2	4	0	4	4	5	2
<b>People in our community treat people living with HIV fairly</b>										
Strongly agree	0	0	0	0	0	0	0	0	0	0
Agree	34	18	12	18	10	25	5	16	15	19
Don't know	45	68	40	69	15	66	30	58	33	65
Disagree	21	6	40	3	50	6	50	25	40	10
Strongly disagree	0	8	8	10	25	6	15	1	12	6
<b>People are keen to know their HIV status</b>										
Strongly agree	2	7	1	10	2	5	0	9	1	8
Agree	42	78	41	72	35	73	34	80	38	76
Don't know	35	8	26	7	29	7	29	3	30	6
Disagree	18	7	31	8	30	11	31	6	28	8
Strongly disagree	3	0	1	3	4	4	6	2	4	2
<b>People are keen to have an HIV test</b>										
Strongly agree	8	7	6	6	4	5	2	2	5	5
Agree	56	68	57	65	53	64	56	71	56	67
Don't know	16	22	17	18	20	24	18	16	18	20
Disagree	18	3	18	11	17	7	19	11	18	8
Strongly disagree	2	0	2	0	6	0	5	0	4	0

The results shown in Table 9 suggest that knowledge about HIV and about where to find out about ones status has clearly improved, across all groups, and differences across groups have been reduced. Knowledge of where to access testing has shown similar changes.

It is interesting that the changes around openness and fair treatment were less clear. By the post intervention survey there was a stronger perception that people were not open around their HIV status, and while fewer people felt that PLWHA were treated unfairly, neither did they think they were treated fairly. It may be that the knowledge they gained in the process led them to look at these issues more critically. These changes, unlike the more simple transfer of knowledge, take longer to achieve.

Yet as the last two issues in Table 9 show there has been a shift in willingness to know ones HIV status and to have an HIV test, indicating that attitudes have shifted over the PRA intervention. It is significant that the greatest shift was in adolescents. This is important given the potential HIV risk in this group.

**Table 10 Knowledge about available testing and treatment services**

	Women N=20 %		Men N=20 %		Community and religious leaders N=20 %		Adolescent boys and girls N=20 %		Total N=80 %	
	Pre	Post	Pre	Post	pre	post	Pre	Post	Pre	post
<b>Is there a treatment for HIV/AIDS?</b>										
Yes	80	18	50	8	10	2	80	4	55	8
No	20	82	50	92	90	98	20	96	45	92
<b>Are treatment facilities available?</b>										
Yes	5	80	0	73	0	74	0	73	1	75
No	95	20	100	27	100	26	100	27	99	25
<b>People in our community know where to go for an HIV test</b>										
Strongly agree	2	2	3	1	2	1	5	7	3	3
Agree	23	54	23	53	28	60	36	65	28	58
Don't know	42	28	10	13	18	8	3	3	19	13
Disagree	25	10	58	20	45	31	47	11	44	18
Strongly disagree	8	6	6	13	7	0	9	14	8	8
<b>People in our community know where to go for treatment for AIDS</b>										
Strongly agree	0	4	0	5	0	4	0	4	0	4
Agree	20	47	20	48	20	45	15	40	19	45
Don't know	10	29	35	28	5	26	5	13	14	24
Disagree	70	14	20	18	50	20	70	28	52	20
Strongly disagree	0	6	25	1	25	5	10	15	15	7
<b>People living with HIV (PLWHIV) in our community understand how to take Antiretroviral therapy (ART) treatment for it</b>										
Strongly agree	0	0	0	0	0	0	0	0	0	0
Agree	0	4	0	2	15	2	5	0	5	2
Don't know	35	45	30	42	20	32	5	17	22	34
Disagree	65	48	60	50	50	45	40	65	54	52
Strongly disagree	0	3	10	6	15	21	50	18	19	12

The knowledge around treatment and testing also improved over the intervention, as awareness increased that AIDS has no treatment to cure but a therapy to manage the problem, and that testing and treatment is available in the area, although treatment is found outside their own community. Knowledge of where to access treatment had increased. More specific knowledge on how to take ART had not changed in the period, possibly as access to

treatment had not widened in the short time frame and this depends on more direct service contact around this.

Accessibility is still a major challenge for that population as the nearest VCT centre is found about 7 km (and the furthest at 12 km), which is a long distance for most of the community who have to go on foot. There are just now three VCT centres, in Bunia, and all of them are located at the centre. Not surprisingly therefore, there has been little change in the assessment of access to testing or treatment (Table 11). While knowledge of where to access services has increased, therefore, real access is not easy, as it is only Bunia Referral Hospital which provides some treatments for AIDS.

There has also been less change in the support given to PLWHA, with larger changes in attitudes of men and community and church leaders on this parameter. as it was confirmed by 56% of the participants compared to 42% in the baseline study. Please still largely feel that health workers in their community do not communicate well with people on HIV testing and treatment, although there has been a small positive change in this (Table 11).

**Table 11. Accessibility of and support for testing and treatment**

	Women N=20 %		Men N=20 %		Community and religious leaders N=20 %		Adolescent boys and girls N=20 %		Total N=80 %	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	post
<b>People in our community find HIV testing services easy to access</b>										
Strongly agree	0	0	0	0	0	0	0	0	0	0
Agree	8	6	6	6	3	7	4	1	5	4
Don't know	30	30	16	30	14	27	4	14	16	25
Disagree	45	55	48	53	49	53	74	80	54	60
Strongly disagree	17	9	30	11	34	13	18	5	25	9
<b>People in our community find AIDS treatment services easy to access</b>										
Strongly agree	0	0	0	0	0	0	0	0	0	0
Agree	5	15	20	14	10	5	5	14	10	12
Don't know	20	25	35	29	10	36	5	30	17	30
Disagree	75	35	20	40	50	48	85	56	58	45
Strongly disagree	0	25	25	17	30	11	5	0	15	13
<b>People living with HIV (PLWHIV) are given support for their needs in our community</b>										
Strongly agree	0	0	0	0	0	0	0	0	0	0
Agree	5	4	0	2	5	3	5	3	4	3
Don't know	35	40	65	36	30	28	20	12	38	29
Disagree	55	50	30	58	40	65	45	51	42	56
Strongly disagree	5	6	5	4	25	4	30	34	16	12
<b>Health workers in our community communicate well with people on HIV testing and treatment</b>										
Strongly agree	0	0	0	0	0	0	0	0	0	0
Agree	10	10	5	14	10	18	10	14	9	14
Don't know	20	38	30	29	20	20	15	13	21	25
Disagree	55	45	55	40	60	45	60	50	58	45
Strongly disagree	15	7	10	17	10	17	15	23	12	16

Comparing to the baseline results where the major barriers to using HIV testing services were identified as fear and shame, stated by the majority of adolescents (76%) and women (60%); and ignorance stated by the majority of men (80%) and community and church leaders (55%), post intervention results show a major change in this. The main barrier to using services has shifted to the inaccessibility of these services (83%), and this is the view of all groups (Table

12). This is a strong indicator that the intervention has reduced stigma. Addressing the non availability of treatment services in the area would thus seem to be an important step to sustain this positive change.

**Table 12 Barriers to testing and treatment**

	Women N=20 %		Men N=20 %		Community and religious leaders N=20 %		Adolescent boys and girls N=20 %		Total N=80 %	
	Pre	Post	Pre	post	pre	post	Pre	Post	Pre	post
<b>Barriers to using testing services</b>										
Fear and shame	60	18	20	8	40	6	76	9	49	10
Stigma	0	0	0	0	5	4	0	0	1	1
Inaccessibility	0	80	0	85	0	79	5	89	1	83
Ignorance	40	2	80	7	55	11	5	2	45	06
Don't know	0	0	0	0	0	0	14	0	4	0
<b>Barriers to using treatment services</b>										
Ignorance	42	5	45	2	38	1	40	0	41	2
Fear and shame	45	10	40	6	38	8	35	8	40	8
Stigma	5	2	8	6	10	4	5	1	7	3
Services unavailable	0	83	0	86	14	86	12	85	7	85
Don't know	5	0	7	0	0	1	8	6	5	2
<b>The barriers stopping PLWHIV from accessing treatment are being dealt with by health workers</b>										
Strongly agree	0	2	0	2	0	3	0	1	0	2
Agree	5	2	0	2	5	4	0	0	3	2
Don't know	15	35	20	25	20	20	15	20	17	25
Disagree	75	60	55	70	70	72	75	78	71	70
Strongly disagree	5	1	25	1	5	1	10	1	9	1
<b>We have committees or mechanisms where communities and health workers discuss testing and treatment services</b>										
Strongly agree	0	7	0	8	0	11	0	2	0	7
Agree	0	15	0	15	10	37	5	13	4	20
Don't know	10	47	5	32	15	27	5	17	9	31
Disagree	80	31	90	40	55	25	65	68	72	40
Strongly disagree	10	0	5	5	20	0	25	0	15	2
<b>Our community leaders are taking action to improve access to HIV testing and AIDS treatment</b>										
Strongly agree	0	4	0	3	0	4	0	1	0	3
Agree	0	20	0	10	5	8	5	2	2	10
Don't know	10	28	20	20	15	10	5	2	13	15
Disagree	90	41	55	60	45	78	65	44	64	56
Strongly disagree	0	7	25	7	35	0	25	51	21	16
<b>People in my social group meet regularly to discuss HIV testing and ART treatment issues</b>										
Strongly agree	0	13	0	4	0	8	0	15	0	10
Agree	0	25	5	20	10	10	0	45	4	25
Don't know	10	35	15	20	5	27	0	30	7	28
Disagree	85	25	70	40	45	50	75	10	69	31
Strongly disagree	5	2	10	16	40	5	25	0	20	6

These service factors have not been dealt with in the short time of the intervention. Hence not surprisingly there has been little improvement in the perception of health worker contribution to dealing with barriers to access to treatment. There has also been a relatively small change in the perceived support from community leaders to improve access to treatment, as access



itself had not changed. There were some perceived improvements in social dialogue on treatment and in the presence of mechanisms to deal with the barriers to testing and treatment. Least change in perceived presence of mechanisms for dialogue was found amongst adolescents, although both adolescents and women had changed perception before and after the intervention on the extent to which their own social group meet to discuss testing and treatment. This shows to some extent the effectiveness of the peer group training organised through the sensitisation methods used.

## **4. Lessons learned**

### **4.1 Lessons learned on PHC responses to AIDS**

This setting, like others in peripheral communities, is one in which social attitudes and lack of information combine to add social barriers to health service barriers caused by distant and inaccessible services. So while early reporting for testing and treatment is more necessary in these areas, the social barriers found discourage this.

The participatory intervention described in this report shows that community led action can have significant impact on these social barriers to essential health services. The changes observed in knowledge, information, willingness to test for HIV and to know ones HIV status, including across vulnerable groups like women and adolescents, and the closing of differentials in these indicators across groups in the community show that marked positive changes are possible through these processes, including in reducing stigma.

A major lesson learned for Primary Health Care responses to AIDS is thus that communities are able to make significant changes in barriers to testing and treatment if organised to do so, particularly using participatory processes. Community based sensitisers are an important resource in the community and can produce a measurable change in attitudes that discourage early testing and treatment.

*“We are all responsible to fight against HIV/AIDS in our area. One of the key elements is through raising people awareness about it. HIV/AIDS exists. It is not something from bad spirit, but it is a disease that we can easily avoid”* (Comment from a woman during the community based sensitisers training).

Distant services are still a challenge for that community. The problem of road infrastructure has been dealt with by making a bridge so that motorcycle and vehicles can reach that place to support transfers. But distance to services is now major deterrent to service access. The organisation of the community to take up the issue with the Bunia district health authority is one step towards addressing this. Certainly making VCT more widely accessible through all available services would assist to promote prevention and entry points for ART.

This study showed us that information is indeed power. It was an important entry point to addressing disabling conditions within the community and to building cohesion around addressing wider service problems. PHC interventions for AIDS that do not invest in these dimensions in an empowering way undermine the effective use of other resources and the necessary synergy between communities and health services needed to manage a chronic condition such as AIDS.

## 4.2 Reflections on lessons learned on participatory approaches

The action research demonstrated that participatory approaches are an effective means to facilitating these social changes. The community by itself is able to come up with its own problems and plan for them, provided there are good facilitation skills to support this. From the baseline study, to PRA sessions and post intervention survey, for the rural community of Bembeyi, according to the results from the post intervention survey, the PRA approach has made a big change within the population.

In approaching this work we asked *“how is it going to be, dealing with that community, introducing the tools?”* What we learned was to get started! The easiest way to get started with a rural community is with picture codes. In this case, it led people to be immediately involved.

For the PRA team as a whole, we learned how quickly a community can identify its priority problems using these approaches.

*“This meeting really came up with the reality that happens in our community”* (A community leader)

The degree of involvement of the community members then supported the programme. We learned that rural communities have something to say about their own development. They can act- but need to be empowered.

It was thus a learning experience for all of us. As one of the participants said, motivating all of us:

*“Had I known those methods before, I would have done a lot of things in the past”.* A woman giving her testimony

In everything one does with the community, there is always something to learn. While we learned about stigma in testing and treatment services, we also learned about patience during the community work, and about the developmental factors within society that need to be understood to produce change. Perhaps the greatest challenge has been to communicate these social dimensions of the work, in whatever language!

## 5. Next steps

The learning from the participatory approach and intervention that communities are able to identify their needs, problems and plan for actions on them and the skills we have built as facilitators are now a foundation for further reflection and action. The rural population of Bembeyi has just moved from one step to the next. We have begun to address the problem of information and stigma. We now need to consolidate the community based PRA committee in order to deal with other issues, including peer health promotion activities in the area, and to address the real barriers to service access in the area.

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**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.

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