

Prevention of vertical HIV transmission in Kamwenge and Kiboga districts, Uganda



A Participatory Reflection and Action (PRA) Project Report

Coalition for Health Promotion (HEPS), Uganda,
in the
Regional Network for Equity in Health in East and
Southern Africa (EQUINET)



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Forward

Since 2007, HEPS-Uganda in collaboration with the Regional Network for Equity in Health in east and southern Africa (EQUINET) through Training and Research Support Centre and Ifakara Health Institute has through participatory Reflection and Action (PRA) approaches worked to improve services at primary health care and community level. This work has aimed to generate improved demand for and utilization of maternal and PMCT in Kamwenge sub county in Kamwenge district. In 2008, this programme was extended to Mulagi sub-county Kiboga district.

Over all, the findings paint a bleak state of affairs in regard to Uganda's long fight against HIV and AIDS and particularly prevention of parent to child transmission of HIV (vertical transmission), which is the second most common mode of HIV transmission in Uganda accounting for 24% of infections. This state of affairs adds to the already lingering opinion across different stakeholders that Uganda may fail to achieve health related Millennium Development Goals (MDGs), particularly those relating to health.

On the basis of this, all stakeholders need to design interventions that can remedy the situation. The intervention described in this report shows that participatory methods provide a responsive approach to delivering community-level initiatives in rural settings of Uganda.



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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

About 1.2 million women become pregnant each year in Uganda, of whom 78 000 are living with HIV. About 25 000 children are infected by their mothers each year in Uganda, and about 21 percent of HIV transmission is currently is due to mother-to-child transmission. A government programme for prevention of parent -to-child transmission of HIV (PMTCT), launched in 2005, targeted women delivering in health facilities. However, given that only 38% of expectant mothers deliver in formal health facilities, many women could not access these PMTCT services. The programme still lacks a comprehensive plan to reach out to the community settings where most of the women deliver their children.

This project sought to identify the barriers to delivery, coverage and uptake of PMTCT services at primary health care and community level and to generate improved demand for and utilization of PMTCT within Kamwenge sub-county in Kamwenge district and Mulagi subcounty in Kiboga district in Uganda. It was implemented by HEPS Uganda as a follow-up of work in 2007 in Kamwenge sub-county, Kamwenge district using participatory reflection and action (PRA) approaches to improve demand for, access to and utilisation of maternal health services by expectant mothers (HEPS Uganda, (2007). HEPS-Uganda sought to consolidate its work through the follow-up project described in this report.

The work was implemented within a programme of the Regional Network for Equity in Health in east and southern Africa (EQUINET) 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+). TARSC and Ifakara in particular provided peer review support and mentorship to this work.

In both areas a baseline questionnaire was completed in 30 households in Kamwenge and 35 in Kiboga. In the post intervention survey 11 households from the original 65 were not found and were substituted by the nearest households to these not already in the survey. In both areas community meetings using PRA approaches were held in August 2008, The meetings aimed to explore the barriers to using services to prevent vertical transmission and to identify actions to improve uptake. In the first PRA meeting, participants drew a work plan in each district to address the priority barriers, and activities were implemented based on the community work plan. In Kamwenge, the activities undertaken included sensitization and training of thirty religious leaders, broadcasting messages on a local FM radio station, and production of sensitization materials. In Kiboga, the activities included sensitization of the community through dance and drama, broadcasting messages on a local radio station, and producing T-shirts carrying sensitization messages. The project was monitored and reviewed during the implementation of the activities and after four months of implementation, participants from the first PRA meeting were gathered in January 2009 in both districts to review the changes. Prior to this meeting, post intervention questionnaires were administered in both areas.

The intervention led to a number of community led sensitisation and social interventions that addressed prioritised problems. Communities and health workers through PTRAs approaches identified barriers to supply, access and uptake of

PMTCT services and what they could do to improve the situation. This itself improved shared understanding and knowledge between communities and health workers of each others barriers to service provision and uptake, and possible actions to act on them. In both districts, facilities were far apart, with inadequate health workers and drugs to support demand. There were many societal challenges that inhibit women's access to these services, with male dominance a key challenge for access to PMTCT services.

Health workers appear to face their own problems in delivering services at primary care level, and the work in the two districts points to a need for improved investment at these levels, including incentives for work in remote, hard-to-reach locations.

The findings suggest a need to emphasise couple counselling and testing; encourage local leaders to mobilise communities for antenatal care, PMTCT and other primary health care services and to address cultural barriers like male dominance.

The PRA process is useful for building capacity in communities to respond to community problems and build a sustainable people centred approaches to addressing them. The communities themselves appreciated the process as being empowering, inspiring, effective, and interesting.

The baseline indicates that even where services are provided, while health workers may be effective in referring those who attend services for testing, PMTCT and ANC, there is a gap in people actually getting to services which breaks this link. Weak links are also made with some other maternal health services. Women complained, for example, that during PMTCT counseling, they were not given information on family planning, teenage pregnancy or child health. This calls for a more consistent, holistic approach, to strengthen linkages, with greater level of outreach and involvement of communities in addressing the barriers to uptake. While distance and costs of transport are barriers, so too are social factors such as male roles, authorities and perceptions. Communities thus need to be involved in designing interventions that encourage male participation in demand and utilisation of testing and PMTCT services. This would appear to be a core element of any PHC oriented AIDS programme to prevent vertical transmission, as essential as other more biomedical elements.

Involving local leaders in community interventions appears to be key for the success of any PRA Intervention. If the community is facilitated through PRA approaches, there is evidence that people can influence change among themselves. For instance in Kamwenge the community group emerged as result of the intervention, with people willing to testify on their sero-status. These approaches can be cost effective as a means of facilitating change and community development, when they are community centred and community driven. However, this does not negate the need for real shifts of resources to improve services at community level.

1 Introduction

This report describes a programme of work to enhance *prevention of parent -to-child HIV transmission (PMTCT)* between August 2008 and January 2009 in the districts of Kamwenge and Kiboga in western and central Uganda respectively. It was implemented by HEPS Uganda as a follow-up of work in 2007 in Kamwenge sub-county, Kamwenge district using participatory reflection and action (PRA) approaches to improve demand for, access to and utilisation of maternal health services by expectant mothers (Muhinda et al., 2008). HEPS-Uganda sought to consolidate its work through the follow-up project described in this report.

The work was implemented within a programme of the Regional Network for Equity in Health in east and southern Africa (EQUINET) 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+). TARSC and Ifakara in particular provided peer review support and mentorship to this work.

According to estimates from the 2008 UNAIDS Report on the global AIDS epidemic, by 2008 around 30.8 million adults and 2 million children were living with HIV, with 65% of these in Sub Saharan Africa. Women and children are some of the most infected and affected groups (UNAIDS, 2008). In 2007, around 370,000 children aged fourteen or younger became infected with HIV. Over 90% of newly infected children are babies born to women with HIV, who acquire the virus during pregnancy, labour or delivery, or through their mother's breast milk. Almost nine-tenths of such transmissions occur in sub-Saharan Africa. Africa's lead in mother-to-child, or vertical transmission of HIV is firmer than ever. Ante-retroviral drugs are available to minimise the dangers of mother-to-child HIV transmission, but these are still often not reaching the places where they are most needed.

In Uganda, The Ministry of Health estimates that two million people have been infected with HIV and that about half of them have died since 1982, when the virus was first detected in the country. The ministry also estimates that in 2005 alone, about 135,000 people were infected, while 91,000 lost their lives to AIDS. Official statistics show that sex is the main channel of HIV transmission, accounting for more than three quarters of new infections, with infections within marriage contributing 42% (largely due to extramarital sex); commercial sex 21%; and casual sex 14% (MoH, 2005).

The ministry also estimates that about 1.2 million women become pregnant each year in Uganda, of whom 78 000 are living with HIV (MoH 2005). About 25 000 children are infected by their mothers each year in Uganda, and about 21 percent of HIV transmission is currently due to mother-to-child transmission (Uganda AIDS Commission 2007). A government programme for prevention of parent -to-child transmission of HIV (PMTCT), launched in 2005, targeted women delivering in health facilities. However, given that only 38% of expectant mothers deliver in formal health facilities, many women could not access these PMTCT services (MoH 2005). The programme still lacks a comprehensive plan to reach out to the community settings where most of the women deliver their children.

The Ministry of Health in Uganda has developed guidelines as part of a wider policy on feeding for infants and young children (MoH, 2009). The guidelines include breastfeeding recommendations for HIV-positive women. According to the guidelines, women should exclusively breastfeed for the first six months, regardless of their infants' HIV status, unless adequate breast milk replacements are available; health workers should determine the HIV status of pregnant and breastfeeding women and that such women should disclose their status to prevent mother-to-child HIV transmission.

According to the Uganda 2006 Demographic and Health Survey Report, 73 percent of women and 63 percent of men know that HIV can be transmitted from a mother to her child through breastfeeding (UBOS 2007). A lower proportion of women (65 percent) and about the same proportion of men (64 percent) know that there are drugs that a doctor or nurse can give to a pregnant woman infected with HIV to reduce the risk of transmitting the virus to the baby during pregnancy and delivery. About half of women (52%) and 43% of men aged 15-49 years know that HIV can be transmitted through breastfeeding and that the risk of transmission can be reduced by special drugs. This report acknowledges the fact that there is conflicting information flow on infant feeding among HIV positive mothers in communities.

Figure 1: Map of Uganda showing the location of Kamwenge and Kiboga Districts



Source :UBOS 2007

1.1 The study areas: Kamwenge and Kiboga districts

Kamwenge is a remote, rural district located in western Uganda, about 530km west of the capital Kampala. It borders with Kabarole and Kyenjojo districts to the north; Ibanda and Kiruhura districts to the east; Bushenyi district to the south; and Kasese district to the west. The district covers a total area of 2 458sq.km, and has an estimated total population of 308,715 people (UBOS, 2005). It is divided into two counties, Kibaale and Kitagwenda; eight sub-counties and one town council (with three wards); and 48 parishes.

According to the Ministry of Health's national health delivery structure, each district should have a hospital, each administrative county (health sub-district) a level-four health centre (HC IV), each sub-county a level-three health centre (HC III), and each parish a level-two health centre (HC II). The structure specifies that each household should have a hospital or health centre within 5km.

Kamwenge, however, has a shortfall on health facilities. The district has a total of 27 health facilities, nineteen government and eight non government owned. It does not have a hospital but two-referral level facilities (HC IVs). It does not have a private-for-profit health facility of at least referral-level standard. The district does not have a hospital to handle emergency obstetric cases, has only two referral facilities (health centre IV) which also lack functional theatres; has seven health centre IIIs, providing basic primary health care like treatment of common illnesses like cough, anti-natal care, deliveries, post natal, immunisation and health education; and 10 health centre IIs that only handle simple illnesses like cough, headache, malaria and makes referrals. The district also has two non government organisation (NGO) health facilities that provide basic primary health care services.

The delivery rate in health units in the district is one of the lowest in the country at 19% (UBOS 2007). This is below national levels of delivery at health units at 41% (UBOS 2007). Fifteen of the twenty seven available health facilities provide PMTCT services and rates of vertical transmission are the second highest nationally at 24% (Kamwenge District Administration, 2005).

HEPS-Uganda responded to this situation with a community intervention that sought to build awareness on PMTCT services and encourage utilization. Experience from the interventions from the districts indicate that many expectant mothers do not seek PMTCT services from the public health facilities for a range of reasons, choosing to deliver from their homes and private clinics, despite the presence of PMTCT services at selected public health facilities in the district.

Kiboga district is located in the central region of Uganda, about 120km from Kampala. The district comprises of 13 subcounties, one town council and eighty three parishes. HEPS-Uganda implemented this programme in Mulagi subcounty, with collaboration in the Kiboga town council. Mulagi sub-county had a total population of 10 949 in the 2002 National Population Census (Kiboga District Local Government 2006,) . According to the district authorities, this has since risen to about 12 000 people, most of whom are young people.

Kiboga is one of the districts whose population is generally poor, with high levels of illiteracy and general ill health, including a high HIV prevalence at 16.5% compared to the national figure of 7.1%. The majority of the households survive on peasant agriculture with very little other economic activities taking place. According to the three-year District Development Plan 2006/7-2008/9, Mulagi subcounty is ranked

sixth lowest in respect to life expectancy, which is estimated at 46.7 years at birth compared to the national average of 59 years. Household surveys show that 60% of the population is in the lower quartile of income. Malnutrition is prevalent among children, the majority of who are stunted (Kiboga District Local Government 2006).

The district has high school drop out rates among girls due to teenage pregnancy, leading to early and forced marriages. Knowledge of HIV status is poor because few people have tested for HIV, in spite of the large number of orphans in the district (Kiboga District Local Government 2006). The district has a total of 41 health units: 34 of them government-aided, and seven NGO-owned. They include one hospital, two health centre IVs, 13 health centre IIIs, offering ANC and PMTCT services, and 25 health centre IIs. Health centre II is first level of interface between the formal health sector and the communities; it provides only ambulatory services. Health centre III offers continuous basic prevention, promotion and curative services and support supervision of the HC IIs and the community. It should have laboratory, maternity care and first referral services. However, these are missing in most centres at this level in Kiboga district.

1.2 The objectives of the work

This project sought to identify the barriers to delivery, coverage and uptake of PMTCT services at primary health care and community level and to generate improved demand for and utilization of PMTCT within Kamwenge sub-county in Kamwenge district and Mulagi subcounty in Kiboga district in Uganda.

It thus aimed, in the two study areas, to:

- Facilitate male and female parents, primary health care workers and community leaders to identify the perceived and real barriers to the provision, coverage and utilization of PMTCT services
- Examine links between PMTCT and other sexual and reproductive health, family and child health and AIDS services at primary health care level and the extent to which these linkages adequately provide for entry points to PMTCT and follow up of PMTCT
- Identify priority barriers that can be acted on at community and primary care level and strengthen the communication and joint work between health workers, communities and families in acting on selected barriers to improve coverage and utilization of PMTCT services, assess these interventions for their progress in improving coverage and uptake of PMTCT, and identify barriers outside the community and primary health care system control that constrain progress.
- Build the capacity within the two subcounties to use PRA approaches to identify and act on issues health service uptake and coverage at the primary health care level.

2 Methods

The project targeted health workers and community members, community leaders, and expectant mothers and their spouses in two subcounties – Kamwenge in Kamwenge district in western Uganda, and Mulagi in Kiboga district in central Uganda. In Kamwenge, the participants geographical scope was Kamwenge Sub County which is comprised of eight (8) parishes including: Kyabandara, Nyamashegwa, Kabambiro, Busingye, Kakinga, Kiziba, Ganyenda and Nkongoro where previous project had been implemented. In Kiboga the participants were

drawn from Mulagi sub-county which is comprised of seven parishes including: Kiganda A, Kiganda B, Vumba, Kiwaguzi, Luwawu, Kalagi and Kidada.

HEPS-Uganda assigned two members to each of the two project areas. Members of the project team had earlier in February 2009 attended an EQUINET training workshop on participatory methods for a people centred health system, and the trainees implemented the project with technical mentoring and support from TARSC throughout the process.

In May 2009, the project team/facilitators identified and worked with key contact persons in the communities to mobilise the community for the participatory meetings for project in the two project areas. In Kamwenge, the project built on the structures and capacities built during the earlier HEPS/EQUINET PRA intervention on maternal and child health. Through the district administration, community members from the prior PRA intervention mobilised others. In Kiboga, as the work was new, a meeting was held with community leaders and participants for the community meetings were identified.

In both areas a baseline questionnaire was completed in 30 households in Kamwenge and 33 in Kiboga, starting from a random starting point in both and systematically interviewing the households in that sentinel site. The same questionnaires were administered to the same households three months after the project intervention. The majority of the respondents in both areas were female. In the pre-test survey, as it was during the planting season, the survey in Kamwenge found many people not at home and the sampling continued until 30 households were included. This problem was not found in Kiboga. In the post intervention survey 11 households from the original 63 were not found and were substituted by the nearest households to these not already in the survey.

In both areas community meetings using PRA approaches were held in August 2008, involving 36 people in Kamwenge, and 35 in Kiboga. The meetings aimed to explore the barriers to using services to prevent vertical transmission and to identify actions to improve uptake. The PRA approaches used in the meeting included a transect walk, group discussions, market place, ranking and scoring, spider diagrams and wheel charts, among others.

In the first PRA meeting, participants drew a work plan in each district to address the priority barriers, and activities were implemented based on the community work plan. In Kamwenge, the activities undertaken included sensitization and training of thirty religious leaders, broadcasting messages on a local FM radio station, and production of sensitization materials. In Kiboga, the activities included sensitization of the community through dance and drama, broadcasting messages on a local radio station, and producing T-shirts carrying sensitization messages.

The project was monitored and reviewed during the implementation of the activities and after four months of implementation, participants from the first PRA meeting were gathered in January 2009 in both districts to review the changes. Prior to the meeting, the post intervention questionnaires were administered.

The project team encountered some problems: there was some difficulty in accessing households for the pre and post intervention survey noted earlier. In Kamwenge where the project built on prior PRA work there were less problems than in Kiboga, the new area, where there were misplaced expectations that HEPS would be bringing services or money to the community.

3 The findings

3.1 Mobilisation

In both Kamwenge the HEPS-Uganda contact person briefed the relevant authorities, Mr George Tumushabe in Kamwenge and Dr Vincent Muhanguzi, the district health officer. The HEPS-Uganda team met the Kamwenge district health team, to review the previous intervention and outline the new project and its rationale. The DHO welcomed the team and pledged support for the project. He requested that HEPS-Uganda implement the new project where the previous one was implemented. Given that the proposed duration seemed short for the impact intended the meeting resolved that the project reports be used to lobby donors to fund longer interventions, say of three years; and use radio to widen outreach to the entire community.

In Mulagi, Kiboga district, mobilisation activities were implemented by visiting members of the community, including a few families with expectant mothers, in Mulagi to orientate and build rapport with them. The team visited the district hospital and met with administrators, as well as the district health team to introduce the project and HEPS-Uganda. They also had brief meetings with the local and religious leaders. This familiarised the project team with the community and offered an opportunity to respond to preliminary questions about the project and what the community should expect and not expect from it. The question that kept coming up in the mobilisation meetings was whether an intervention of a few months would really create lasting change in the community especially since changing people's attitudes is a process. The chairman in charge of primary health care noted:

“We must understand from the start the creating change is a process which will take more time than what the project is intended to last...”

The HEPS team emphasised the importance of setting the foundation of community participation if lasting change was to be effected in the community. It gave the example of Kamwenge district where a similar exercise had been done. The team also informed the leaders that it was up to the community to identify solutions to problems that are workable within the community. The visit was a foundation for the first PRA meeting as most of the people that had been visited attended this meeting.

3.2 The baseline questionnaire

To determine the pre-intervention situation and develop community driven interventions for improving PMTCT services, a baseline questionnaire was used.. Table 1 below summarises the results from the questionnaires.

Community knowledge about PMTCT services was perceived to be high as was possession of child health cards. However uptake of services was rated less highly. Between a quarter and a third of women felt that women in the community do not voluntarily test for HIV when they are pregnant, do not voluntarily attend PMTCT services when pregnant, and do not find Antenatal care (ANC) services accessible, while a similar share report that health workers in the community do not communicate well with the pregnant women. Those that do access and use services were seen to have a relatively high rate of referral for HIV tests, and those referred for HIV tests to access PMTCT. A major barrier to using services was, however, seen to be male partner support, with over 90% noting that husbands do not support or accompany their wives in attending HIV testing or PMTCT. While some action was seen to be taking place to address barriers to access in

communities and health services, respondents also reported weak mechanisms for discussing maternity and PMTCT services.

The same baseline survey was implemented in Kiboga. Table 2 provides the findings.

As in Kamwenge community knowledge about PMTCT services was perceived to be high as was possession of child health cards, but uptake of services was rated less highly. Between a quarter and a third of women felt that women in the community do not voluntarily test for HIV when they are pregnant, and do not find Antenatal care (ANC) services accessible, although a higher share reported that women do voluntarily attend PMTCT services when pregnant than in Kamwenge. Health workers in the community are not perceived to communicate well with the pregnant women, although those that access and use services were seen to have a relatively high rate of referral for HIV tests and PMTCT services. As in Kamwenge a major barrier to using services was seen to be male partner support, with husbands not supporting or accompanying their wives in attending HIV testing or PMTCT. In Kiboga there was a higher perception of action taking place to address barriers to access in communities and health services, but respondents still reported weak mechanisms for discussing maternity and PMTCT services.

Table 1: Baseline questionnaire results for Kamwenge sub county (N=30)

Statement	Percent total that				
	Strongly agree	Agree	Don't know	Dis-agree	Strongly disagree
People in our community know about services for prevention of mother to child transmission of HIV (PMTCT) (giving treatment to pregnant women) at primary health care level and where to find them	67	30	0	3	0
Women in our community voluntarily test for HIV when they are pregnant	7	73	0	20	0
Women in our community voluntarily attend PMTCT services when they are pregnant	13	63	0	23	0
Health workers in our community communicate well with the pregnant women	20	43	4	33	0
Health workers in our community always advice pregnant women to test for HIV and attend PMTCT services if they are infected	7	86	7	0	0
Pregnant women in our community can easily get access to Antenatal care services	0	67	0	33	0
Pregnant women in our community who use Antenatal care services are always referred for HIV tests	10	80	10	0	1
Pregnant women in our community who have a positive HIV test are always referred for PMTCT	13	70	7	10	0
Pregnant women in our community can easily get access to PMTCT services	13	60	10	17	0
Pregnant women in our community know about how to breastfeed if they are HIV positive	10	57	20	13	0
Pregnant women in our community get post natal care after delivery	0	53	20	27	0
Husbands in our community go with their expectant wives to test for HIV	0	3	0	53	43
Husbands in our community go with pregnant women when they go for PMTCT	0	7	0	50	43
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by communities	3	67	10	17	3

The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by local leaders	7	60	10	16	7
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by health workers	3	64	13	20	0
All mothers in our community have child health cards for their babies	17	83	0	0	0
Our community has committees or mechanisms for communities and health workers to discuss maternity and PMTCT services together	13	50	13	23	0
Community members, especially women and health workers meet regularly to discuss maternity and PMTCT services	13	44	30	13	0

Table 2: Baseline questionnaire results for Mulagi subcounty (N=33)

Statement	Percent total that				
	Strongly agree	Agree	Don't know	Dis-agree	Strongly disagree
People in our community know about services for prevention of mother to child transmission of HIV (PMTCT) (giving treatment to pregnant women) at primary health care level and where to find them	0	68	18	18	0
Women in our community voluntarily test for HIV when they are pregnant	0	39	15	42	3
Women in our community voluntarily attend PMTCT services when they are pregnant	0	67	12	21	0
Health workers in our community communicate well with the pregnant women	15	36	9	39	0
Health workers in our community always advice pregnant women to test for HIV and attend PMTCT services if they are infected	15	67	12	6	0
Pregnant women in our community can easily get access to antenatal care services	6	33	6	55	0
Pregnant women in our community who use Antenatal care services are always referred for HIV tests	3	66	24	7	0
Pregnant women in our community who have a positive HIV test are always referred for PMTCT	6	82	9	3	0
Pregnant women in our community can easily get access to PMTCT services	0	30	24	46	0
Pregnant women in our community know about how to breastfeed if they are HIV positive	3	33	30	34	0
Pregnant women in our community get post natal care after delivery	3	9	33	55	0
Husbands in our community go with their expectant wives to test for HIV	0	6	9	73	12
Husbands in our community go with pregnant women when they go for PMTCT	3	3	21	61	12
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by communities	0	12	18	64	6
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by local leaders	0	9	24	64	3

The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by health workers	0	24	18	58	0
All mothers in our community have child health cards for their babies	12	64	9	15	0
Our community has committees or mechanisms for communities and health workers to discuss maternity and PMTCT services together	0	42	12	42	3
Community members, especially women and health workers meet regularly to discuss maternity and PMTCT services	0	33	15	48	3

3.3 The PRA meetings

The work was introduced at the beginning of the first PRA meeting in **Kamwenge subcounty**, and participants in three groups of ten to twelve people discussed what their understanding of the links between PMTCT and sexual and reproductive health; PMTCT and family and child health; PMTCT and males and AIDS services at primary health care level using a spider diagram. Using the legs of the spider diagram, each group was asked to write the barriers to identified on supply, access and uptake of PMTCT services in the subcounty on the legs. This was done by the three different groups- mothers, health workers and men.

Table 3: Barriers identified to PMTCT in Kamwenge district

Groups	Prioritised barriers	Other barriers
Mothers	<ul style="list-style-type: none"> ▪ Husbands do not support/go with their spouses to attend PMTCT services/Male dominance ▪ Stigma ▪ Ignorance about the importance of testing 	<ul style="list-style-type: none"> ▪ Inaccessible hospitals / hospitals are far apart ▪ Poverty ▪ Husbands do not support/go with their spouses to attend PMTCT services ▪ Male dominance /fear of husbands ▪ Fear of the outcome from testing ▪ Ignorance about the importance of testing ▪ Inaccessible hospitals / hospitals are far apart ▪ Poverty
Health workers	<ul style="list-style-type: none"> ▪ HIV and AIDS-related stigma; ▪ Little awareness among male about the need to attend PMTCT services ▪ Lack of support from husbands/male partners to the expectant mothers 	<ul style="list-style-type: none"> ▪ Household poverty makes it difficult for parents to afford necessary logistics like transport and others to travel to hospitals; ▪ Understaffing and shortage of health workers; ▪ Long waiting periods for services; ▪ Poor motivation of health workers (pay is small, no housing and are overworked) ▪ Insufficient space at the hospital (often there is congestion which compromises privacy)
Males	<ul style="list-style-type: none"> ▪ Cultural beliefs and taboos; general feelings that it is time wasting to go with a woman for PMTCT services ▪ Stigma ▪ PMTCT sensitisation campaign often target women 	<ul style="list-style-type: none"> ▪ Polygamy (a man with two wives prefers not to go with any) ▪ Long distances to health facilities ▪ Bad attitude of health workers ▪ House hold poverty ▪ Hospitals lack supplies like test kits;

Participants were then given three beans each and distributed them on the spider legs against the three barriers they felt to be most important and, therefore, needing

greatest attention. Based on the total number of beans on each leg, the three top barriers for the groups were identified as:

- Inadequate male support to their spouses during pregnancy;
- Low awareness about the importance of attending PMTCT services; and
- Stigma

Male participants identifying barriers to scale up PMTCT services in Kamwenge



Source: HEPS 2008

Again, in mixed groups, participants proposed solutions to these three top barriers as below, ranked in order of priority as expressed by the group. Other issues raised that were not in the top three priorities are shown in the bullets.

Group I suggested the following solutions to inadequate male support:

1. Men should have time to communicate with their wives
2. Impose a by-law requiring men to support their wives during pregnancy
3. Door-to-door sensitisation of husbands
 - Support to expectant mothers with antenatal needs
 - Men to fulfil their parental obligations

Group II suggested the following solutions to AIDS-related stigma:

1. Use of expert clients
2. Sensitisation of health workers on stigma
3. Use church leaders, CBOs and other stakeholders to pass on the message
 - Use of post-test clubs and networks of people living with HIV and AIDS
 - Use of drama groups, video shows, radio programmes, TV, etc

Group III identified the following solutions to limited awareness on the importance of PMTCT services:

1. Sensitising communities
2. Encouraging males to attend health programmes

3. Use women to convince their spouses to accompany them for PMTCT services
 - Improving communication between health workers and parents
 - Use testimonies
 - Discuss benefits of attending PMTCT services
 - Sharing of experiences

Spider diagram from male participants indicating barriers to scale up PMTCT services



Source: HEPS 2008

Participants noted that there were partners already implementing some of the suggested solutions but with limited success. The challenges identified were limited manpower and space at health facilities, where priority is given to PMTCT services at the expense of voluntary counselling and testing (VCT) services for the general community. Services were reported not to be youth-friendly, in case of teenage pregnancies, and some programmes, such as Catholic Relief Services (CRS), were seen to give priority to expectant mothers against the rest of the people seeking VCT when testing kits are insufficient.

Five participants acted a role play that emphasised the current barriers to access to and utilisation of PMTCT services. The role play showed how much power men have to influence decisions in the home, especially on health issues. After the role play, a brainstorming session followed. During the discussion, one health worker testified that out of a hundred women who come for PMTCT services at her hospital, only about three come with their spouses. She added that even out of the three partners who turn up, only one or two will agree to be counselled and tested for HIV. She said

men think PMTCT services are for women. The men present at the meeting did not challenge the health worker's story.

During the walk of the previous day to administer pre-test questionnaires, one of the male respondents confessed in the presence of his wife that he could not go with his wife to attend PMTCT services. Asked why, the man laughed before wondering, "How will my fellow men see me; that is wasting time!"

In order to demonstrate the need to work together to successfully implement the agreed activities, participants were asked to assemble in the front open space of the workshop room and imagine that they were on one side of the river and needed to cross to the other. The "river" represented gap to be crossed to enhance access to and uptake of PMTCT services, to overcome the barriers identified. The stepping stones were the actions to address the barriers, with different coloured cards used to identify different actors taking these actions (health workers; community leaders; religious leaders; HEPS; and the district administration). The process highlighted the need for joint and complementary actions across groups:

- "We need each other to cross the river";
- "Each one has to play his/her role in time to cross the river"
- "Working together eases the workload";
- "There is always need for a leader to cross the river";

The facilitators used a wheel chart to guide the participants to measure the extent to which they thought they could work together to solve the identified barriers to PMTCT services and where they wished to be after the intervention. The wheel chart had three parts, each indicating one of the three prioritised problems: stigma, inadequate male support, and limited awareness of the importance of attending PMTC services (written in vernacular). The parts were marked 1-3 to indicate the degree to which the participants thought stakeholders were working together to solve the identified problems and where they wished to be after intervention.

The Wheel chart



After identifying the barriers and prioritising those they would work to address, the participants drew a work plan detailing the activities to be undertaken. The activities were:

- Produce sensitisation messages for broadcast on radio over a three-month period, targeting male involvement in demand and utilisation of PMTCT services;
- Sensitisation workshop for 20 religious leaders who were to pass on the message to their congregations (expert clients to lead the training); and
- Produce education materials (leaflets or T-shirts).

Source HEPS 2008

The PRA meeting in Mulagi, Kiboga district started with opening remarks from the district HEPS mobiliser, Mr. David Kabanda, who briefed the community about the work of HEPS and EQUINET and the participatory approach. He and the HEPS team outlined the outcomes and lessons from the first Kamwenge project and explored the community expectations, where people indicated that they expected to better understand PMTCT and how they could deal with the barriers to the utilising services.

Following the same process as reported for Kamwenge above, the health workers discussed the link between sexual and reproductive health and PMTCT; the mothers the link between family and child health and PMTCT; while fathers discussed the link between AIDS services at the primary health care level and PMTCT. The health workers had the clearest understanding, and used their feedback to the plenary to present information to the wider group on sexual and reproductive health and PMTCT. The women and men groups had much weaker understanding. The women saw a need for greater support if PMTCT services were to be used, in terms of awareness; positive living; and male support. The male group reported themselves to be “the peoples with power”, but they too had limited knowledge of AIDS and PMTCT services at primary health care level, and called for both parents to test for HIV; for men to accompany their wives for antenatal (ANC) care; for improved nutrition in pregnant women and improved community awareness.

Using ranking and scoring, participants identified the major barriers to use of services to be long distances to health centres, fear of HIV tests, high levels of poverty, few health workers, limited health care facilities for mothers, lack of equipment in existing health centres, and ignorance and not being aware. Women identified fear of disclosure of positive HIV status to husbands; husbands making their wives “work like donkeys”; not getting transport from husbands to go to health centres; husbands refusing advice from health workers; some health workers being rude to them; inability to afford charges at health centres; and negative attitude of husbands to HIV testing. Men identified male dominance over women, poverty, reluctance, health workers’ poor attitudes towards patients, negative cultures, lack of awareness and fear, long distances to health centres, and ignorance.

After ranking them, the most critical barriers were seen to be
By the health workers:

- limited health care facilities for mothers;
- lack of equipment in existing health centres; and
- low awareness.

By the mothers:

- lack of money to pay for health services;
- husbands refusing advice from health workers; and
- husbands’ negative attitude towards HIV testing.

By the men:

- long distances to health centres;
- lack of awareness and fear;
- health worker attitudes towards patients; and
- poverty.

For the health workers the barriers were mainly those within the services (facilities, equipment) and awareness, while communities raised social and economic issues (money, negative attitudes, distances to services). Each group thus referred to the challenges they encountered in their lives and work, and was less aware of the others issues and barriers.

In discussion of the different priorities, participants identified their three shared priority barriers as

- lack of awareness;
- health workers' poor attitudes, and
- lack of cooperation from husbands.

The participants in groups identified actions to deal with each problem identified:

- For lack of awareness and fear, the groups suggested sensitisation targeted at the village health teams, antenatal care providers and the community. The group also suggested that drama, role-plays and songs could be used as well as mass media, including local newspapers and radio, and religious gatherings, where there are groups like the fathers and mothers unions.
- For health workers' attitudes towards patients, participants proposed meetings involving health workers and the communities; to communicate the importance of listening to information from health workers and the need for improving personal hygiene before visiting health centres; and to communicate the need for health workers to better understand the community.
- For uncooperative husbands the participants proposed sensitisation for men on the importance of PMTCT services; empowering women by improving their economic standards; and promoting understanding in families.

Participants suggesting solutions to the prioritised problems



Source HEPS 2008

The river crossing was used in Kiboga as in Kamwenge with a similar effect in clarifying roles and the need for co-operation.

The wheel chart on the three prioritised problems of lack of awareness and fear; poor health worker attitudes towards patients; and uncooperative husbands set their perceptions of current levels of action and where they hoped to be after implementation actions that they proposed. What was striking was the emergence of uncooperative husbands as the community's biggest barrier to access to and utilisation of PMTCT services. This was followed by the poor health worker attitudes towards patients, and then limited awareness.

Wheel chart



Source: HEPS 2008

The community prepared a plan of action on the prioritized problems as follows:

- Sensitise 20 village health teams, parish development committees, antenatal care providers, church leaders;
- Present a short drama on radio once a month;
- Sensitise 10 health workers and 10 local leaders on health rights and responsibilities;
- Visit and sensitise households about the role of husbands in PMTCT;
- Disseminate flyers with sensitisation messages about the importance of PMTCT through religious leaders.

Table 4 below summarises the key issues, barriers, solutions proposed and activities in the two districts. Fear, stigma and negative male attitudes were raised as barriers in both areas, although in Kiboga, where the prior PRA work had not been implemented, negative health worker attitudes were also raised. Both areas proposed interventions to sensitise communities and health workers on services and barriers, and to encourage male support, while in Kamwenge, the role of expert clients was also raised. Each area proposed activities as shown in Table 4 to deal with these issues.

Table 4 Summary of key issues from Kamwenge and Kiboga districts

	Barriers	Solutions	Planned activities
Kiboga	Lack of awareness and fear Health workers' attitudes towards patients Uncooperative husbands	Sensitising communities and health workers Informing women on services Encouraging males to attend health programmes	Sensitise 20 village health teams, parish development committees, antenatal care providers, church leaders; Present a short drama on radio once a month; Sensitise 10 health workers and 10 local leaders on health rights and responsibilities; Visit and sensitise 20 households about the role of husbands in PMTCT; Disseminate flyers with sensitisation messages about the importance of PMTCT through religious leaders

Kamwenge	<p>Husbands do not support/go with their spouses to attend PMTCT services/Male dominance</p> <p>Stigma</p> <p>Lack of awareness about the importance of HIV testing</p>	<p>Sensitising communities</p> <p>Use of expert clients</p> <p>Encouraging males to attend health programmes</p>	<p>Produce sensitisation messages for broadcast on radio over a three-month period, targeting male involvement in demand and utilisation of PMTCT services;</p> <p>Sensitisation workshop for 20 religious leaders to pass on the message to their congregations (expert clients to lead the training);</p> <p>Produce education materials (leaflets or T-shirts).</p>
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4 Implementation of the interventions

During August – November 2008 the PRA team worked with the communities in Kamwenge and Mulagi (Kiboga) subcounties to implement their respective planned activities.

In Kamwenge, sensitization materials, particularly T Shirts, were produced with a simple message in a local language literally meaning, '*Is your wife pregnant? Go for HIV tests to save the unborn child*'. This message was generated by the community and edited by the Kamwenge district health department. The message was aimed at encouraging men to go with their expectant wives to test for HIV with a view of protecting their unborn child. T-shirts were produced and distributed to the PRA participants and religious leaders who were sensitized and encouraged to pass on the message to their followers. T-shirts were also given to members of the Kamwenge district health team.

Working with the Kamwenge district health department and HEPS person, 35 religious leaders were mobilized to attend a one-day sensitization workshop on PRA approaches to increase male support for wives in utilising PMTCT services. The meeting was held with participants were from the different churches (Anglican, Catholic, Pentecostal) and from the Islamic mosque, and included health workers. The workshop sensitized the religious leaders on their role in addressing the existing barriers to uptake of PMTCT services; and discussed strategies to prevent the vertical transmission of HIV. Members of the district health team in Kamwenge presented the maternal health situation in the district, while "expert clients" shared their experience in supporting each other as a couple in the context of HIV, and the importance of religious leaders promoting partner support. The couple explained that it was far easier to own the results and develop mutual trust when a couple tests together. The workshop launched the sensitisation campaign and provided materials and T-shirts to the participants.

The project team worked with the Kamwenge district health team to design and produce a spot message on PMTCT in the local language. The message, broadcast on local Kamwenge FM, encouraged men to go for PMTCT services with their wives in order to save the unborn children from HIV. In total, 90 messages were aired on the radio, at the rate of two per day, for a period of about three months from late October 2008. With support from EQUINET, HEPS sponsored 60 of the spots, while the district administration funded the other 30 as its contribution.

In Mulagi, Kiboga, the project team and local council personnel held meetings with local leaders, health workers, religious leaders and community members who participated in the first PRA meeting, to develop the strategies to implement the community work plan. The councillors had raised the community work plan in the district council meeting as part of the update of activities in the area they represent. The district leadership was reported to have praised the project work and recommended that similar participatory approaches be used in other sub-counties in the district.

Working with community leaders in Mulagi sub-county, the project team designed and produced posters inviting community members for a drama show that had been planned as part of the sensitization campaign. The drama illustrated the need for men to support their expectant wives in seeking and utilising PMTCT services. The posters had a simple message in the local language meaning, “Enjoy as you learn; why you should go for an HIV test with your expectant wife.” The posters were hung at churches, market places, and along roads and paths and other strategic places, to attract as many people as possible to the drama that was to be shown in an open area in the sub-county’s trading centre.

T-shirts with the message in local language, “*Is your wife pregnant? Go for an HIV test to save your unborn baby*” were used during the drama show and given out as prizes to people in the community who correctly answered questions relating to male support to their partners to go for PMTCT services. The T-shirts were also given to people who attended the PRA meeting and were actively participating in the implementation of the community work-plan.

Kiboga facilitators in their T Shirts planning the drama



Source HEPS 2008

Working with the community, the project team identified, trained and engaged a drama group from a church-affiliated school to act a play portraying the identified barriers to uptake of PMTCT services and how community members should overcome them. The play was titled, “Test for HIV: Save the unborn”. The drama illustrated the importance of men working together with their wives to test for HIV during pregnancy and to attend PMTCT services in case they test HIV-positive. The play also emphasised the need for health workers to give appropriate counselling PMTCT clients, respect their dignity and the confidentiality of their test results. The

drama, which included songs composed to emphasise the message, demonstrated the primary beneficiary of PMTCT programme to be the unborn child.

Kiboga PRA drama group performance



Source HEPS 2008



Participants watching the drama

Source HEPS 2008

Over 200 people watched the play. They included local councillors, health workers, people working on village health teams, members of parish development committees, church leaders, and ordinary men, women and children. The master of ceremonies engaged the audience throughout the show by asking questions on their experiences on

the play's messages and rewarding whoever had an exciting story with a T-shirt. The show was staged on a Sunday afternoon when most people were free. It was initially planned to last four hours, but it ended up taking more than six hours as the community debated the issues raised. Two community songs on utilizing PMTCT services have been composed. The project is supporting the drama group to record them so they can be played on the local radio.

The project team, the drama group, community leaders and the participants of the first PRA meeting developed and recorded spot messages promoting PMTCT services. These messages supplemented the sensitisation effort and urged every community member to play their role to promote and utilise PMTCT services. The project paid Kiboga FM, the only radio station in the area, to air 82 spots over a period of two months (November and December 2008). The radio station also promised to play the community songs the drama group sang.

5 Review of the process and outcomes

The post-intervention survey questionnaire administered to community members, as outlined in the methods section, provided a further assessment of the changes in perceptions and report of practices arising from the intervention. The participants that had completed the pre-test questionnaire also completed the post test questionnaire and the questions asked were the same. The project also organised a second PRA workshop in each area to evaluate the impact of the intervention involving participants from the first PRA workshop, through group and plenary discussions, market place, wheel chart and progress markers.

5.1 In Kamwenge

Table 5 summarises the results from post-test questionnaire responses.

The results of the post-test questionnaire show improvement in some areas:

- Awareness of services, which was rated as high in the beginning (98%), was still rated as high (96%), although with a greater share now strongly agreeing on this. Knowledge of breastfeeding was rated to have improved (from 10% strongly agreeing to 21%)
- Voluntary use of services had improved as the share strongly agreeing that services were used rose from 7% to 40% for HIV testing services; and from 13% to 23% for PMTCT services.
- On the performance of health workers in communicating with pregnant women, the post-test found that 40% strongly agreed that health workers communicated well, rising from 20%; while 79% strongly agreed that health workers advised expectant mothers compared to 7% in the baseline.
- Similar improvements were noted in the share reporting referral for HIV testing and PMTCT at antenatal care, although less marked improvements were reported in access to PMTCT and ANC services;
- Perceptions of whether the barriers to access were being dealt with had also changed: Improvements were noted in perceptions of action on barriers to women going for testing and PMTCT by communities, local leaders and health workers.
- However the perceived role of men had not changed significantly, with an increase from 0% to 8% strongly agreeing that men go with their wives for HIV testing or PMTCT.
- Nevertheless the mechanisms for addressing these issues were seen to have improved.

Table 5: Post intervention questionnaire results for Kamwenge sub county (N=30)

Statement	Percent total that				
	Strongly agree	Agree	Don't know	Dis-agree	Strongly disagree
People in our community know about services for prevention of mother to child transmission of HIV (PMTCT) (giving treatment to pregnant women) at primary health care level and where to find them	54	42	0	0	4
Women in our community voluntarily test for HIV when they are pregnant	40	40	8	12	0
Women in our community voluntarily attend PMTCT services when they are pregnant	23	62	0	12	3
Health workers in our community communicate well with the pregnant women	40	56	0	4	0
Health workers in our community always advice pregnant women to test for HIV and attend PMTCT services if they are infected	79	21	0	0	0
Pregnant women in our community can easily get access to Antenatal care services	21	54	0	25	0
Pregnant women in our community who use Antenatal care services are always referred for HIV tests	72	28	0	0	0
Pregnant women in our community who have a positive HIV test are always referred for PMTCT	80	16	0	4	0
Pregnant women in our community can easily get access to PMTCT services	29	46	8	13	4.
Pregnant women in our community know about how to breastfeed if they are HIV positive	21	46	4	25	4
Pregnant women in our community get post natal care after delivery	5	50	18	14	14
Husbands in our community go with their expectant wives to test for HIV	8	75	0	13	4
Husbands in our community go with pregnant women when they go for PMTCT	8	58	4	19	11
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by communities	56	12	12	12	8
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by local leaders	62	17	0	20.7	0
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by health workers	52	29	4	7	7
All mothers in our community have child health cards for their babies	56	26	0	15	4
Our community has committees or mechanisms for communities and health workers to discuss maternity and PMTCT services together	12	54	4	23	8
Community members, especially women and health workers meet regularly to discuss maternity and PMTCT services	30	52	4	12	2

The project organised a second PRA workshop in January 2009 to evaluate the impact of the intervention. The workshop was attended by participants from the first PRA workshop, religious leaders, a journalist, and five district health officials. The group and plenary discussions revealed that participants were well informed about the activities as planned and implemented. The religious leaders indicated that they

had passed the message to at least 900 members of their congregations during their weekly sermons, while as even larger number had been reached using messages on the T-shirts distributed and the radio broadcasts.

Repeating the wheel chart guided on the community work plan, the participants indicated that they had reached their desired levels on all three areas.

The claim that some people in Kamwenge could indeed freely talk about their HIV status was demonstrated when 37-year old Bernard, a married man with five children, shared his experience with the difficulties of accessing HIV and AIDS treatment and testing services in the rural community. Bernard related to a crowded community meeting how he had been ill for a long time before his brother advised him to go for an HIV test. Such tests were not available locally, and although feeling very sick, he travelled over 50km to the neighbouring Kabale district to access the HIV testing services. *“I was told by the nurse who carried out the test that I was positive and that she could confirm that I had HIV”.*

He said the news frightened him but that the nurse counselled him and helped him understand it. Back at home, he felt too ashamed to disclose the bad news to his family and asked them to support him. As advised by the nurse, Bernard persuaded his wife to go for the test. She was found negative! Not convinced, Bernard insisted on witnessing his wife’s test, but again she was found negative. This made Bernard doubt his own results and presented himself for the tested again. Unfortunately, his results were again positive. Bernard then turned his attention to his children. *“I took all my children for the test and they were found negative.”*



Mr Bernard giving a testimony at the follow up meeting. Source HEPS 2009

In Kabale, Bernard was prescribed two tablets of Septrine daily but unfortunately he cannot access this medication at his local health facility. He has to walk more than 10km to access the medication, and he may have to do it for the rest of his life. Despite this, Bernard’s is thankful that his family members have been supportive. *“My children and wife often remind me to take my medication in-case I forget”.* In his closing words, Bernard told the gathering, *“AIDS is a terrible disease and I would not wish anyone to have it. I was moved to give the testimony after HEPS sensitisation*

campaign and advertisements on the radio. I didn't get this disease elsewhere; it came from right here in my own community".

Table 6 shows the change in attendances at the PMTCT services, with some improvement in Kamwenge and Kabunga of attendance by couples.

Table 6: Table of couple attendance of PMTCT services at three selected health outlets in Kamwenge sub-county

Month (2009)	Rukunyu		Kamwenge		Kabunga		Padre Pio	
	Total clients	No Couples						
July	136	4	170	8	103	16	57	4
Aug	75	0	95	6	92	18	28	6
Sept	110	1	95	10	143	17	35	3
Oct	76	0	90	12	103	46	53	1
Nov	95	4	118	27	81	31	37	5
Dec	62	2	164	12	50	40	35	9

Source: Kamwenge District Health Reports 2008

5.2 In Mulagi, Kiboga

As in Kamwenge, a post intervention questionnaire was administered to determine perceived change in outcomes. Table 7 summaries the results.

Table 7: Post intervention questionnaire results for Mulagi subcounty (N= 33)

Statement	Percent total that				
	Strongly agree	Agree	Don't know	Dis-agree	Strongly disagree
People in our community know about services for prevention of mother to child transmission of HIV (PMTCT) (giving treatment to pregnant women) at primary health care level and where to find them	58	30	3	10	0
Women in our community voluntarily test for HIV when they are pregnant	33	27	12	27	0
Women in our community voluntarily attend PMTCT services when they are pregnant	27	55	12	6	0
Health workers in our community communicate well with the pregnant women	15	42	15	24	3
Health workers in our community always advice pregnant women to test for HIV and attend PMTCT services if they are infected	46	48	6	0	0
Pregnant women in our community can easily get access to Antenatal care services	3	58	3	36	0
Pregnant women in our community who use Antenatal care services are always referred for HIV tests	37	48	6	9	0
Pregnant women in our community who have a positive HIV test are always referred for PMTCT	58	30	3	9	0
Pregnant women in our community can easily get access to PMTCT services	21	45	0	33	0
Pregnant women in our community know about how to breastfeed if they are HIV positive	30	30	21	12	6
Pregnant women in our community get post natal care after delivery	12	30	24	33	0
Husbands in our community go with their expectant wives to test for HIV	15	24	3	52	6

Husbands in our community go with pregnant women when they go for PMTCT	18	24	18	33	6
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by communities	33	18	33	15	0
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by local leaders	30	27	18	24	0
The barriers stopping pregnant women in our community from testing for HIV or attending PMTCT are being dealt with by health workers	27	31	27	15	0
All mothers in our community have child health cards for their babies	15	61	15	9	0
Our community has committees or mechanisms for communities and health workers to discuss maternity and PMTCT services together	6	39	19	36	0
Community members, especially women and health workers meet regularly to discuss maternity and PMTCT services	21	37	15	27	0

The results of the post-test questionnaire show improvement in some areas:

- Awareness of PMTCT services, which was rated as high in the beginning (60% agreeing people know about PMTCT services), improved (with 58% strongly agreeing and 30% agreeing).
- Voluntary use of services improved with a greater share indicating strong agreement and agreement combined than in the baseline, while health worker communication with pregnant women was also seen to have improved. Referral to testing and PMTCT services, already seen to be high at the baseline (77% strongly agreeing and agreeing) rose to 93% combined at post test.
- Perceptions of whether the barriers to access were being dealt with had improved, with a shift from disagreement to about a third strongly agreeing barriers to PMTCT and HIV testing were being dealt with.
- Two areas remained somewhat resistant to change: men were still seen as being relatively unsupportive and mechanisms for discussion between communities and health services, while improved, were still seen to be unavailable.

Both districts thus showed positive changes, although greater perceived improvements in Kamwenge in communication between pregnant mothers and health workers and in perceived support from men, could relate to the effect of the prior PRA intervention carried out in the district, while the work was still at early stages in Kiboga. Further Kiboga is a more patriarchal society, unlike in Kamwenge, where women are more empowered.

A second PRA work shop was held in January 2009 in Kiboga to evaluate the intervention. The meeting attracted 40 participants of which 35 had participated in the first PRA meeting and five were new participants. PRA techniques were used to evaluate the project activities, including a wheel chart. Participants reviewed the activities implemented, and the gap in implementing some of the drama and sensitization activities. A community drama called “**learn as you are entertained**” was felt to have high impact. It targeted men to support their wives during pregnancy to save unborn children. This was felt to have highest impact in the community.

6 Reflections, lessons learned and next steps

6.1 PHC approaches to improving uptake of PMTCT services

Uganda faces a challenge for scaling up PMTCT, as the experiences of both districts are that facilities are far apart, with inadequate health workers and drugs to support demand. There are many societal challenges that inhibit women's access to these services, and for PMTCT it was established that male dominance is a key challenge.

The findings suggest a need to emphasise couple counselling and testing; encourage local leaders to mobilise communities for antenatal care, PMTCT and other primary health care services and to address cultural barriers like male dominance.

Health workers appear to face their own problems in delivering services at primary care level, and the work in the two districts points to a need for improved investment at these levels, including incentives for work in remote, hard-to-reach locations.

The baseline indicates that even where services are provided, while health workers may be effective in referring those who attend services for testing, PMTCT and ANC, there is a gap in people actually getting to services which breaks this link. Weak links are also made with some other maternal health services. Women complained, for example, that during PMTCT counseling, they were not given information on family planning, teenage pregnancy or child health. This calls for a more consistent, holistic approach, to strengthen linkages, with greater level of outreach and involvement of communities in addressing the barriers to uptake. While distance and costs of transport are barriers, so too are social factors such as male roles, authorities and perceptions. Communities thus need to be involved in designing interventions that encourage male participation in demand and utilisation of testing and PMTCT services. This would appear to be a core element of any PHC oriented AIDS programme to prevent vertical transmission, as essential as other more biomedical elements.

6.2 Lessons learned on using PRA approaches

The PRA process is useful for building capacity in communities to respond to community problems and build a sustainable people centred approaches to addressing them. The communities themselves appreciated the process as being empowering, inspiring, effective, and interesting.

“ PRA approaches are effective in mobilising communities to respond to their own problems and the impact is easy to assess as the community is involved ”
Chairman Local Council 5 Kamwenge district ”

Involving local leaders in community interventions appears to be key for the success of any PRA Intervention. If the community is facilitated through PRA approaches, there is evidence that people can influence change among themselves. For instance in Kamwenge the community group emerged as result of the intervention, with people willing to testify on their sero-status. These approaches can be cost effective as a means of facilitating change and community development, when they are community centred and community driven. However, this does not negate the need for real shifts of resources to improve services at community level.

6.3 Next steps

We will share our findings with others, particularly policy makers, to inform them about the ways of strengthening uptake of PMTCT services. We propose that we now need to consolidate the achievements made through planning long term programmes through which we can enrol more sub counties and districts. This means mobilising more resources to train PRA facilitators among communities and civil society organisations to provide adequate ground for expanding PRA interventions in the country. For this we need to build on the learning network within and beyond the country to share our work with other teams and stakeholders and to keep monitoring and learning to better improve our future PRA interventions.

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Acronyms

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
CBOs	Community Based Organisations
CRS	Catholic Relief Services
CSOs,	Civil Society Organisations
DHO	District Health Officer
HC III	Health Centre Three
HC IV	Health Centre Four
MOH	Ministry of Health
HSSP	Uganda's Second Health Sector Strategic Plan (HSSP II)
MCH	Maternal Care Health
NGO	Non Government Organisation
PMTCT	Prevention of Mother to Child Transmission of HIV
PRA	Participatory Reflection and Action
RH	Reproductive Health
TBAs	Traditional Birth Attendant
UBOS	Uganda Bureau of Statistics
UDHS	Uganda Demographic Health Survey
UMOLG	Uganda Ministry of local government
UNICEF	United Nations International Children's Education Fund
VCT	Voluntary Counselling and Testing

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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.

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

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