

“Strengthening community focused, primary health care orientated responses to prevention and treatment of HIV and AIDS”

TRAINING WORKSHOP ON PARTICIPATORY METHODS FOR A PEOPLE CENTRED HEALTH SYSTEM

MEETING REPORT



**Training and Research Support Centre (TARSC),
The Ifakara Health Research and Development Centre
(IHRDC)**



**in co-operation with
REACH Trust Malawi and Global Network of People
living with HIV/ AIDS (GNP+)**



In the

**The Regional Network on Equity in Health in east and
southern Africa (EQUINET)**



**Bagamoyo Tanzania
February 27- March 1 2008**

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1. Background

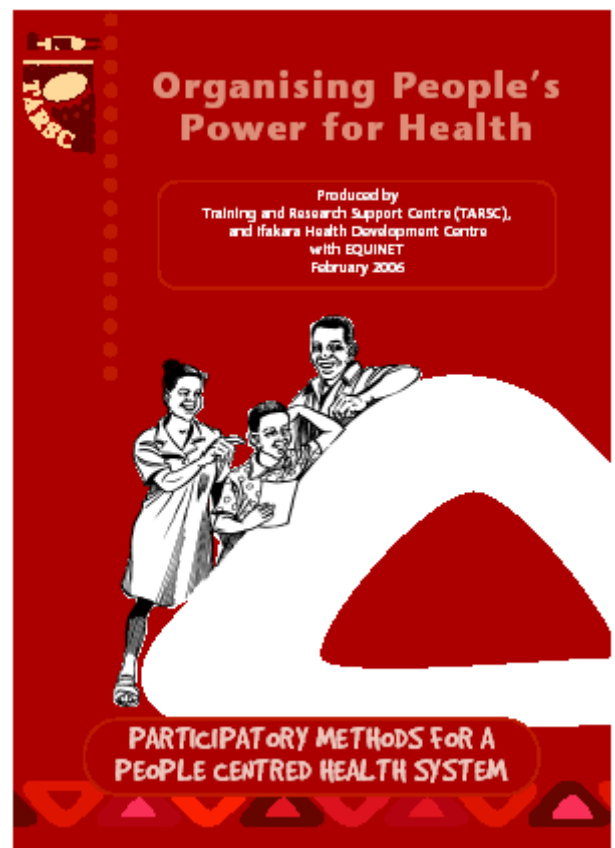
The third regional training workshop on participatory methods for a people centred health system was hosted by the Regional network for equity in health in east and southern Africa (EQUINET) , TARSC, Ifakara HRDC, with REACH Trust and GNNP+ in Bagamoyo Tanzania from February 27 to March 1 2008. It involved 36 delegates from east and southern Africa (See delegate list in Appendix 1) It aimed to build skills, share experiences and strengthen work on participatory methods for research and intervention towards people centred health systems, with a **focus on overcoming community and health systems barriers in accessing comprehensive prevention and treatment for HIV and AIDS and strengthening equitable primary health care responses to HIV and AIDS.**

The workshop is the third in a series run by TARSC and Ifakara on participatory reflection and action (PRA) methods in health, using a toolkit developed by TARSC and Ifakara in EQUINET, with support from IDRC and SIDA and peer review by CHESORE Zambia. The EQUINET Steering Committee in April 2007 resolved to understand equity issues in HIV and AIDS by integrating a focus on AIDS in other areas of work (eg on health workers, health financing). The PRA training focus in 2008 on strengthening equitable primary health care responses to HIV and AIDS was adopted by the steering committee, and the training aimed to build skills for follow up action research work in this area. REACH Trust Malawi, having co-ordinated theme work on equitable health systems responses to AIDS thus co-operated in planning and facilitating the workshop, and we were also happy to include the Global Network of People living with HIV/ AIDS (GNP+).

The 2008 training thus aimed to

- build understanding of PRA approaches and their use in strengthening people centred health systems, particularly community focused and PHC oriented HIV and AIDS interventions.
- draw on experiences in the east and southern African region for strengthening community focused and PHC oriented HIV and AIDS interventions.
- work through practical examples of PRA approaches and their application in areas of work that participants are practically involved with at community level.
- provide initial mentoring and support to development of research and training proposals for EQUINET support on equitable, community driven responses.

The training also provided an opportunity for the 2007 PRA group to review the work done on **strengthening communications between health workers and communities**, identify lessons learned, draw conclusions and recommendations across the work done



on strengthening communication between communities and health workers and using PRA approaches in health systems. This is separately reported. It provided an opportunity for the group completing work implemented in 2007 to act as resource people for the training and to share the experiences of the work done, as part of a learning network. These delegates were Kathe Hofnie //Hoebes Namibia, Clara Mbwili Zambia, Therese Boulle South Africa, Aaron Muhinda Uganda, Caleb Othieno Kenya and Jacob Ongala Kenya. In addition to the inputs from the 2007 group, the facilitators for different sessions of the meeting were Rene Loewenson, Barbara Kaim and Senele Dhlomo from TARSC, Selemani Mbuyita and Ahmed Makemba from Ifakara, Ireen Makwiza REACH Trust and Kevin Moody GNP+.

The meeting was held in the context of EQUINETs overall work on building people centred health systems, with features of:

1. Values of equity, social justice and the right to health.
2. Comprehensive, universal and integrated national health system.
3. People led, people centred health systems that organise, empower, value and entitle people.
4. Fair financing with debt cancellation, 15% govt funding to health, equitable mobilisation and deployment of resources.
5. Ethical and equitable human resource policies at national, regional and international level that recognise health workers concerns, and confront perverse south-north subsidies.
6. Fair global policy (just trade, reversing unfair flows of resources) with national and regional policy flexibility to exercise policies that improve health.

This report doesn't go into detail on EQUINETs approach to people centred health system as these can be found in other documents on the EQUINET website www.equinet africa.org.

The toolkit is separately available and provides the detail on the sessions and how they were conducted so this report doesn't record this detail. As a training workshop using PRA methods the meeting involved dialogue and exchange of experiences, activities to encourage reflection and discussions on follow up, exchange on work done in 2006 and the lessons learned and many other activities(See programme). We don't aim in this report to provide all of the rich and diverse exchanges that took place in the meeting. We capture through quotes, pictures and some reports some of these exchanges and the major agreed areas of action and reflection arising from the meeting.

The 36 participants from 10 countries brought a diversity of skills, experience and knowledge from different work contexts ranging from community, non government, local government, academic to regional and global networks! We came from different points of the region and left as a learning community.



"The Baggamoyo Experience
by Wilson Damien Asibu, Malawi

I still see the faces, though far
I can see the dancing antics, though fade
I can feel the hot atmosphere, though not real
I can hear Rene's voice,
Smell the food,
I know you all but fail to pronounce all the names correct,
I still feel the warmth of your departing hugs and embrace
George are you there? Dumie are you there?
We are a family. Are we not?
Fighting for our brothers and sisters' equity in health.
We may forget all but not the training and skills.
We may have the skill but what matters is implementing them.
If we don't meet anywhere, let's meet in Baggamoyo next year
And have another Baggamoyo experience!"

Thanks to all participants for the notes for the report, photos and quotes! The report is compiled by TARSC from all these inputs.

2. Introductions and current experiences in preventing and managing HIV and AIDS

Selemani Mbuyita warmly welcomed delegates to Tanzania and introduced the country and local area, and delegates all introduced themselves and their organisations. Rene introduced the aims and process of the workshop and its focus on responding to HIV and AIDS in a people-centred manner, to build skills to shape effective people centred responses.

We started by sharing people's current experience of the health system responses to HIV and AIDS, from different perspectives community; health workers; and their interaction. Delegates presented their experiences, while people took turns to listen with each of the three different views, and note what they heard in the stories from these perspectives. Everyone then wrote what they heard on flip charts so we could see how communities and health workers are experiencing the current responses, and what we learn about how they are interacting.

The stories were many!

- ♦ From Kenya, we heard about how services only provide supplementary food to people if their body weight is below a certain level, and how people try to cheat the scales to keep getting free food, and how they are confused by the relationship between food and taking their medicines. Similar confusion was reported in Zambia, especially in cases where people are drinking alcohol during treatment. In Zimbabwe and DRC we heard about how getting food supplements are a major reason for why people are coming for testing, even to the point where a negative diagnosis leads to disappointment as people then don't get the food!
- ♦ Others pointed to many continuing areas of confusion people have about AIDS, especially in rural areas. This is important as people who are ill often return to villages for care. At the same time local health promoters feel they are not adequately involved in treatment and care programmes.
- ♦ From Zimbabwe we heard about how new students at college campuses were encouraged by the university administration to have voluntary HIV testing, but how those who did so and were found positive had no support groups and no access to treatment.
- ♦ From Malawi we heard about how policies for and benefits of HIV testing of pregnant women to prevent mother to child transmission are not well known by women in communities, so that women run away from the testing. In South Africa we heard about a PMTCT support group that helps the health workers as part of counselling before people are tested and they exchange ideas on problems women face, such as with medication or children's health. With mothers and youth joining the support group fewer people are running away when tested.
- ♦ From Zambia we heard that when TB and HIV programmes were integrated so that people coming for TB were told that they would be tested for HIV the services faced a lot of suspicion from people who felt they did not need to be tested. When this experience happened in Malawi we heard how health workers would take them into counsellors room so that they cannot escape.

People noted from these stories that

- ◆ Social issues are very important in how communities respond to AIDS. People use services for what they see as their needs, like food supplements, so services like testing need to make the benefits clearer to communities, and provide intensive and planned counseling. In contrast, community involvement helped health workers to achieve more, but the community is not always given information. Where support groups exist these have helped with informing and supporting communities in their response.
- ◆ In contrast the health services operate from a very biomedical model and have poor strategies, procedures or skills for dealing with the social dimensions of treatment and care. Hence for example, while testing of pregnant women may be beneficial for both mother and child, women don't go for testing. While eating food is essential for treatment, a punitive approach to withdrawing supplementary foods demotivates people from treatment. This makes the services seem to have a more punitive and forceful approach to services, and leaves health workers frustrated by people's behaviours. We hear little about the advocacy skills, motivation and involvement strategies from health services, or about how health services are working with teams from the community.
- ◆ These experiences signal a lot of problems in the interactions between health services and the community, although each are vital to the other! Health workers feel they are wasting efforts and time on ungrateful clients and community members feel they need to cheat or challenge services to get what they think they need. New initiatives are misinterpreted, hindering programmes and the number of people accessing care.

We can see two different types of health system in these situations

- ◆ One in which communities are unaware, deprived, fearful and trying to "beat the system" to meet their needs. A system where health workers appear as all knowing, but are not well trained or oriented to work with people and the social issues in prevention and care, are pressed for time, so do not appreciate community roles and are frustrated and discouraged by community behaviours, but also trapped by commands from higher levels. In this system communication between communities and health workers is poor, the relationship controlling from the health worker side and resistant or escaping from the community side, where resources are seen to be scarce by all and decisions imposed without shared dialogue. We felt this was a lose-lose situation! Neither health workers, communities nor services gain from it!
- ◆ Another in which communities know and understand the problem and the services for it, are motivated, involved in shaping and organised around these services so they address their real needs. A system where health workers are trained, able to listen to and take on board other factors affecting treatment and care beyond the biomedical aspects, and are supported by clear policies and guidelines for this, where health workers work as a team and with community members to provide services and practice their professional skills. In this system community members and health workers recognize and communicate about each others roles and needs, have some flexibility and support for this local

dialogue, and are respectful and make best use of scarce resources along priorities for intervention that all have ownership of, trust and seek to sustain. We felt this was a won – win situation, good for all!

While many services are not one or the other, and we are living in a mix between the two, our experiences show that we often experience the first, despite the fact that its bad for all. What is producing this lose-lose situation? Why is it perpetuated? How can we produce change to move to the positive picture?

This session, facilitated by Rene Loewenson, was the entry point for the meeting. It showed the need to move from discussions of technical interventions alone on HIV and AIDS to wider issues of how health workers, services and communities interact around these interventions. Our current experience was the entry point for this discussion. We examined how drawing out current experience is generally the strongest starting point for building any change towards a people-centred health system. We discussed the methods we used (stories, listening and market place) and explored other methods in the toolkit, such as the human sculpture. These are good methods for the key starting point of listening to current experience, to allow people to collectively bring forward how things are working, and reflect on where they would want to see positive change.

We also realised that producing the difference was a social change process, and an outcome of the way people organise their services. Building a people centred health system is not simply a technical question, but calls for ways of work that build the power of individuals, communities, health workers, supporting institutions and others. Participatory methods provide a means for this.

2.1 Building people centred health systems

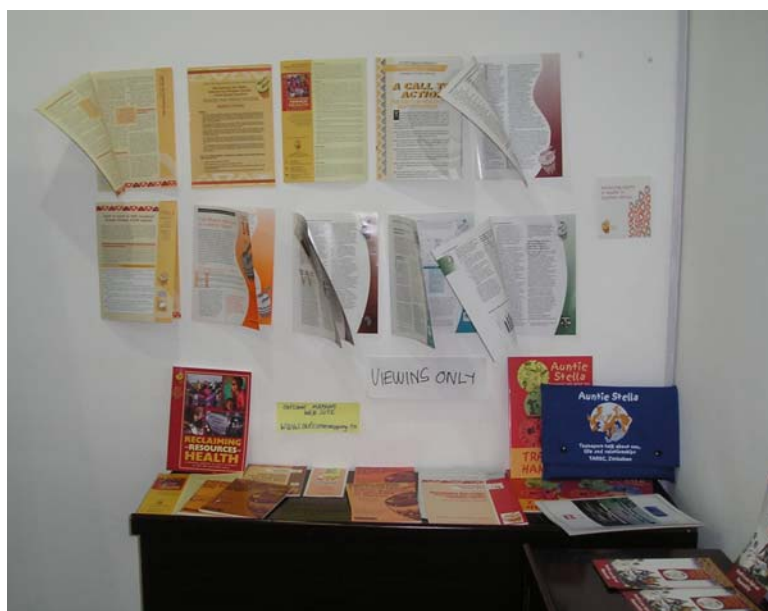
A slide presentation presented by Rene for EQUINET gave the wider context to building a people centred health system. Drawing from the regional equity analysis “Reclaiming the Resources for Health” published by EQUINET, the presentation showed that improved growth has occurred in countries in east and southern Africa (ESA) with falling Human Development increased poverty and widening national inequality in wealth. There is evidence of inequalities in health, in access to the household resources for health and in access to health services within and across ESA countries. Longstanding commitments to equity have sought to overcome unfair differences in health, and to allocate more resources to those with greater health needs. To do this we will need to reclaim the resources for health for poor households to access a fairer share of national resources; for the health services used by these communities and for countries to meet obligations to health. Against a background of significant resource flows out of Africa and economic and trade policies that weaken public health, many countries in the region face challenges in implementing the public sector, redistributive health systems that respond to health needs and redistribute resources to provide health care in accordance with need. EQUINET’s goals of reclaiming the state is based on the understanding that addressing our health challenges needs as a precondition an effective public sector, able to exert leverage over the system as a whole.

Reclaiming the resources for health systems and households for health calls for adequacy of health financing, progressive means of resource mobilization within a framework of universal coverage, and needs based resource allocation. Experience from the region suggests that steps towards this calls for

- Recognition of the real costs of financing a health system of about \$60 in the public sector, with additional demands from AIDS and the MDGs
- Governments to increase their own financing to health so that this reaches at least the 15% commitment made in Abuja, *excluding donor resources*

Without health workers there is no health system. Strengthening national health systems cannot be done without valuing and “reclaiming” our health workers. Equity also includes the power and ability people (and social groups) have to direct resources to their health needs, particularly for those with worst health. Addressing equity thus means relooking at health systems: overcoming longstanding blocks in administrative systems, health worker attitudes and health system processes that disempower people. This calls for mechanisms, resources, participatory reflection and action approaches and civil society and parliamentary contributions that facilitate analysis and action. Health systems organised around social participation and empowerment create powerful constituencies to protect public interests in health .

She outlined the various areas of work in EQUINET aiming at supporting this, through research, knowledge, capacity building, promoting dialogue, policy support and social activism. The EQUINET website at www.equinet africa.org has many of the publications of this work and the EQUINET newsletter provides monthly information on the work taking place in the region on equity in health.



3. Elements of a Community / PHC oriented response to HIV

Delegates used a PRA process to draw out and discuss features of communities that affect people living with HIV and prevention treatment and care uptake and outcomes. The experience of the previous session indicated that responses to HIV need to be built around the features of communities concerned. A number of tools were outlined by Senele Dhlomo and Ahmed Makemba for mapping and understanding communities, including *community mapping and transect walks*. **Social maps are a** way of identifying existing social groups and their distribution. Delegates were guided in drawing social maps that reflected social groups in fictitious communities affected by HIV and AIDS drawn from the



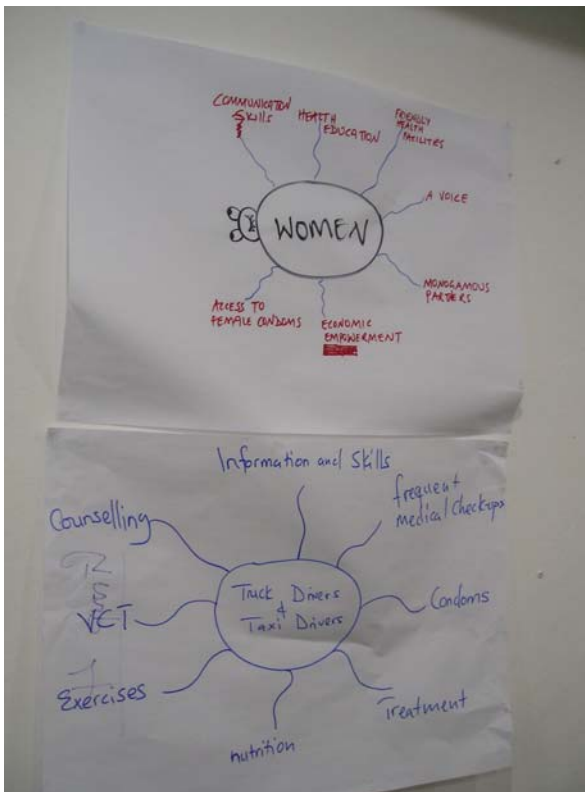
region. In a gallery display delegates reviewed the main features identified in the different maps, which were a mix of physical, social, economic, institutional and political features. For communities, many features related to the social environments that communities use to gather, interact, care for dependents and earn and organise household income.

A number of features of health services were noted, including access and availability, the nature of the services provided in the community and the facilities, as well as qualities of the services and their staff. A range of other features were noted from other sectors: loans, toilets, schools, property laws, media, as well as the social relations and networks that enable access to these resources.



The delegates identified four social groups from the list identified in the social mapping and used a spider diagram to identify the needs of the groups around HIV and AIDS and health. Other tools for obtaining information on needs were discussed,

including key informant interviews, ranking and scoring, focus group discussions, role playing, questionnaires, pictures, storytelling, marketplace.



These needs were reviewed and organised into how they affect interventions for the community; for the health system and in how the community and health system interact. These were organised into a pie chart to see how a more people centred response would organise actions within communities and health services, but also in the range of social institutions and services that relate to the needs and to the bridges between communities and health services.

In the community the interventions related directly to issues concerning HIV, such as information on using condoms, testing, but also to the forms of social organization and networking within families and communities that enable

Spider diagrams of needs around HIV

people to access information and services. For example enhancing the power that women have over household income was acknowledged to be an area of intervention to promote effective responses to AIDS. While the services encompassed the range of prevention, treatment and care services, equally important were the distribution and qualities of these services (access, availability, timeliness, staff orientation, privacy). Bridging the health services and the community were a range of supportive interventions, to support issues like shelter, clothing, food, information access, income, to support social roles and capacities of vulnerable people, and to support communication with and uptake of services.

It emerged from the discussions that a people centred, primary health care response to HIV would

- ♦ Centre responses around people's needs, roles and environments, strengthening peoples roles, information, power and capacities to promote their health and use services
- ♦ Support these community roles with a range of interventions across different sectors and through social networks and organization, and
- ♦ Organise reliable, accessible interventions in health services in a manner reflecting social concerns and community needs and capacities, recognizing and supporting community roles.

3.1 Current PTC options and people centred health systems

Kevin Moody GNP+ outlined the current options for prevention, treatment and care. He noted that people with HIV can feel threatened by doctor driven interventions that promote testing and intervention in ways that do not give people a say in decision-making, or give them ownership over the follow up. This is especially the case when people return from services to communities where there are scarce resources available to support prevention or care, such as harm reduction tools through needle exchanges, approaches deal with social problems such as gender based violence, or adequate food.

This calls for a paradigm shift. He suggested that a person centred approach using a chronic care model was a more appropriate one, and one which health workers know all about from other conditions like diabetes. Providers are coaches as well as service providers, tools initiated by and for PLHIV and vulnerable groups. Strategies change depending on the needs of the group. People need to have the power to use preventive strategies and support to manage their medicines. There is an urgent need for scale up of testing, but done in a manner that is confidential and voluntary, and as part of a continuum of prevention, treatment and care, so that testing is not abused leading to people avoiding it. Task shifting involving different levels of professionals doing different things to roll out ARVs more quickly has been an important means of delivering care, if supported to ensure quality and is happening at a practical level in many services.

An approach that puts the person with a chronic condition or the person at risk at the centre of the intervention has challenges. For example in the discussion it was observed by participants that social issues need to be recognised, understood and responded to, together with access to basic needs like food. While it is critical that drugs are available, affordable and used before their expiry dates, It is also important to address the perceptions that people have about their drugs and the information they are given to support their care within the community.

4. Reflections on PRA approaches

What do we mean by participatory methods?

Participants were divided into 4 groups to brainstorm key on key feature of participatory approaches, reflecting on their own work and what made it participatory. Common to the feedback, facilitated by Barbara Kaim was

- ♦ Common words - *involvement, participation, identification of needs and possible solutions, community ownership, own experiences, representation of certain social groups.*
- ♦ Tools identified-use of theatre, drama, music, art, role-plays, group discussions, focus groups discussions, key informant interviews, questionnaires.
- ♦ Processes that provide for reflection, planning and action, as they produce change.
- ♦ Common goals of what people seek to achieve, unifying people.

These approaches not only relevant to community level, but to all levels of action on problems.

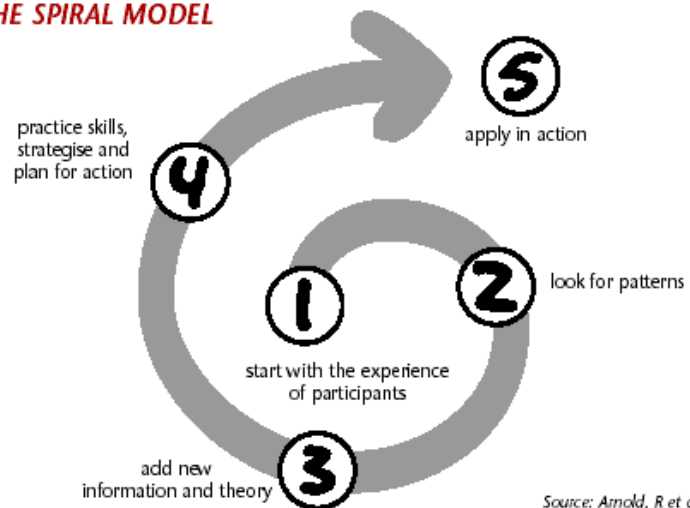
“We are using PRA to learn PRA”

Workshop delegate

We discussed the basic principles of PRA methods, why they are central to people centred health systems, and the way they support transformation. We also discussed that learning about PRA is not achieved in a four day workshop! It means building skills to listen, facilitate and work in ways that are a constant process of learning. It has a theoretical basis that people were encouraged to read more about.

The PRA process is like a spiral with a regular cycle of reflection and action, from this a community can draw lessons from their experiences and continue to find better solutions to their difficulties, this continues to move them closer to their positive change in their lives. We discussed the basic approach of reflection and that it gives communities opportunities to share their opinions and contribute to decisions or plans being developed and that this encouraged a bottom-up approach.

THE SPIRAL MODEL



Source: Arnold, R et al (1991)

It was emphasized that the spiral becomes a cycle in which after every action there is an experience good or bad that is then used to move forward. It was also recognized that there was a healthy tension that existed between thinking, reflecting and taking action.

Participants discussed a series of statements to label whether they were true or false:

- ♦ PRA is central to building a People Centred Health System-*True*
- ♦ PRA is just a pack of fancy methods-*False*
- ♦ PRA has no theoretical basis-*False*
- ♦ PRA approaches are quick and easy to use-*No consensus*, after much discussion participants agreed that PRA approaches are time consuming, involving and because they are aimed at change which is not easy they take time. However it was also recognized that the PRA methods are fun to use.

4.1 Experiences in using participatory methods in strengthening health worker- community interactions

The group implementing work using PRA approaches for health systems research and interventions were focused on Strengthening relationships between frontline health workers and their communities. The group, included Kathe Hofnie //Hoebes Namibia, Clara Mbwili Zambia, Therese Boulle South Africa, Aaron Muhinda Uganda, Caleb Othieno Kenya and Jacob Ongala Kenya. The reports of their work are found at www.equinet africa.org . The group were involved in parallel sessions to review and draw lessons learned from this experience, separately reported. They implemented work on various areas of health, including mental health, maternal health services, HIV and AIDS care, environmental health, as well as more broadly on strengthening mechanisms for community involvement in health planning.

The group reported on the lessons learned from the work that they had done. A conducive environment was vital for people's involvement in changes, particularly stable political and economic situations, and government policies supporting bottom –up approaches. The availability of demographic statistics and facts helps provide the evidence for PRA work, and work on participation also needs to produce evidence that is quantitative on changes as this influences people at national level.

They work done by the group produced challenges to ensure that the people have a voice, equality and the same footing. PRA becomes weak if the expectations are not met so it is important to make sure that you do not raise the community's expectations and be clear about the process. When people begin to see the results, commitment to the process is enhanced.

Some tools work better than others depending on the community so facilitators need to study their community and use the relevant tools and be prepared to have an alternative should the tool prove too difficult to manage. This means a knowledge and understanding of people's history and culture was vital, as well as of existing structures to make the correct point of entry into a community. Facilitators need to be very respectful, and patient with the communities, and flexible, to know that even after much consultation there is room for mistakes. Specific examples of the 2007 work were integrated into other sessions of the meeting, where individuals from the group also facilitated sessions.

4.2 Identifying change and monitoring progress towards goals

Participants were divided into four clusters based on the follow up work they planned to implement, with clusters in

- 1: Prevention
- 2: Access to Treatment
- 3: Community and OVC Care
- 4: Other Primary Health Care

Prior to the training participants had submitted concept notes, which were peer reviewed by TARSC and revised. It was intended that participants would now work on their concept notes with mentoring from facilitators. As a first step each group collectively discussed with their mentors a set of changes they would want to achieve, within the community, the health system and in how the community and health system interact. They used a ranking and scoring approach to prioritise those changes they felt they MUST achieve.

The plans were posted in the wall for all groups to see what the other groups had done. Each participant was then asked to use the exercise to clarify the changes in their own concept note.

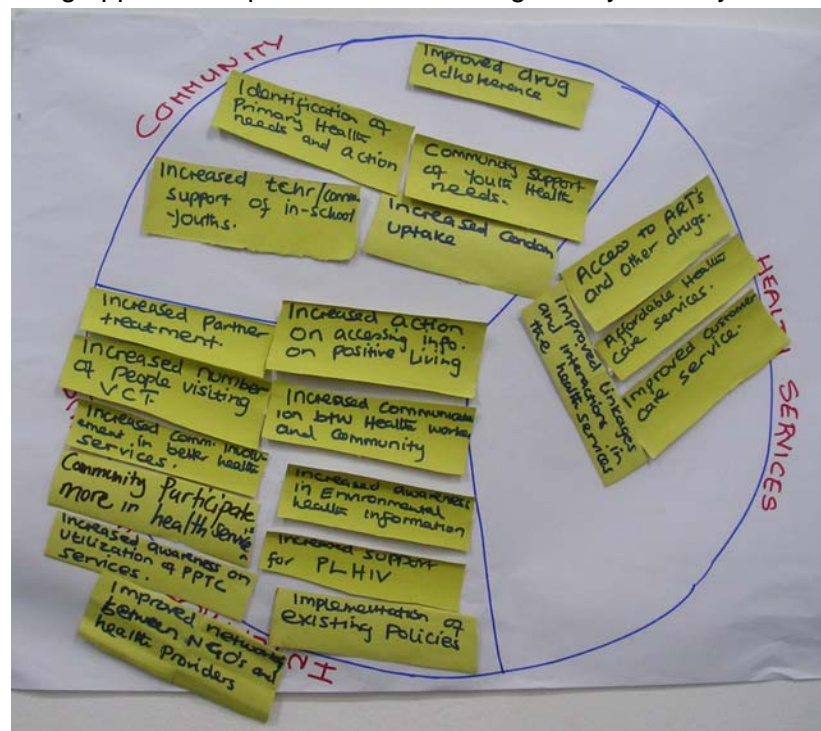
The Prevention group identified changes involving

- ◆ More support between community and PLWHA and reduced stigma
- ◆ Reduced levels of domestic and sexual violence of women, with young women having a voice on their Sexual Reproductive Health Rights, a reduction in cultural practices that are barriers to RH and more positive attitude of health workers to young people in improved youth friendly services.
- ◆ Improved provision and access to condoms, increased condom use correctly and consistently and increased community control and management of HIV

The Access to treatment group identified changes involving

- ◆ Strengthening access to drugs and monitoring of drug and treatment distribution
- ◆ Strengthening roles for communities in treatment, and more positive attitudes of health workers/communities towards PLWHA.
- ◆ Improved adherence /psychosocial skills among treatment providers, enhanced health workers-patient communication and improved knowledge of treatment and care amongst health workers, communities and patients.

The group exploring community and OVC care proposed



- ◆ Increased community awareness of food and nutrition support for PLWHA.
- ◆ Strengthened co-ordination of available resources and inputs and equitable distribution of resources for OVC needs
- ◆ Increased community knowledge and capacities to plan, implement and evaluate OVC oriented activities.

The Primary Health Care Group identified the range of changes proposed by the other groups but with increased involvement of others outside the health services, including teachers and schools, increased communication within families and communities, such as in partners involvement in testing and PTC, and increased community involvement in better health services.

Clara Mbwili. Lusaka district health board, presented options for measuring progress towards and levels of identified changes in participatory work. The approaches were used in the PRA Intervention in Lusaka which aimed at strengthening health worker and community interaction towards improved health services.

Quantitative measures of change can be gathered before and after the intervention through

- ◆ Pre and post test baseline questionnaires administered. This is a quantitative approach that is used to measure how they communities involved perceive, know or report practices before and after the intervention. It is administered to exactly the same group of people before and after, using a set of questions that measure conditions before and after (using a ranking scale from 1-5 for example) with exactly the same questions asked to see how things have changed after the intervention. It gives a quantitative assessment of change.
- ◆ Using data from facilities or surveys to measure the situation before and after the intervention on the area where change is expected (for example mothers attendance at ANC, or compliance with treatment).

Further, participatory methods can be used to review programme before and after. The outcome mapping strategy can be implemented after the problem has been identified, as you are developing your action plan. Progress markers are set the indicate

- ◆ The things people feel they **MUST** achieve
- ◆ The things people feel they would **LIKE** to achieve
- ◆ The things people feel they would **LOVE** to achieve

These can be reviewed by the participants to the process during the process to assess progress and to plan how to overcome problems. Reviews could also be done through monitoring visits to review the progress makers.

A further approach is to use a wheel chart to measure where people feel they are at different stages of a process in a key aspect being changed (such as how well local committees are known in communities; how friendly services are and so on.). The method is shown overleaf. Participants in their four groups tried using a wheelchart with some sample questions. They noted that the questions need to be those that will reflect on wider community conditions, such as for how common things are in the community, or how well people feel they participate as a group in services. It is not very useful for areas where there is significant diversity in views, although if there is debate people can be divided into smaller more homogenous groups and the differences discussed. Wheelcharts can be used at the beginning and end of a process to assess change.

Activity 19:

TO ESTABLISH LEVELS OF COMMUNITY PARTICIPATION IN DIFFERENT AREAS OF HEALTH SYSTEMS

METHOD: WHEEL CHART

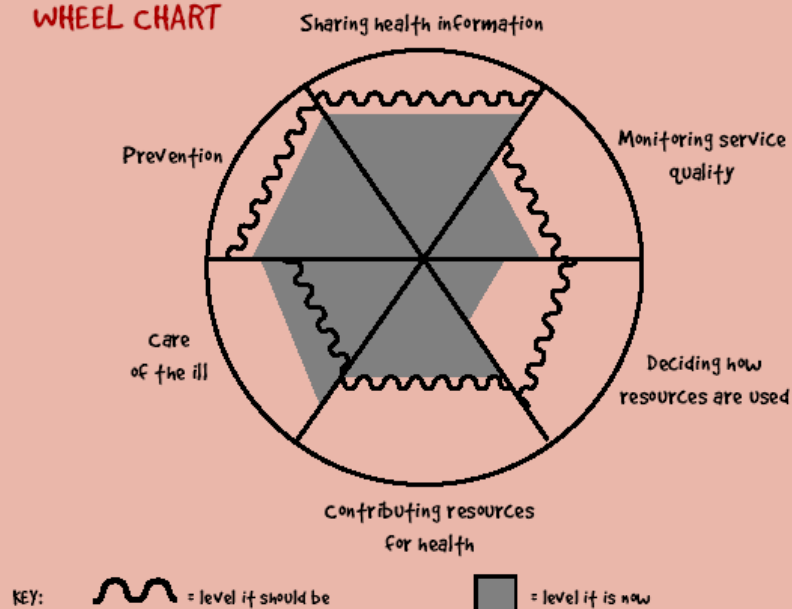
Time: 30 minutes

Materials: flipchart paper and pens or, if doing this activity on the floor, charcoal or chalk

Procedure:

- 1 Ask participants to list the areas of community participation.
- 2 Divide participants into groups of about 10 and ask them to draw a wheel on a piece of flipchart paper with about eight spokes (the number of spokes is determined by the number of participation areas identified). Areas of participation could include: sharing health information, monitoring service quality, deciding how resources are used, caring for the ill, and so on. Label each segment of the wheel with one of the participation areas.
- 3 Explain that the group has to decide how much the community participates at present in relation to each area of participation and note the level on the wheel chart. For example, a high level of participation in health resource allocation means a lot of the segment will be shaded, a little means only a small part of the segment will be shaded.
- 4 Ask participants to make a line with a different colour pen on the wheel chart to show how far communities feel they should be involved in each area (the line should be at the top if they want to be more involved and lower down if they don't).
- 5 At the end of this exercise, ask the different groups to show their wheel charts. Discuss what you have learnt about community participation in health.

WHEEL CHART



Source: R. Loewenson (2001)

5. Identifying problems to address and barriers to health interventions

Participants used **picture codes** as a way of discussing the causes of problems as well as moving toward defined solutions. Other options for this were introduced by Selemani and Ahmed: the *But why method*, *problem tree*, *spider diagram*, and *line ups*.

The problem tree can be used to look at a number of the health problems prioritised, asking *but why does it occur* for each problem to get more deeply into understanding the causes of the causes of these problems. Picture codes are a further way of exploring problems. The toolkit provides examples of picture codes, and these were used as examples to discuss the causes of the problems, using the “but why approach”.

We discussed how different groups in communities and health workers see the causes of problems identified in the clusters and how to use PRA to raise different views on problems and approaches to addressing them. We then discussed how these approaches can be used in the proposed work of the clusters.

Participants were each given two seeds and asked by Barbara to place their seeds where in the PRA cycle they felt they were acting in their own work. In the discussion most mentioned that it was easy to ignore reflecting with communities, and most felt they were at the stage of sharing experiences or in the point of adding information to support action.

“Once I am told the problem I quickly move to action without thinking more about anything else.”

Participant

5.1 Barriers and facilitators of health interventions in ESA

Ireen Makwiza outlined the findings from work implemented by REACH Trust on barriers and facilitators to health sector interventions on HIV and AIDS.

Most ESA countries are expanding HIV/AIDS treatment, the success of which depends on equitable access and maintaining high adherence rates among patients on ART.

From review of evidence in the region

- ♦ Free ART at point of delivery has enhanced access, while user fees hinder access for the poor and reduce long term adherence. Free ART has resulted in more women, younger patients and those at an earlier stage of immunosuppression initiating ART. In contrast high costs of CD4 count testing is a barrier to initiating treatment and monitoring of improvement.
- ♦ Analysis of data from the ART registers in 5 districts in Malawi (Patients initiating in 2006) for 40% male against 60% female, with more women accessing treatment than men. Men had a higher death rate as compared to women (10% against 9%). The default rate was higher for men compared to women.

Challenges to accessing and adhering to treatment mainly came from economic problems, due to lack of money for transport to the ART clinic, inadequate food, worsened by loss of income due patient and some patients selling household assets to finance their treatment. Some patients stopped as they were sold alternative traditional remedies, or switched as they felt their medicines were not working.

'While I was on ARVs, it was when this man with chambe came, he told me to stop taking ARVs and take his medicine instead' (Female patient who stopped treatment)

There has been limited Integration of ART and Tuberculosis treatment, which run as parallel vertical programmes with different structural arrangement. ART is centralised while TB is decentralized, ART is managed by highly trained personnel while TB managed by low cadre health workers. There is lack of understanding and cooperation, and illiteracy.

"I think the main problem is that there is always lack of cooperation and understanding between us and the carers. Because when they come here we tell them that whilst here the child is not supposed to take any other meal we are going to be feeding them with milk only. But there are always some carers who object to this". (in-depth interview with homecraft worker)

Factors that expose PLWA to stigma include open disclosure of HIV+ status and their physical appearance. Those who do not seem to improve despite being on ART or simply being on ART or belonging to AIDS support groups brings stigma and discourages people from accessing care.

In discussing the issues raised in the presentation, participants debated the reasons why men delay accessing treatment and drugs, amongst other findings.

"Burn-outs by health personnel create psychological problems, and people are still in fear despite awareness"

Participant Remark

6. Building community, PHC oriented actions

Participants were divided into their four clusters for their follow up work to develop their proposed work, using the approaches and tools discussed in the meeting. This exercise was a continuation of the individual desired changes identified previously by participants. The five areas people worked on with mentor support were

1. What changes are desired?
2. What context, entry point and ownership will the changes are brought up?
3. How to apply PRA process/approach
4. How to assess changes?
5. Who is in the team?

6.1 Prioritising problems and developing actions

Senele divided participants into two groups, implementing one of the two activities below, and then rotating to the next.

- ♦ **Group 1:** Prioritising issues or interventions - identifying an issue and use the ranking and scoring method (facilitated by Senele and Ireen). The Other methods for prioritising actions were also discussed, including *pairwise ranking, and line ups*, with examples of how they can be used in the PRA cycles being developed by the clusters
- **Group 2:** Developing actions with communities and health workers - Using the incomplete story (facilitated by Selemani and Ahmed). Other methods for developing actions were also discussed, including the *spider diagram, market place, snakes and ladders*, with examples of how they can be used in the PRA cycles being developed by the clusters

6.2 Improving communication between communities and health services

Kevin introduced the session by drawing the attention of participants to communication barriers that exist between people and health workers. PRA approaches can be used to reflect on how people and health workers communicate with each other. For example, Jacob Ongala presented the experience of using Johari's Window in EQUINET supported work in Kenya. He described the situation of how the community realized that it was insufficiently informed with poor communication between health workers and people attending the facilities for treatment. Through using the Johari's window identifying the perceptions of the community members and that of the health workers, joint dialogue between the two groups was stimulated on how to overcome poor perceptions and communication between health providers and the community improved quite significantly.

PRA tools that can also unblock communication barriers, and examples were discussed from the toolkit such as focus group discussions, Stepping Stones, transect walk, *Margolis Wheel* and others that build better understanding, respect and joint action between the two. Barbara provided participants with a one page summary of the *Margolis Wheel* that describes the method and how it could be used.



In the final discussion participants reviewed options to improve communication, increasing opportunities for health workers to be involved in community processes and vice versa (such as by bringing health workers to give talks to community, bringing community members (including PLHIV) as representatives on clinical teams and working with joint committees to strengthen linkages between community and health service caring. It was also noted that each

groups needs to be willing to listen to and use each other's language, for health workers to avoid jargon and community members to learn key terms from health workers. Participants noted that each needed to understand the constraints, challenges and goals of the other. Building such dialogue could be a challenge, and it was observed that it needed to be stimulating, interactive, visual through forums that provide equal opportunities of contribution of ideas.

Later Kathe presented her experience on using the Stepping Stone tool to resolve misunderstandings between health workers and the community during the implementation of her project. She reported that, in the beginning, the community thought that government was responsible to provide everything and they were reluctant to take part in any development activity. Similarly, health workers were looking at community as ignorant and people who need to be directed in everything. However, through the PRA process and after using the Stepping stone tool (outlined in the manual), both sides realized the potentials amongst themselves and it changed the situation in terms of the communication.

6.3 Communities and health workers roles

During the after afternoon session Ahmed, Ireen and Senele introduced the approach to implementing stakeholder mapping to analyse roles in the responses and explore how to build linkages across roles and identify and address gaps. They used Venn diagrams to map out stakeholders and their respective roles. Different sized circles were used to ascribe the perceived importance of the various institutions/organizations in a given community and the role they can play towards solving a particular problem of interest to the community. The chosen health problem/need was "access to Anti-Retroviral Therapy" A range of institutions were listed, covering different providers of health services, local community organisations, other state services, legal institutions and business.

The distance the circles were placed from the core problem depicted the perceived relevance and reliability of the stakeholder in participating or contributing in efforts to address the health problem in question. This session generated a lot of discussion around the roles, linkages and gaps.



Participants were invited to review and apply the approaches learned in their own area of work and concept notes, to be discussed on the final day.

6.4 In summary

The meeting identified some important concerns in and dimensions of a primary health care oriented response to HIV and AIDS across the various sessions:

- ♦ **Interventions and services cannot be simply defined by biomedical models**, and the current over-emphasis on biomedical models in health service functioning needs to be complemented with and strengthened by strategies and skills for addressing the social determinants of access to and use of prevention, treatment and care interventions.
- ♦ **Community needs, conditions and responses need to be understood**, through participatory processes that involve and organise communities, so that health services build on and respond to this information. Starting with community experiences and perceptions is vital to planning and implementing interventions and services on HIV and AIDS.
- ♦ Community level networks and more powerful groups need to be explicitly engaged to provide greater support to OVC and PLWHA.
- ♦ **Medical interventions need to be complemented by interventions in the wider social and economic environment**, including access to food, transport, social support, loans, schools and property laws that support land ownership in women. Health systems can play a role in enhancing local knowledge and control over such inputs, such as by supporting with community food plots, strengthening local support networks, participating in programmes to organise around and reduce domestic and sexual violence, or supporting local womens and youth enterprises.
- ♦ **Testing services should be well understood within communities**, done in a manner that is confidential and voluntary and effectively linked to follow up prevention and treatment services. Specific activities should be implemented to identify and discuss with communities the reasons for default from testing, to address these.
- ♦ **Treatment and care services should be affordable and accessible**. Health services at primary care level should be offered free, ie no charges, with adequate staff to primary care and district services to ensure quality. Treatment providers need to receive greater formal and in-service training in psychosocial skills and greater reward and resources for use of these skills in services.
- ♦ **HIV and AIDS services should be integrated with TB treatment** and draw on lessons learned from TB services on decentralisation and involvement of less qualified health workers.
- ♦ **Treatment and care approaches should be well known within communities and patients**. Specific attention should be given to understanding reasons for and reviewing support for groups where default rates are high.
- ♦ **This often means a progressive redistribution over time of resources and staff** away from central hospitals to district hospitals and clinics, in ways that do not disrupt services. This calls for governments to meet their Abuja commitment of 15% of government budgets spent on health.
- ♦ **Communication is vital**. HIV infection is a chronic condition that depends on client centred care, where the PLWHIV is the centre of a management strategy and knows and is able to effectively use supporting prevention and treatment services and inputs. Health workers and communities need improved communication skills, using terms that are understood by communities, whether

- in individual communication with PLWHIV or in more collective processes. Health systems need to organise consistent mechanisms and processes for sharing of information between communities and health workers.
- ♦ **Local systems should build in planning and review processes that involve communities**, draw and reflect on experiences and needs, and shape actions from shared understanding between health workers and communities of the barriers to prevention, treatment and care and how they can be addressed.
 - ♦ These should also **aim for greater co-ordination of actors involved in the response to AIDS**, and stronger links across service providers, between services and communities, and within communities. This co-ordination should engage with traditional health services.

7. Follow up work and next steps

Barbara explained that many of the tools that have been used in the workshop are in the participatory toolkit file. However, she said there were many more PRA methods that could be sourced on the internet and used. She recommended for example resources available at the that the London School of Hygiene & Tropical Medicine website (<http://www.lshtm.ac.uk/>). In designing the participatory process, participants would need to find and select tools appropriate to the circumstances, communities and issues they would be studying.

Rene explained the process forward, outlining how participants could develop their proposals and access resources for follow up work to build new knowledge, skills and evidence on primary health care responses to HIV and AIDS. Even if participants did not receive funding, mentoring would be ongoing via the PRA mailing list, pra4equity@equinetafrica.org . She encouraged dialogue in the mailing list between participants.

After the PRA training in Bagamoyo, EQUINET will put out a call for proposals for those attending the training in 2008 and those trained in 2006/7, including proposals that build on work done in 2006/7. The proposals aim to provide an opportunity for follow up work to support implementation of PRA capacities, with peer review and some mentoring of that work.

These are usually small grants awarded for follow up research and training field work projects using the PRA skills. In 2008 these focus on overcoming community and health systems barriers in accessing comprehensive prevention and treatment for HIV and AIDS and strengthening equitable primary health care responses to HIV and AIDS.

Building on the concept notes developed before and at the workshop, participants were invited to prepare and submit a proposal to the EQUINET secretariat admin@equinetafrica.org by March 14 2008 according to a guideline distributed at the workshop. The proposals would be peer reviewed, with feedback given for revisions, and final proposals submitted by mid April. Selection of proposals for funding is done in EQUINET through a peer review process.

Mentors then worked again with participants on their concept notes, integrating the approaches and issues discussed in the workshop into the ongoing work and working with participants to advance the core elements of their proposals.

7.1 Strengthening facilitation skills

A discussion on facilitation skills examined was aimed the expectations of facilitators on the follow up work, with delegates raising issues such as stimulating discussion, motivation of participation of all the participants, being clear of what the aims of discussion will be as well as staying focused.

This means that facilitators need particular characteristics:

- To be cheerful, patient, attentive, quick to learn people's names and quick also to change the direction of discussions as appropriate.
- To be capable of instilling self-confidence among other people in order that they are encouraged to contribute their ideas.
- To be constantly aware that facilitation is neither teaching nor instructing, but guiding people through the PRA process
- To be consistent, follow up and evaluate together with the community members the whole process and the plan.

It was suggested that participants can continue the process after the workshop:

- read further and get into the debates about the advantages/disadvantages, strengths and weaknesses of PRA
- practice! Learn from experiences, and mistakes.
- if possible, try to find a more experienced PRA facilitator to work with the first few times using PRA
- avoid being overly ambitious. Keep things simple and clear; plan programmes carefully and be flexible. Listen to the needs and experiences of the people you are working with.
- If possible put together an interdisciplinary team: perhaps one person who is knowledgeable in the subject you are researching, another who is an experienced PRA facilitator, a third person from the community you're working in, etc. In this way, each team member brings in a different perspective, different strengths.
- level the ground ie while people are using a PRA tool, be aware where you are in relation to them. Don't stand above them - best to sit with them. Watch your body language. Your attitude and behaviour is key.
- Don't throw away what you're already doing in favour of PRA (unless you think it's not worth keeping!). PRA is designed to complement, rather than replace, other methodologies. It's the philosophy behind PRA - the focus on respectful participation of all people - that is important to infuse in whatever you are doing.

7.2 Links to follow up networking

Kevin, Ireen and Rene outlined the opportunities for follow up networking on work on HIV and AIDS, both in relation to wider advocacy and social movements, to networks working on research and policy on HIV and AIDS, and to the specific work in EQUINET the work on participatory methods. Ireen pointed to opportunities to feed into National AIDS Councils and to the SADC Regional processes, including through networks like EQUINET, ARASA and organisations of PLWHIV.

Sharing of ideas across the region, and of experiences and skills within areas of work and areas of specialization were also seen to be vital. Regional communication mechanisms exist, including a mailing list pra4equity@equinetafrica.org for those involved in participatory work. A regional database is being compiled of people with experience in this area and participants were encouraged to visit the EQUINET website for other work on equity in health and on participation and health. A Regional EQUINET conference is planned for 2009, while national and theme activities are also taking place in 2008 and 2009.

8. Reflections on the workshop and closing

At the end of the training workshop we used the 'ballots in the hat' method set out in the toolkit to assess the usefulness of the workshop with three questions:

- What do you feel most confident about? What do you feel least confident about?
- How has the workshop changed your work?
- What other comment do you have?

We read the responses collectively and had a general discussion at the end. Some of those responses reflecting the common areas of feedback are shown below.



What are we most confident about? What are we least confident about?

- *I have gained renewed energy and motivation to continue, when energy levels were flagging. I am most confident about what we want to achieve.*
- *I enjoyed and gained confidence in working with the tools.*
- *I am most confident about the change that I want to achieve*
- *Im most confident in consolidating learning experience from the region.*
- *I am confident about imparting PRA skills to the community and will be working with.*
- *Im not confident on using the wheel chart*
- *I am less confident about engaging other stakeholders when implementing PRA*
- *I am worried about the health systems' response how they are they going to accept my feedback*
- *I am least confident about negotiating a way through with health department*
- *I am least confident about the appropriate use of some of tools as in most cases, I think they require learning by doing approach*
- *I am least confident in proposal writing*

How has the workshop changed your work?

- *The workshop has changed me on how I approach participants from the leading methods into participatory methods*
- *Think big – influence those in powerful places. This is in our hands*
- *Change the way I do my proposal writing ie to take every step of the activities seriously than to just assume*
- *People's participation is inevitable, motivating*
- *Learned to open my ears more and to truly listen and how to help the communities make their voices, concerns and issues louder*

What other comments do you have

- *The team was great and very helpful, the hotel was super it was a paradise indeed. Logistics and personal organization was fantastic and you are there for us*
- *PRA training is improving every year. This year was very good- not lecturing but really participatory*
- *Impressive workshop, but more time is needed to go through what was planned*
- *The workshop was empowering*
- *Loved the networking- meeting with people doing similar work, it was a really privilege*
- *More reading material, resources please*

We closed the workshop with thanks to TARSC for their logistic organising of the workshop, to the facilitators from TARSC, Ifakara, REACH and GNP+ and participants, to IDRC and SIDA and to the hosts in Bagamoyo. Ahmed Makemba representing the hosts and EQUINET Steering committee closed and wished delegates safe travel and reminded them to use their skills to improve the health system. Thoto Mbatsha, one of the participants, relayed the positive energy that would be carried from the workshop into the follow up work. We said goodbye- until our next exchanges on the pra4equity list.

Appendix 1: Participant list

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Appendix 2: Programme

DAY ONE – WEDNESDAY 27TH FEBRUARY

TIME	SESSION CONTENT	SESSION PROCESS	ROLE
8am	Introductions and welcome	Delegate introduction Introduction to facilitators and objectives of the workshop	All
EXPERIENCES AND OPTIONS FOR PREVENTING HIV AND MANAGING AIDS			
8.30-10.00am	Current experiences in preventing and managing HIV	Experiences of preventing HIV and managing AIDS	RL SM
10.30am	Context on equity oriented people centred health systems	Contexts for, challenges and progress in building equity oriented health systems in ESA.	EQUINE T (RL)
ELEMENTS OF A COMMUNITY / PHC ORIENTED RESPONSE TO AIDS			
11.30-1300	Parallel session for 2007 group		
11.30pm	Tools for mapping and understanding communities	PRA process to draw out and discuss features of communities that affect PLWHIV and PTC uptake and outcomes	IM, AM
12.30pm	Understanding the needs of different groups	Identifying the needs of the groups around HIV and AIDS and health	SD, PN
13.00pm	LUNCH		
14.00pm	Understanding the needs of different groups (continued)	Groups report back and discuss	RL, BK
15.30am	Interventions for prevention, treatment and care (PTC) at community and primary health care levels.	Session to share information on the current PTC options and challenges of a people centred approach to PTC, particularly from the perspective of PLWHIV.	KM , IM
16.30pm		Concluding discussion on the day- organizing delegate feedback and note of areas for follow up	RL, SM

DAY TWO – THURSDAY 28TH FEBRUARY

TIME	SESSION CONTENT	SESSION PROCESS	ROLE
8.15am	Review	♦ Review of materials read and Day 1 feedback	SM
815-945	Parallel session for 2007 group		
REFLECTIONS ON PRA APPROACHES			
8.45am	What do we mean by PRA?	Guided discussion on PRA– basic principles, methods, goals , emphasizing transformative nature of PRA. Agree/ disagree tool. Discussion on why PRA methods are central to people centred health systems.	BK
945am	Using PRA approaches	Panel from the 2007 group on lessons learned on implementing PRA approaches after the course and in programme work and discussion	2007 gp
DEVELOPING FOLLOW UP WORK			
11am	Identifying areas of follow up work and organization of people into clusters to discuss their work.	Using a PRA approach to make clear the goals and outcomes to be achieved, each cluster having shared goals with possibilities of local variations in action	ALL
12.00pm	Reflection on where we are and how we are progressing towards goals	Session to introduce ways of assessing and discussing with communities and health workers current levels of key features or outcomes aimed at (baseline surveys, wheel chart) and progress in achieving goals: progress markers of changes	CM Lusaka DHB

		desired (outcome mapping tools)	
13.00	LUNCH		
IDENTIFYING BARRIERS OR PROBLEMS			
1400-1600	Parallel session for 2007 group		
14.00pm	Problematising: identifying options for acting on health needs / problems	Identifying causes of problems/gaps	SM, AM, PN
15.30pm	Barriers and facilitators to access to health interventions-evidence from field work in ESA	Presentation and discussion of findings from field work in ESA	IM
USING THE PRA PROCESS IN OUR WORK			
16.30pm	Moving work forward: The PRA spiral	Review the PRA cycle. In buzz groups to discuss in programmes:	BK, TB, CDU SA
17.30	END OF DAY TWO		<i>Videos onPRA</i>
615pm	Facilitators planning meeting		

DAY THREE – FRIDAY 29th FEBRUARY

TIME	SESSION CONTENT	SESSION PROCESS	ROLE
8.15am	Work on PRA cycle	Steps of the PRA cycle Review and discussion	ALL
BUILDING COMMUNITY, PHC ORIENTED ACTIONS			
1100-1300	Parallel session for 2007 group		
11.00am	Prioritising problems and developing actions	Group 1: Prioritising Issues or Interventions Group 2: Developing Actions with communities and health workers	SD/BK AM/SM
12.30pm-	LUNCH		
14.15pm	Improving communication between communities and health services	PRA approaches on how people and health workers communicate with each other and tools that can unblock communication barriers	KM BK and JO
15.45pm	How can health systems give meaningful roles to communities?	Discussion on roles of health workers and communities in PTC programmes.	IM, AM KH
1700	Final session	Review of materials and Day 2 feedback	SM
1800pm	Facilitators planning meeting		

DAY FOUR – SATURDAY 1st MARCH

TIME	SESSION CONTENT	SESSION PROCESS	ROLE
830am	Review of the toolkit	“Walkthrough” of the toolkit and the resources	BK, SM
DEVELOPING FOLLOW UP WORK			
900am	Review of next steps	Outline of follow up research/.programme opportunities and guidelines for proposals	RL
1030-1130	Parallel session for 2007 group		
900am	Mentored work in clusters	Proposals for future work with mentored inputs.	ALL
1100am	Facilitating PRA processes	PRA Session Experiences of facilitation from the 2007 group (20 mins)	BK, SM CO (Ke), AM (Ug)
12.30	Links to social networking and policy engagement on HIV and AIDS, EQUINET networking	Discussion of opportunities for networking on community / PHC oriented strategies on PTC	KM, IM, RL
1300pm	Evaluation of the workshop	Ballots in the Box	ALL
13.30pm	CLOSING		
		Brief closing comments	