

**PARTICIPATORY METHODS FOR A PEOPLE
CENTRED HEALTH SYSTEM
Regional results and review workshop
REPORT**



Source: M Chigama 09



**Training and Research Support Centre
(TARSC),
with Ifakara Health Institute (IHI)
in the
Regional Network for Equity in Health in East And
Southern Africa (EQUINET)**



**Munyonyo, Uganda
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with support from SIDA (Sweden)

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1. Background and objectives

Training and Research Support Centre (TARSC) working with Ifakara Health Institute under the EQUINET umbrella have since 2005 been carrying out capacity building on participatory reflection and action for research and training for a people centred health system. The work has used participatory action research (PRA) methods to explore different dimensions of health systems to explore how they empower both communities and local health workers. The capacity building in PRA is taking place in the context of EQUINETs overall work towards building people centred health systems, based on values of equity, social justice and the right to health, based on attainment of comprehensive, universal and primary health care oriented health systems, that .

1. organise, empower, value and entitle people.
 2. are fairly financed with equitable mobilisation and deployment of resources.
 3. retain and value health workers,
- and backed by fair global policies that reverse unfair resource flows and provide national and regional policy flexibility to exercise policies that improve health.

The work in the PRA programme has targeted both national and district/community level cadreship to link research to action and change at primary health care service and community levels. The research programme has sought to build understanding of the nature of health worker-community interactions at primary care level, and how these can be organised to strengthen positive health outcomes. We have also in the programme examined the health sector responses to AIDS at primary care level to explore how these can reflect PHC orientation. Finally the programme has build capacities to 'keep eye on equity' using photography.

The workshop on Participatory approaches to people centred health systems was held on the 22nd of September 2009 in Munyonyo Uganda before the EQUINET regional Conference held at the same venue on 23rd -25th of September 2009. This gave participants from the workshop an opportunity to engage with the wider regional community working on health equity, but also to feed input from the participatory work into the conference process and resolutions.

The regional review workshop gathered researchers from the PRA research programme since 2005. The studies implemented that were used as the basis for the discussions are separately reported and are shown in Appendix 8.3. The workshop reviewed the learning from, policy issues and knowledge gaps from the research studies, to inform planning of future work on empowerment and health and on people centred health systems in the ESA region and to explore the role of PRA approaches and community photography in this work (see workshop programme, Appendix 8.1). The workshop gathered those who had led the studies, community photographers and others involved with work on empowerment and health (see delegate list Appendix 8.2). The facilitators were Dr. Rene Loewenson, Barbara Kaim, Fortunate Machingura, Senele Dhlomo from TARSC and Thandiwe Loewenson (University of London). Selemani Mbuyita if IHI sent apologies due to personal circumstances beyond his control.

This report documents the proceedings of the meeting and has been compiled by TARSC.

2. Overview of the work on participation and health in EQUINET

Dr Rene Loewenson, TARSC gave an overview of the work on participation and health in EQUINET. The interest in understanding the role of power and participation in health started from the beginning of EQUINET work in 1998. Even the definition of equity integrated a dimension of people's power, as shown below:

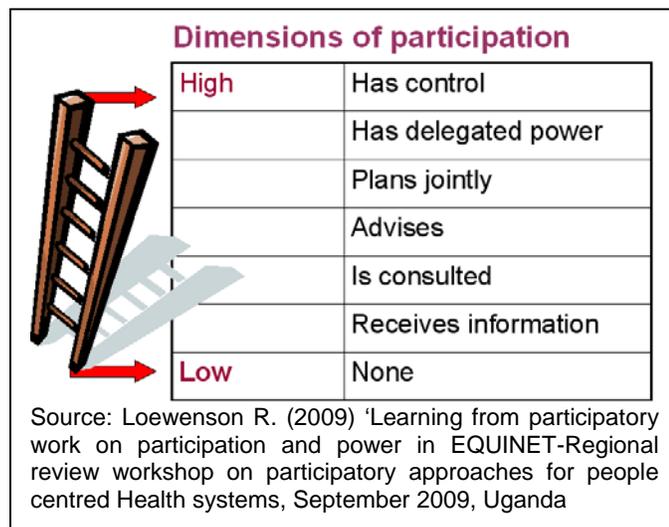
'Equity in health implies addressing differences in health status that are unnecessary, avoidable and unfair'

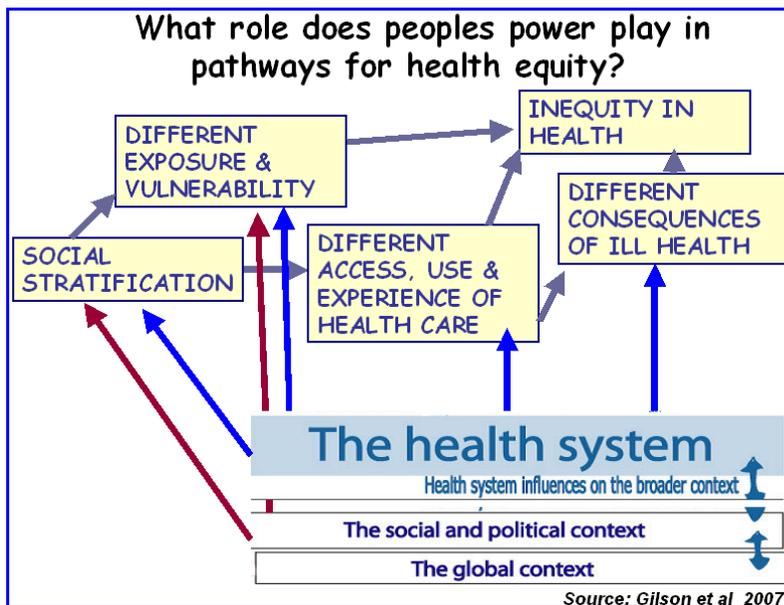
'Equity in health implies directing more resources for health to those with greater health need'

'Equity in health means having the **power** to influence decisions over how resources for health are shared and allocated' EQUINET SC 1998

This dimension is often ignored, but is fundamental. Understanding participation involves understanding the way in which power and control over resources enables or undermines the achievement of health and universal access to the determinants of health, like safe water, food or health care. Different social groups have different levels of power to access these resources, even when constitutions provide that all have equal rights. Imbalances in power arise for example due to asymmetries in information, in wealth, in social position or in access to public services and resources. While water, food and resources may be distributed, power is not given, it is claimed. So people cannot really be empowered by others- but people can create the contexts, conditions, processes, institutions and relations that are empowering or disempowering.

EQUINET work in 1999-2000 through TARSC, CHESSORE and Ifakara explored different dimensions of participation and how the organization of health systems in ESA provided for public participation. She noted the different levels of participation that were found. While each dimension of participation has value, higher levels where vulnerable social groups have some say in health planning and budgets may allow more directly for resources to be used for their health needs. Clearly controlling the resources for health directly gives more power than persuading others to put resources towards ones needs, so that building the organization of communities to claim their socio-economic entitlements is an important tool for health equity. Hence rights to health are useful for health equity when they are accompanied by processes that build collective power and processes in vulnerable groups; and where rights are operationalised through the social actions of those groups.





Source: Gilson, Doherty, Loewenson and Francis 2007 in Loewenson R. (2009) 'Learning from participatory work on participation and power in EQUINET' Regional review workshop, 22 September 2009, Uganda

Health systems can themselves support the conditions for greater or lesser degrees of social control and empowerment. The knowledge network on health systems in the Commission on the Social Determinants of Health identified that health systems can take account of and influence the power imbalances in society, (such as in the way they treat women); can enable or disable peoples control over the resources that affect their exposure to disease (such as in how they promote nutrition); can influence the access to, uptake of and experience of health care

(such as through PHC and outreach approaches) and the consequences of ill health (such as in how they engage with and respond to their specific needs) (see figure above). The knowledge network provided evidence that health systems can stimulate vicious or virtuous cycles around the power dimensions of health equity. They can withhold information, reduce autonomy and weaken local control of health resources, or they can be a site of transformation, informing, supporting and resourcing local decision making and action for health. While health systems have developed approaches for technical dimensions, they have less capacity for addressing the factors that disempower disadvantaged groups, or for communicating and facilitating social action. Health workers may have strong technical skills, but weak facilitation skills. These issues become even more important in systems where resources are scarce and social, living and working environments themselves produce high burdens of disease.

Equitable health systems were found in the global review of evidence to

1. Strengthen comprehensive PHC oriented health systems across all providers
2. Provide clear public leadership to other sectors in health
3. Redistribute resources within the health system
4. Recognise and invest in the central role of people in health systems

The research studies, PRA network and 'PRA4equity' email list have begun to explore this further. Through 20 studies in 9 countries, PRA methods have been used to explore the nature of interactions between health workers and communities, to examine their role in the reach and uptake of and adherence to key services, such as treatment for AIDS, maternal health, environmental health, mental health or primary care services. In a second phase the studies have explored more deeply PHC approaches to prevention, treatment and care of HIV and AIDS. In a third phase work has been done to explore the

role of community photography in communicating the process, actions and learning, and as a tool for further PRA work to support social analysis and action.

Participatory research

- systematises local experience
- organises reflection, analysis on relationships, causes
- uses collective validation to generate knowledge; and
- links analysis to community voice and action

But is it an effective source of new knowledge or an effective approach to social power?

The 20 studies all followed steps of problem identification; a baseline assessment (survey); PRA processes (with range of tools to organise evidence and perceptions from communities, health workers and others); action planning and intervention, with progress review using progress markers and follow up assessment and review to assess change in the determinants and outcomes under study.

In terms of learning on health equity, the 20 studies showed that

- Communities understand and prioritise causes of ill health, sometimes at a more structural level than health workers;
- Social, cultural, family, partner relations play a major role in recognising and acting on health problems;
- Economic issues- food, transport, incomes- play a role in health for most households;
- Children rate psychological support and caring as high as food, shelter in their health.
- Workplace and production causes of ill-health are often hidden;
- Communities don't raise ill health issues they don't think services will respond to;
- HIV may disempower or empower, depending on the social response;
- Dehumanising social treatment leads to vicious cycles in ill health. and
- As peoples power over health improves, so their expectations for health also increase.

The studies showed that health systems do respond to community priorities, but don't detect or respond to all. They don't link well across sectors and resources in responses and narrowly perceive community roles. They have high legitimacy but weak capabilities for social roles, have top down planning and weakly address barriers and facilitators to health service uptake and adherence, leading to resource inefficiencies. They often do not have adequate resources at primary care level to lead adequate responses.

However the studies show that these issues are amendable to change: Communication and perception gaps can be closed, such as through changes in work organisation or client networks. Increased awareness within communities supports early detection of and response to problems and uptake of services and activating joint mechanisms increases co-operation and trust between communities and health systems. Shared diagnosis improves co-operation and co-ordination across agencies, actors and sectors. This led in the studies to strengthened detection of health problems, more effective uptake of local resources for health, reduced risk environments, risk behaviours and morbidity and increased resource inflows for promotion, prevention and care. It also led to improved uptake of and adherence to services. She raised the issue of how these

processes and gains are institutionalised within health systems. While the studies are all at too early a stage for longer term institutionalising this is an important issue to address.

Using PRA approaches was found to support recognition and community detection of health problems and their causes; enhance dialogue and shared community-health worker analysis of priorities and needs. It overcame some power imbalances, organised networking in vulnerable groups and supported co-ordinated health action from local institutions. However there were limits and challenges experienced. The methods need facilitation skills and time, and there are limits to generalisability of findings. The approach has been effective in dealing with determinants within community or local service control, but not so far in dealing with deeper structural determinants. She raised the need to explore further the link between the changes in power and participation at local level through these processes and the wider national level processes and interactions that change policy and resource allocation.

The discussion on the work was then continued through the three parallel sessions in the morning reviewing the two streams of PRA research and the community photography. The next three sections present these parallel discussions. The three groups reconvened as a plenary in the afternoon to bring together the learning across the streams and review the proposals for follow up work.

3. Participatory research on health worker community interactions

The participatory work on health worker-community interaction began in 2006 to explore how participatory approaches could bridge the communication/interaction gap between the community and health providers. This work in different countries focused on relations between communities and health workers. The researchers prepared in advance and presented at the meeting major points of the problem they explored, the aims of their work, what they did, what changed. These are fully reported in the reports of the research on the EQUINET website. The studies showed in different ways lack of trust between communities and health workers and high levels of suspicion. Power dynamics were significant and affected access to utilization of health services.

“In most cases, you find health workers thinking that they are doing the community a favor by providing health care services, and communities felt that access to health care services was a right and not a privilege for them. This is usually difficult for poor members of the community to their health needs to 'topo busy' health workers clearly. If an informed person comes, the Health workers are usually threatened and challenged, however, those who do not may not come back again or will use more resources to access a much further health center, so while we have effected some change, we still need to push even further to address interactions between health workers and communities”.

Dr. Clara Mbwili-Muleya, Zambia

Participatory mechanisms brought health workers and community members to collectively share, plan and execute. Local committees were thus seen to provide an interface between communities and health workers, such as community health

committees, and health facility committees. They act as a buffer between communities and the health worker while also encouraging collective resource mobilization, planning and execution.

"PRA has opened opportunities for meaningful dialogue; community members are now able to challenge our policies and are pushing to more action and results!"

Mr. Moses Lunga- Zambia District Health Management Zambia

Participants noted the need to set up these mechanisms and to foster an appreciation of their role and of participatory approaches in policy levels of the health systems. While most of participants worked at community level there was concern that the issues needed a platform with legislators and policy makers.

" At present, implementation of health policies is ad-hoc particularly with health workers, who lack and need exposure to PRA methods to widen the opportunities of this work".

Mr. Jimmy Wilford-SAYWHAT Zimbabwe



Discussion chart on Health Worker - Community interactions: 22 September 2009 Source TARSC

The work on health worker-community interaction showed that communication needs to also bring in influential powers in the district councils/local government, including managers and frontline primary care workers in communities, as this improves communication skills and validates community knowledge. This is critical as differences in culture and power relationships between health workers and their clients can act as barriers to effective and sustainable health development. The health workers involved in the PRA processes became more open to listening to community members, and to communicating information to communities demystifying perceptions. The processes enhanced team working, participatory decision-making and use of local ideas for solving health problems collectively.

Power dynamics are 'real' and 'difficult' to change, and need stronger force to change supported by policy and rights-based approaches. Attitudinal change among district-level workers was slow and there is resistance from health workers to such change. Language is often a barrier. Health workers often use *english* or *medical terms* that are unknown to communities, giving the health workers a status of knowledge and power, but compromising communication with communities. Community members continue to be seen as passive recipients of health services, undermining their role in health.

4. Primary Health Care oriented responses to AIDS

The work on PHC oriented responses to AIDS began in 2008 to build knowledge and action on community and health systems barriers in accessing comprehensive prevention and treatment for HIV and AIDS and in strengthening equitable primary health care responses to HIV and AIDS. The study reports are on the EQUINET website. The work was supported by TARSC, IHI and REACH Trust Malawi.

The studies indicated a common conclusion that people living with HIV (PLWHA) should be involved in interventions from planning stages. This was particularly felt to be important for vulnerable groups like Commercial Sex Workers (CSWs) for services to be 'friendlier' to and used by such groups.

"I think to effectively deal with responses to AIDS targeting CSWs, one key issue is that we should first identify the team that is seen as role models by such a social group such as ex-commercial sex workers. We train them in participatory responses to HIV and AIDS and work with them to reach out to people currently in the trade. Former CSWs could be used as role models to use peer education methodologies to influence current CSWs."

Kingsley Chikaphupha-REACH Trust-Malawi

The response to the epidemic provides new opportunities for participation in prevention, care and resource allocation for interventions. The studies indicated that participatory approaches enabled communication across groups with wide communication barriers or gaps in status. At the same time all the sites found that an essential package needed to be defined for a PHC approach to AIDS. It was suggested that this include access to Voluntary counselling and testing (VCT) and treatment (ART), basic reproductive and child health services including family planning, maternal care, nutrition education, psychosocial support, immunization as well as control of selected communicable diseases, curative care, treatment literacy and behavior change communication through participatory approaches. Prevention services including VCT, condom distribution, prevention and treatment education should be decentralized down to primary care level to assure both coverage found to and community involvement. This package should be delivered through different levels of the health system in an integrated manner with other services, supported by mechanisms for participation at community level to facilitate dialogue, transparency and trust and by monitoring and evaluation systems. Rural communities particularly were have difficulties in accessing and adhering to treatment due to several socio-economic impediments, shortages of health workers and poor road networks. The cost of ARV treatment was found to be a barrier in responding to AIDS in ESA. If costs are reduced, such as by use of generic drugs and inexpensive laboratory monitoring techniques, access can be widened. Further this needs to be supported by nurse based treatment and care systems backed by informed communities. Training activities targeting clinic level personnel and primary care workers in treatment literacy, care, management of opportunistic infections and appropriate referrals. Treatment literacy needs to be widened to cover the range of primary care based prevention, treatment and care services supported by trained primary care workers such as home based care givers, and village health workers and health literacy facilitators should be involved to promote adherence and facilitate access to and uptake of treatment.

5. Eye on Equity

The community photography work was implemented in communities already implementing the PRA research. We used some photography in the PRA work, to communicate the realities of people's lives and actions. In 2008, we proposed to go further, and use photography as a tool for visual literacy, to support reflection and action. Through the facilitators of the participatory work in seven of the nine areas a community member and facilitator was brought to a regional workshop for training in photography skills.

COUNTRY and area	PRA facilitator, work focus and url for report on the work	Community photographer and role in the work on people centred health systems
Zimbabwe, Victoria Falls	Dumisani Masuku, Holistic Support for Children Initiative, Primary Health care and community responses to support of orphans and vulnerable children	Maria Chigama Chinotimba, Victoria Falls, A volunteer field worker, and member of the team in the participatory work. She follows up cases and actions to support vulnerable children with participants in the community.
Kenya, Rachuonyo District, Western Kenya	Jacob Ongala, Rachuonyo Health Equity (RHE) Intersectoral responses to nutritional needs among people living with HIV in Kasipul, Kenya	Samson Ouma Juma is a member of Victory Fellowship Centre, a local church in Kaisipul Division where he serves as youth leader. He is involved in mobilizing community members with HIV to form or join support groups then link them with health workers and local institutions providing nutritional support.
Uganda, Kamwenge rural	Aaron Muhinda Coalition for Health Promotion and Social Development (HEPS) Promoting access to maternal health and prevention of vertical HIV transmission	Josely Musingye lives in Kamwenge, and is a teacher by profession and a district woman chairperson. She is part of the team working on the participatory work on women's maternal health.
South Africa, Cape urban	Ashraf Ryklief, Industrial Health Research Group (IHRG) Health Workers' Experiences and Needs around Occupational Health Services in Cape Town, South Africa	Dorothea Renatha Baatjies is a health worker at Brooklyn Chest TB Hospital, a union member and shop steward of HOSPERSA and participant in the participatory work of the Public Health Sector (PHS) Trade Union OH&S Forum.
Zambia, Lusaka Urban	Clara Mbwili, Lusaka District Health Board Strengthening community–Health Centre partnership and accountability in Zambia	Adah Zulu Lishandu is a health worker at a primary care clinic in Lusaka. She is one of the pioneers of the participatory work and her health centre is recognised as a model centre in the city.
DRC, Bunia	Amuda Baba, Institut Panafricain de Santé Communautaire (IPASC), Improving acceptability and accessibility of HIV testing and treatment services in Bembeyi, Bunia, North eastern DR Congo	Meso Ulola is an IPASC graduand who lives in the community. He has college education and is an active member of the participatory work team.
Tanzania, Bagamoyo periurban	Mwajuma Masaigana, Training and Research Support Centre Tanzania	Selemani Ally Joe, Msichoke Seaweed Group and Cooperative Society works with children on malaria prevention and control in Bagamoyo on through Ifakara Health Institute, in collaboration with the district. He is also a Community Health Worker.

At the training in Bagamoyo in early 2009, we shaped a programme of work using photography that would be embedded within work on strengthening people's power in health. We wanted the photos to enlarge the lives of the people involved, to show the diversity of views, to allow both painful and hopeful images to surface, to pose questions, probe, give visions of solutions and actions. It was as much a means to encourage local community discussion to reinforce other processes underway as it was a means to raise wider awareness and community voice on issues. We called it "Keeping an eye on equity: Community visions of equity in health",



Discussing the photography experience D Baatjies 09

A set of photographs were selected from each country and mounted into an exhibit to be displayed at the EQUINET Conference. The community photographers and facilitators (R and T Loewenson) reviewed the experiences and exhibit and developed the collective messages to be portrayed.

Looking across the different countries we saw how much children and women featured in our work: Across the countries children were a vulnerable group and women filled the photographs with many different kinds of work.

Generally one is drawn to photograph children. But when it comes to health equity, children are even more in focus, as a sign of how well we are doing in society. We feel the injustice strongly when we see children in unfair and harmful situations. It motivates us to act. The photographs make one realise how much women are doing in the community, often without recognition, and sometimes at the cost of their own health. This is not just about burdens. The images show the many ways that that women can make a real difference in health, but also how they are restrained by lack of time and lack of resources.

Many of the photographs show the ways communities can and do act to protect their health. Often this may be shown through images of people marching or protesting. But people, especially women, act in many ways for their health and to promote health and care for others.

"To advocate for social justice in health we need dynamic and powerful approaches- photography is definitely one of these"

"I saw in the photos a woman sitting in an impossibly long queue outside a clinic waiting patiently to see a health worker...it was an image of how the right to health is violated"

"This is the inequality that exists before our own eyes..." "and that we do not see"
Delegates to the EQUINET conference

For the community photographers the process has built skills and provided the space to be creative, to learn new skills, and to discuss, engage on and relook at work underway. They reported feeling:

- motivated to act and use photography!
- Inspired!
- Encouraged
- Pleased to be a part of the group
- proud to be part of change
- I feel great - I am now able to communicate my world.

"I feel free- I am liberated by this new skill- I am now able to communicate my world"

M Ulola, Community photographer, DRC

They still felt a gap in our work in adequately showing the response to the issues that the work is exposing, and in communicating the differences within communities. While the work in health in the communities meant that people did not see the photographers as outsiders, there were challenges. Some people were unwilling to have their photograph taken as they had heard stories of exploitation by people taking images for profit. In one country it took a long time to get permission to take the photographs and then permission from the people individually. However, these challenges also led the photographers to connect with people in unexpected ways, and to hear people's opinions of their health and health care. The camera seemed to open new channels of communication, raising issues that may otherwise have been buried. So while the camera is a powerful tool for communicating through images, it seemed to trigger more than his and to open new dialogue and interaction within the community.

In South Africa, Dorette Baatjies, found that the challenge of getting permission to take photographs gave her work an unexpected new dimension. After weeks of persuading her hospital administration to grant her permission, she then had to get permission from patients individually. However, in doing this, she found that she reconnected with her patients in unexpected ways.



Health worker in the work in South Africa D Baatjies 2009

She found that taking the photographs, discussing and analysing them with patients brought unexpected and new information about their opinions of health services.

The Kenyan experience was different. Samson Juma found that in his community of Kasipul, children acted as good sensitizers to the camera and photograph. Often adults were wary of the camera. After seeing the children with the photographer and hearing from them what the process was about and for, they were willing and engaging both with the photography and PRA process.

In the DRC, one of the biggest challenges was the remoteness of the community. Meso Ulola from Bunia, DRC, found that having to approach his PRA work with the added eyes of a camera lens made him reconnect with his work and community. By having to explain to people his process and the tool of the camera he found that new issues would be discussed. He had also made himself more engaged and approachable as a member of the community involved in PRA activities. He felt this to be a positive outcome of the photography process that may not have happened had he not been equipped with the camera and the ideas of photography and its power.

The photographers felt the exhibit to have been a success. It communicated many of the realities that we experience in our communities and the work that we are doing. However, they grappled with finding the right captions and quotes to convey the full extent of what they were trying to capture with the image. Selemani Ally Joe, in Bagamoyo, Tanzania, resorted to mini films to capture the full extent of the environment of a specific place, or the nature of a conversation between people. Finding ways of conveying a fuller picture, through quotes, caption, or even picture codes alongside photographs, is something that needs further work in the future.



Feedback on the work at the exhibit D Baatjies 09

They agreed that the photograph exhibition was a strong outcome of the work done.

The exercise had not been an isolated incident but a process. The learning retreat to Bagamoyo gave the space and environment to be creative and learn about how others were working in the region, to learn new skills, discuss work, and reflect on how to take the photography back to communities and PRA work. On returning from Bagamoyo, the photographers found ways of capturing the realities and images to show their work, and the reasons for doing it. Uploading the photographs to the internet for peer and mentor review was a further challenge, but the feedback was very encouraging.

The exhibition demonstrated the power of images in communicating. While locally the images promote dialogue on realities shown, they also give new power to those from communities in communicating realities often hidden from people, without feeling limited by language. In fact, the images always seemed greater than the words used to caption them. They produce a lasting effect in peoples minds. .

"We feel this is the beginning and that photography has become an intrinsic part of our work. It has strengthened our work and connection with our communities. It has given us a new tool and outlet to communicate realities with members of the community, policy makers and people in the region. It has allowed us to document and reflect our communities' achievements".

Community Photographers

6. Lessons learned from the work 2005-2009

In plenary, the three parallel groups met to discuss the lessons learned from all the processes of participatory research. Some of these were raised in the presentation by Dr Loewenson in Section 2 and others in the preceding sections 3-5.

6.1 Lessons on empowerment in health systems

Delegates noted the key areas of learning from the prior sessions.

1. *For participation to translate into empowerment some features are needed:* Wide community and health worker involvement at early stages of processes, 'bottom up' approaches to programmes, starting with people's situations, concerns and proposals, a recognition of the social dimensions of health services and investment in these areas, reprioritizing PHC at national level, transparency and accountability in the interactions building trust, space for communities to own and drive actions, respect for community concerns, and positive reinforcement from community led interventions.
2. *These changes call for change in attitudes and perceptions:* People centred approaches call for changes- a shared understanding of needs and priorities, willingness to confront negative power dynamics and mutual respect for community and health worker roles. This calls for commitment to participation as central to the effective functioning of systems;
3. *Processes themselves need to be empowering:* popular approaches like health literacy are able to enhance shared understanding of PHC oriented health systems. The model of PHC needs to be comprehensive and rights based approaches are needed to facilitate people's claims over their services. Processes need to give space for community and local health worker voice, for them to influence policy at higher level.
4. *Mechanisms for dialogue can play an important role:* They strengthen collaboration between health workers and communities that is essential for PHC, provide a focus for other support, such as neighbourhood support groups, social networking or counseling support groups. These community led processes also make these mechanisms function better, especially when health workers and communities are educated on their rights, and when co-ordination is strengthened, such as between services and community health workers, and across community organisations and services.
5. *Contexts influence practice and outcomes:* Political interests and environments enable or disable empowerment within health systems. Poverty overstretches households and health systems limiting possibilities for participation. Poor co-ordination, conflict or competition between institutions weakens the possibilities of action.
6. *Equity is a core value that drives such changes and contexts.*

In the discussion on the features identified, it was noted that those in this EQUINET programme have worked locally on issues with national implications (such as in the PRA work), while in other programmes others in EQUINET have work nationally on issues with local implications (such as in policy advocacy). However, the two sets of processes are often very different and there is little bridging the local to global processes that create conditions for empowerment. It was felt that the bridging approaches and institutions between national and local level processes need to be clarified and that how this is done to sustain and support key positive features of the local level processes may be an important knowledge gap to address in future work.



Discussing the common issues J Ongala 09

6.2 Lessons learned on participatory methods in health

Participatory processes challenge practices that lead to injustice. However building these processes is not without challenge. Delegates observed that building the networks to derive knowledge, learning and change takes time, and requires intensive mentoring and resource support in the early stages. It has to be integrated within routine work and supported by authorities, with orientation of new health workers. Likewise, facilitators need to more carefully address the barriers and distortions in participation, such as the dominance of male over female voice in joint forums, to ensure empowerment of those with greatest health and social need. Finding the balance between local initiative and institutional support is not always easy, particularly with raised expectations of communities. There was an observed challenge to get women, youth and other less empowered community members to participate in joint forums (raised in Namibia, Kenya and Uganda). Furthermore, it is not always easy for health providers to give up power and control at any level of the health system, as found in the Zambia experience. There are language constraints, including in the use of technical jargon, and facilitators need to be able to deal with unexpected experiences, social values and sensitivities (as found in the Uganda study) and to recognize that first impressions are not always correct (Namibia situation).

Delegates felt that PRA approaches are best used in building sustainable learning and change in health systems

- When there are health concerns and there is dissatisfaction among communities
- When there is need to raise awareness and review actions across communities and health workers
- To support processes where communities are involved and actively participate in health planning, budget processes, policy dialogues and interventions;

- Integrated into other community processes eg training, needs assessment,
- To identify problems, needs and priorities from community perspectives and to organize evidence and action.
- To strengthen participation, consensus on priorities together with other approaches.

The studies to date indicate that these processes can meet resistance from authorities and health workers who are unfamiliar with PRA or resistant to giving up power. Uncoordinated programming within the community limits involvement of all stakeholders. The approaches call for skills building and when new health workers come in that may not be aware of the approach, new skills building is needed. PRA processes may also not be appropriate when the political environment is not conducive, where other forms of popular pressure for change are dominant, or where there is an acute crisis that needs immediate solution.

7. Proposals for future work and closing

Delegates discussed and proposed areas for future work, as outlined in the table below:

Area	How and with what actions?
Disseminating the research to date	<ul style="list-style-type: none"> • Produce a book based on Eye on equity exhibit and experiences for communities, civil society audiences within and beyond ESA (underway); • Widen the training using the current manual on PRA for people centred health systems • Develop synthesized policy briefs for parliamentarians and other legislators to inform dialogue and influence policy at that level • Produce popular publications for community level and support this through health forums and photographic exhibitions • Prepare journal paper (underway)
Addressing knowledge and information gaps	<ul style="list-style-type: none"> • Carry out research on knowledge gaps, including on <ul style="list-style-type: none"> • how policies are being made, reviewed and implemented; Who makes policies change? • cultural and structural factors and the role in health systems; • the difference or change that empowerment makes to health resources • Develop a policy brief that define our collective values, goals, work frame and targets • Utilizing existing social empowerment resources in EQUINET such as the Health Literacy manuals for people centred Health systems, publications from other theme areas of work in EQUINET, the photo book, popular publications and promote regional exchange visits to share best practices • Create links and synergies with complementary social empowerment processes in the region such as the Health Literacy Regional work in ESA, SEAPACOH and country networks.
Consolidating	<ul style="list-style-type: none"> • Use e lists and exchange exchange information on practic and

skills to advance action particularly at PHC level	<p>media (community radio, national radio, television, t-shirts, print media and other paraphernalia) to share and update on work and methods</p> <ul style="list-style-type: none"> • Build PRA capacities and skills through national level training in at least 6 countries • Hold regional review forums (rotating country hosts and linked to training activities in that country) • Influence leaders to bring resources to community level
Developing an advocacy agenda	<ul style="list-style-type: none"> • Strengthen, resource and prioritize PHC and intersectoral action for health, with a demand for at least 25% of government spending on health allocated to the primary care and community level of the health system (calling this the 'People's Abuja') • Support rights-based, holistic, integrated and primary care approaches to prevention, treatment and care for disease burdens including HIV/AIDS
Raising resources for the work	<ul style="list-style-type: none"> • Use existing collaborations and partnerships to raise funds at national level • Develop country proposals (national institutions) • Prepare a regional proposal that outlines regional work and appends the country proposals

In summary it was noted that while TARSC and Ifakara had supported national processes regionally, the national level 'hubs' could now take forward the process and skills development, keeping the regional networking to share and exchange experience and build multicountry work.

In the closing Rene thanked all participants on behalf of the facilitators for the rich and diverse contributions and exchange of experiences. She encouraged participants to continue working to strengthen social empowerment in health, particularly using PRA approaches, and reminded of existing resources such as the pra4equity mailing list to keep contact on progress. With this the meeting was closed.

8. Appendices

8.1. Workshop Programme

TIME	CONTENT	PROCESS	WHO
8.00	Registration	NB:Rapporteur E Pecku, Fortunate Machingura, S Dhlomo	M Makandwa
8.30-9.45	PLENARY SESSION		
8.30	Welcome and Objectives of Workshop	<ul style="list-style-type: none"> Welcome Welcome and intros Objectives of and process for the meeting 	M Masaigana R Loewenson
9.00	Overview of the work on participation and health in EQUINET	Overview presentation of work in EQUINET since 2004: aims, issues and processes towards a learning network (20 min) Discussion (25 min)	R Loewenson
9.45 – 11.15	PARALLEL SESSION 1		
9.45	Eye on Equity photographers: reflections on the process	Final preparation of exhibition messages, roles in the conference (60 min) Discussion: Experiences, challenges, learning from the work in 2009 (30 min)	T Loewenson and RL
9.45	Group 1: Health worker- community interactions	Using the PRA work done in these areas, EQUINET researchers Discuss <ul style="list-style-type: none"> What is the learning from the work on the problems and changes needed to strengthen health worker – community interactions for people-centred health systems? What role did PRA processes play in producing these changes? What other methods or processes could be used? What are the implications for future research and policy? 	B Kaim
9.45	Group 2: PHC oriented responses to AIDS	Using the PRA work done in these areas EQUINET researchers discuss: <ul style="list-style-type: none"> What is the learning from the work on the problems found and changes needed to strengthen PHC oriented responses to AIDS? What role did PRA processes play in producing these changes? What other methods or processes could be used? What is their experiences on acceptability of the process by the community in one hand and decision makers at various levels in the other What is the likelihood of sustainability of the process and its outcomes and what is the likelihood of opportunities for scaling up? What are the implications for future research and policy? 	Fortunate Machingura and S Dhlomo
11.15	TEA		
11.45-13.00	PARALLEL SESSION 2		
11.45	Eye on Equity photographers: preparations for the exhibit	Market place: <ul style="list-style-type: none"> Reflection on the use of photography for communication and change Recommendations for future work Discussion (45 min total) Final preparation of exhibition (30 min)	T Loewenson
11.45	Plenary for action researchers: sharing learning from the working groups on empowering health systems	Report back from both groups on (15 mins each) <ul style="list-style-type: none"> learning from the work on the problems and changes needed to strengthen health worker – community interactions for people-centred health systems? learning from the work on the problems found and changes needed to strengthen PHC oriented responses to AIDS? Discussion (20 min) of <ul style="list-style-type: none"> steps and barriers to building such features/ changes. Follow up actions for the EQUINET learning network at local, country, regional level Knowledge gaps and research to be done 	R Loewenson

1.00	LUNCH		
14.00-13.00	PLENARY SESSION		
14.00	Brief sharing of the main learning from the parallel groups	Feedback from eye on equity group of five points of learning and five suggested actions from session (10 min) Feedback from people centred health system group of five points of learning and five suggested actions from session (10 min) Discussion (10 min)	R.Loewenson facilitating Delegate from each group reporting
14.30	Using PRA for social empowerment and people centred health systems	PRA process (40 min;Market place AND discussion) to draw out experience and views, reflect on and consolidate learning on <ul style="list-style-type: none"> ▪ Experiences and perceived capacity gaps in using PRA processes for learning, action and change in health ▪ Reflection on the contexts, potentials and limits of PRA processes for sustainable learning and change in social empowerment and health systems Discussion (20 min): Proposals for next steps (what actions, where, what roles, with what resources) in building PRA capacities and practice in the EQUINET PRA network	Fortunate Machingura
15.30	TEA		
16.00	Future plans	Buzz groups in countries/ institutional teams (30 min) on <ul style="list-style-type: none"> ▪ What people feel they most want to take forward from now ▪ What people feel they are most likely to be able to integrate within their current work ▪ What people feel they are most likely to be able to raise own resources to do Reviewing the cards, discussion on follow up (30 min) <ul style="list-style-type: none"> ▪ Areas for regional support and networking ▪ Future work of the learning network ▪ Future co-ordination of the learning network 	R Loewenson
17.00	Consolidation and closing	PRA process <ul style="list-style-type: none"> ▪ the big messages people want to communicate to the conference and to the wider community on social empowerment for health (20 min) ▪ Closing comments (10 min) 	R Loewenson, and delegates
17.30	CLOSE		

8.2. Delegate list

LAST NAME	FIRST NAME	ORGANISATION, COUNTRY AND ADDRESS
Asibu	Wilson Damien	Country Minders for Peoples Development (CMPD) Box 2353 Lilongwe, Malawi
Baatjies	Dorothea	HOSPERSA 29 Mocavia Street Mamre South Africa
Baba	Amuda	IPASC, D R Congo Box 623 Arua DRC
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Buyana	Kareem	Cavendish University Box 33145, Kampala Uganda
Chigama	Maria	Holistic Child Support Initiative 4207 Chinotimba Victoria Falls Zimbabwe
Chikaphupha	Kingsley Rex	REACH TRUST Malawi Box 1597 Lilongwe, Malawi
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Dhlomo	Senele	TARSC 47 Van Praagh Ave Milton Park Harare Zimbabwe
Gleeson	Nana	Botswana Network of Ethics Law and HIV/AIDS (BONELA), Botswana
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Juma	Samson Ouma	Victory Fellowship Centre Box 433 OYUGIS Nyanza Kenya
Kaim	Barbara	TARSC 47 Van Praagh Ave Milton Park Harare Zimbabwe
Ketshabe	Ronald	Botswana Federation of Trade Unions, Botswana
Loewenson	Rene	TARSC Box CY2720, Causeway, Harare, Zimbabwe
Loewenson	Thandiwe	UCL / TARSC 47 Van Praagh Ave Milton Park Harare Zimbabwe
Lunga	Moses	Lusaka District Health Management Team Zambia Box 30480 Lusaka, Zambia
Machingura	Fortunate	TARSC 47 Van Praagh Ave Milton Park Harare Zimbabwe
Masaigana	Mwajuma Marwa	TARSC Tanzania Box 93 Bagamoyo Tanzania
Mayanja	Andrew	School of Education, Makerere University Uganda
Masuku	Dumisani	Holistic Child Support Initiative Box CT 225 Victoria Falls, Zimbabwe
Mbwili-Muleya	Clara	Lusaka District Health Management Team Zambia Box 30480 Lusaka, Zambia
Muhinda	Aaron	HEPS-Uganda Box 2426 Kampala Uganda
Othieno	Caleb	University of Nairobi Box 19676 Nairobi Kenya
Owiti	Jacob Ongala	Rachuonyo Health Equity Box 433-40222, Oyugis Kenya
Pecku	Enitan	University of Texas Medical Branch, Galveston, Texas USA Home: 2701 Lost Maples Drive
Ryklief	Ashraf	Industrial Health Resource Group PCH-UCT, Bag X3, Rondebosch, South Africa
Selemani	Ally Joe	Msichoke Seaweed Growers Association C/o TARSC Tanzania Box 93 Bagamoyo, Tanzania
Ulola	Meso	IPASC, D R Congo Box 623 Arua DRC
Wilford	Jimmy	Students And Youth Working on reproductive Health Action Team (SAYWHAT) 52 Northampton Crescent, Harare Zimbabwe
Zulu	Idah	Lusaka District Health Management Team Box 50827 Lusaka Zambia

8.3. PRA reports referred to in the meeting

(see www.equinet africa.org for full reports)

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<http://www.equinet africa.org/bibl/docs/PRA%20Rep%20IPASC%20May09.pdf>
3. Chikaphupha, K; Nkhonjera, P; Namakhoma, I; Loewenson, R (2009) Access to HIV treatment and care amongst commercial sex workers in Malawi; EQUINET PRA Paper: EQUINET Harare
4. Community Development Unit, Nelson Mandela Metropolitan University (2008) Promoting partnership between Communities and Frontline Health Workers: Strengthening Community Health Committees in South Africa, EQUINET PRA report:, EQUINET Harare
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<http://www.equinet africa.org/bibl/docs/PRA%20Rep%20RHE%20Jul09.pdf>
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14. Othieno, CJ; Obondo, A; Mathai, M; Loewenson, R (2009) Improving adherence to ante-retroviral treatment for people with harmful alcohol use in Kariobangi, Kenya: EQUINET PRA report: EQUINET Harare

15. SAYWHAT Zimbabwe (2006) Reproductive health challenges in agricultural college communities Zimbabwe: EQUINET PRA report: EQUINET Harare
16. University of Namibia; Ontevrede community (2008) Community action for health in 'Ontevrede' community, EQUINET PRA report: EQUINET Harare