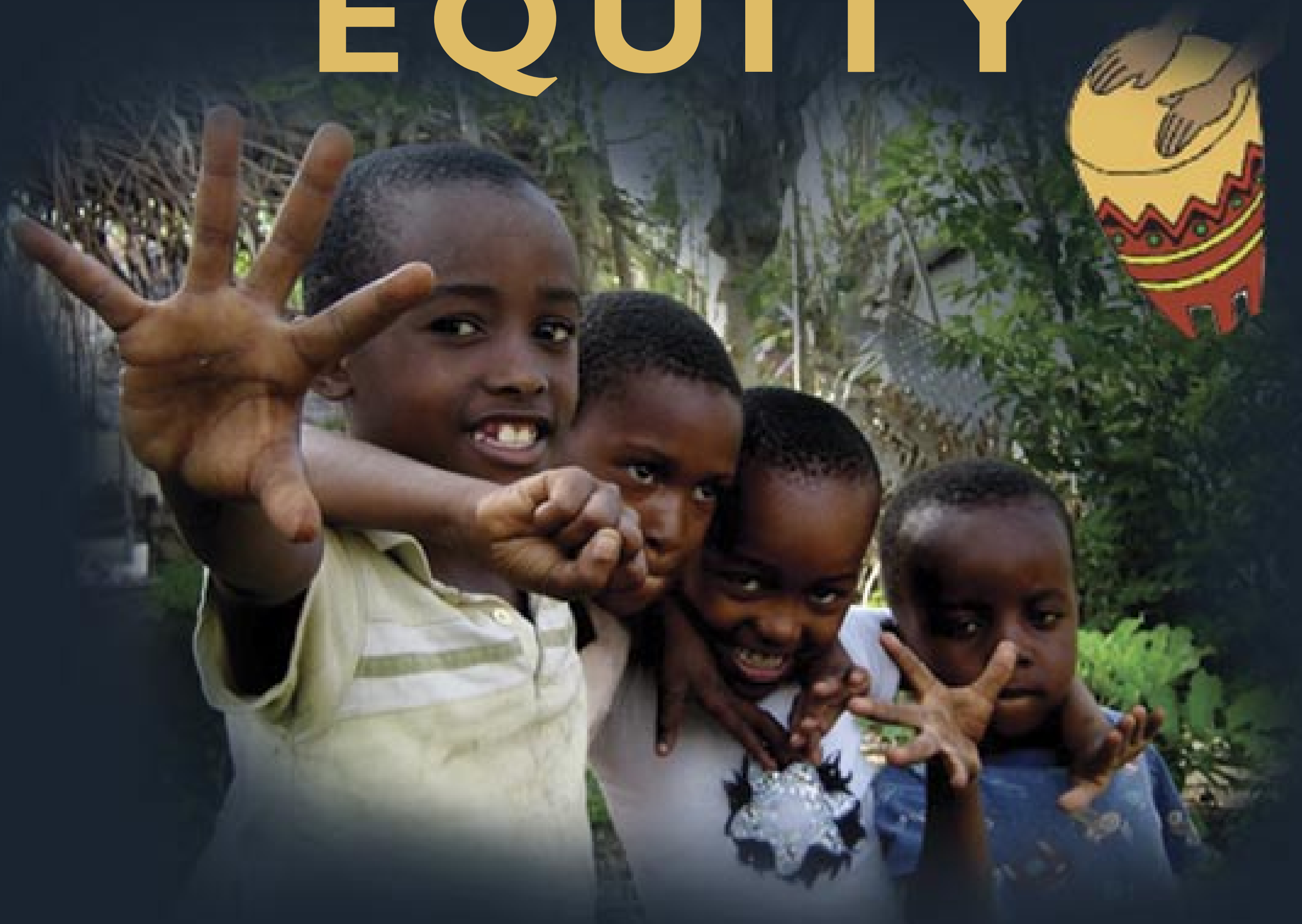
Keeping an eye on EQUITY



Community visions of equity in health

EQUINET

Keeping an eye on EQUITY

Community visions of equity in health

REGIONAL NETWORK FOR EQUITY IN
HEALTH IN EAST AND SOUTHERN AFRICA

Training and
Research Support
Centre (TARSC)

Lusaka District
Health Board Team,
Zambia

Coalition for Health
Promotion (HEPS),
Uganda

Institut Panafricain de Santé
Communautaire (IPASC),
Democratic Republic of Congo

Industrial Health
Research Group,
South Africa

Holistic Child
Support Initiative,
Zimbabwe

Msichoke Seaweed Group
and Cooperative Society,
Tanzania

Rachuonyo Health Equity
(RHE), Kasipul Division Home
Based Care Stakeholders Group
(KDHSG), Western Kenya

Ifakara Health Institute,
Tanzania

In the
**Regional Network for
Equity in Health in East
and Southern Africa**
(EQUINET)

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CONTENTS

FOREWORD

The pictures in this book speak louder than words. Nevertheless, this foreword serves to introduce and explain the origin and context of the work presented here.

Since 1998, the Regional Network for Equity in Health in East and Southern Africa (EQUINET) has generated knowledge, perspective, dialogue, networking and action to advance equity in health. Addressing injustice in health calls for more than technical solutions. It demands public leadership and people's power to assert needs and interests, to influence the allocation of societal resources towards these needs and to challenge the distribution of power and resources that block this. It demands people-centred health systems.

Between 2005 and 2009, coordinated by the Training and Research Support Centre and Ifakara Health Institute, institutions in EQUINET carried out participatory action research studies in nine countries in east and southern Africa, exploring different aspects of community interactions with health systems. We wanted to understand the social dimensions of health and to support the empowerment of groups affected by health issues so they could analyse, act on and change the conditions that undermine their health.

We worked across a range of urban and rural settings, focusing on issues ranging from adherence to antiretroviral treatment in people who consume harmful levels of alcohol to strengthening people's roles and involvement in local health planning. While the focus was determined locally, these programmes had common features.

The facilitators were people who lived or worked in these communities and had a long-term commitment to their health development.

Marching for health
Lilongwe, P Kawale, 2007

Using participatory reflection and action approaches, they strengthened the communities' capacity to identify problems and their causes, they fostered dialogue across the diverse groups affected by these problems and they stimulated collectively agreed actions from those involved. They all sought to build people's power and ability to highlight, understand and act on gaps in access to the resources for health. The research results and evidence on changes is more fully documented in the country study reports. These reports and evidence on the interventions and outcomes are available on the EQUINET website (www.equinetafrica.org) and referenced with websites in the country sections.

We used photography in this work to communicate the realities of people's lives and actions. In 2008, we went further and used photography as a tool for visual literacy and to support reflection and action. Through the facilitators of the participatory work in seven of the nine areas, a community member and facilitator attended a regional training workshop in photography skills. These country teams and examples of their work are presented in this book. In early 2009, we shaped a programme of action using photography embedded within our work on strengthening people's power in health. It was vital for the photos to enlarge the lives of the people involved, to show the diversity of views and to allow both painful and hopeful images to surface. We wanted the process to pose probing questions, give visions of solutions and encourage action.

We know this work will encourage local community discussion as well as reinforce other processes underway. It will broaden awareness and raise community voices on the issues. We call it 'Keeping an eye on equity: Community visions of equity in health'.

The process of engagement around the photos started before we had taken a single photograph. We began by formulating important questions and then engaged with the people in the community to explore the answers. For seven months in 2009 we took this work forward at community level. We shared photos within the group, using the internet for feedback and support and then chose images that best communicated our reality and stories.

Our stories are the stories of insiders. We are members, health workers and health activists in the communities that we photograph. We use the photographs at community and country level to stimulate discussion of the health issues they raise and the actions we can take. At the EQUINET Regional Conference on Equity in Health in Uganda in September 2009, the photographers met to review the experience, the lessons learned and the way forward. The photo exhibition at the conference stimulated discussion not only on the issues raised and action demonstrated in the photographs but also on the power of different kinds of evidence in catalyzing action on health equity. As one participant at the conference commented:

'From other sources of evidence I imagined reality. From the photos I saw reality.'

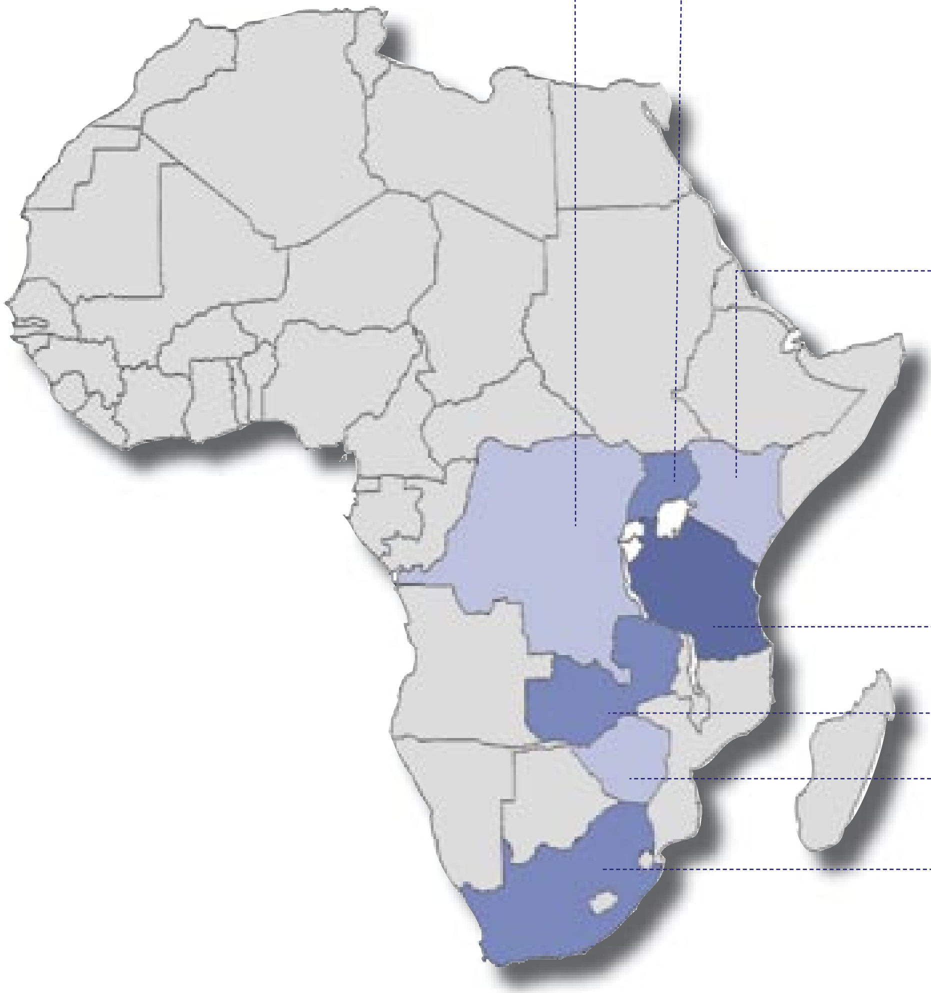
This book introduces the 'Eye on Equity' work and the realities we experience in our communities. It presents the work underway in seven countries in east and southern Africa. Finally it opens discussion on the role of community-based photography as a tool for change.

This book plays a role in the learning process as a tool for our participatory processes. We hope to draw whoever reads it into the dialogue.

Eye on Equity Team, October 2009

THE EYE ON EQUITY TEAM

Community photographers and participatory research facilitators



DR Congo, Bunia

Facilitated and documented by Amuda Baba of the Institut Panafricain de Santé Communautaire (IPASC), an institution that works to improve both the acceptability and accessibility of HIV testing and treatment in Bembeyi.

The community photographer was Meso Ulola, a local IPASC graduate, who is an active member of the team facilitating the participatory reflection and action work.

Uganda, Kamwenge rural

Facilitated and documented by Aaron Muhinda of the Coalition for Health Promotion and Social Development that promotes access to maternal health and prevention of vertical HIV transmission.

The community photographer was Joseline Kabasiime Musigye, a teacher and district chairperson in Kamwenge who is part of the team facilitating the participatory reflection and action work for women's maternal health.

Kenya, Rachuonyo District, Western Kenya

Facilitated and documented by Jacob Ongala of Rachuonyo Health Equity, which is doing work to coordinate intersectoral responses to nutritional needs among people living with HIV.

The community photographer was Samson Ouma Juma, a youth leader at the local Victory Fellowship Centre in Kasipul. He helps mobilize community members with HIV to form or join support groups and links them with health workers and local institutions providing nutritional support.

Tanzania, Bagamoyo peri-urban

Facilitated and documented by Mwajuma Masaigana of the Training and Research Support Centre in Tanzania.

The community photographer was Selemani Ally Joe of the Msichoke Seaweed Group and Cooperative Society. He is a community health worker who works with children on malaria prevention and control through the Ifakara Health Institute in Bagamoyo and in collaboration with the district authorities.

Zambia, Lusaka Urban

Facilitated and documented by Clara Mbwili of the Lusaka District Health Board. The Health Board's participatory action research work has increased accountability and strengthened partnership between the community and the health centres.

The community photographer was Adah Zulu Lishandu, a pioneer of participatory processes who works at a primary care clinic in Lusaka that is recognized as a model centre.

Zimbabwe, Victoria Falls

Facilitated and documented by Dumisani Masuku of the Holistic Child Support Initiative. They work on primary health care and community responses to support orphans and vulnerable children.

The community photographer was Maria Chigama of Chinotimba, Victoria Falls, a volunteer field worker and part of the team facilitating the participatory reflection and action work that follows up cases and actions to support vulnerable children in the community.

South Africa, Cape urban

Facilitated and documented by Ashraf Ryklief of the Industrial Health Research Group. Their participatory work explored health workers' experiences and needs around occupational health services in Cape Town.

The community photographer was Dorothea Renatha Baatjies, a health worker at Brooklyn Chest TB Hospital who is a HOSPERSA union member and shop steward and part of the Public Health Sector Trade Union Occupational Health and Safety Forum.

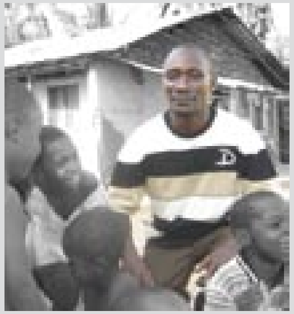
Community photographers
Maria Chigama, Samson Ouma Juma, Joseline Kabasiime Musigye, Dorothea Baatjies, Adah Zulu Lishandu, Meso Ulola, Selemani Ally Joe

Participatory research facilitators
Dumisani Masuku, Jacob Ongala, Aaaron Muhinda, Mwajuma Masaigana, Ashraf Ryklief, Clara Mbwili, Amuda Baba, Selemani Mbuyita

Training and mentoring
Rene and Thandiwe Loewenson, Barbara Kaim, Warren Nelson

Co-ordination, Photography exhibit
Rene and Thandiwe Loewenson

Bembeyi and Bunia



Meso Ulola, Bunia DRC (top)*Amuda Baba, February 2009*
Amuda Baba IPASC DRC (bottom)
Meso Ulola, February 2009

DR CONGO

Accessing acceptable HIV testing and treatment services

Amuda Baba, Meso Ulola, Institut Panafricain de Sante Communitaire (IPASC)

In the Democratic Republic of Congo, where national HIV prevalence is around 5 per cent, services for HIV and AIDS prevention and treatment are not well established, especially in the more remote rural areas. In our area, Bunia, in the north east, with a population of 300,000, people living with HIV and AIDS cannot easily access testing or treatment services. They have to travel to the town some distance away for HIV testing and to treatment centres in other parts of Uganda for antiretroviral treatment. People's lack of knowledge (including about services), the distances involved, fear and discrimination from community members all discourage people from using these services. People are not involved in the responses to HIV and AIDS and past methods to raise awareness have had limited impact.

Left:
The main building of Bembeyi health centre.
Bembeyi, DR Congo
Meso Ulola, 2009

Right page:
No time for rest
Bunia, DR Congo
Amuda Baba, 2009

Between 2007 and 2009 we explored what this means in relation to how our health workers interact with communities. We also considered our primary health care responses to HIV and AIDS.

Different experiences of health systems

We identified two quite different experiences of health systems.

In the first, common in our countries, communities are not well informed about what services are available and lack the resources to choose between services.

They fear the treatment they may get and try to 'beat the system' to meet their needs.

Health workers appear all knowing but are not well trained, nor oriented to work with people or support community roles. They are pressed for time, frustrated and trapped by commands from above.

Communication between communities and health workers is poor. Health workers tend to be controlling and people are resistant to or simply drop out of services. They both lack resources. Furthermore, decisions are imposed on communities and lower level health workers with no opportunity for discussion.

This is a lose-lose situation! The health workers don't gain and nor do communities or services.

The alternative is when communities understand their health issues and needs and are involved in shaping and organizing services to address these needs.

Health workers are trained and supported in providing care in adequately-resourced services at community level. They are able to motivate action in communities and organizations in response to the social causes of ill health.

Community members and health workers recognize and communicate about each other's roles and needs. They respect each other and make the best use of scarce resources to act on shared priorities. All have ownership of and seek to sustain interventions.

This is a win-win situation, good for everyone.

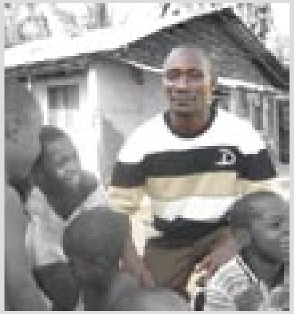
We aim to build people-centred health systems

We are part of a growing network in EQUINET in east and southern Africa mentored by Training and Research Support Centre and Ifakara Health Institute.

The network uses participatory reflection and action methods to understand and promote equity in health. In February 2009, two members from each of our participatory reflection and action teams were trained in photography. We use photography as another tool for change to build and strengthen people-centred health systems and people's empowerment in health.

This book shares our work.

Bembeyi and Bunia



Amuda Baba IPASC DRC (top)
Meso Ulola, February 2009
Meso Ulola, Bunia DRC (bottom)*Amuda Baba, February 2009*

DR CONGO

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Left:
The main building of Bembeyi health centre.
Bembeyi, DR Congo
Meso Ulola, 2009

Right page:
No time for rest
Bunia, DR Congo
Amuda Baba, 2009

The Pan African Institute of Community Health (IPASC) is a faith-based organization operating locally in the north east of the Democratic Republic of Congo. We provide voluntary counselling and testing services and uptake has grown significantly since we began. After testing, as there are no treatment services in this area, we organize a 300km trip for those who test positive – they travel from the town of Aru in the north of Bunia to the neighbouring town of Arua, in Uganda.

We used a participatory reflection and action approach with men and women living with HIV and AIDS, working with people in the 20–49 age group as well as with adolescents, community and church leaders and community health workers in the rural areas. Together we examined and acted on negative perceptions and barriers that block the uptake of these services.

We found that both community members and health workers faced barriers. Health workers lacked resources like drugs and transport while communities faced the barriers listed earlier. Everyone recognized that leaving treatment to the late stages made the situation worse, as people found it difficult to make the long journey to care. Yet social barriers from both health workers and the community discouraged early reporting. We discussed and developed a plan to address these barriers.

Who cares about my health?
Bunia, DR Congo, Meso Ulola, 2009

'I see someone who looks so discouraged, coming from a health centre.'
Young boy

'People are pointing at him, that's what makes him sad.'
Community leader

'I see someone going to the hospital.'
Adolescent boy

'He really feels shameful about being found HIV positive ...'

'Other people regret that this man has tested positive, because maybe he is a relative or an old friend ...'

'He feels so hopeless, not knowing what to do.'

'But he managed to find the courage to go to the hospital.'

'I see a health worker who looks so discouraged, coming from a health centre.'

Community members

'This meeting really came up with the reality that happens in our community.'
Community leader

Top left
Raising community health awareness...with what impact?
Bunia, DR Congo, Amuda Baba, 2009

Bottom left:
Working with whatever is available for participatory analysis
Bunia DRC, Amuda Baba, 2008

Despite recurrent military insecurity in the area, community and church leaders, women representatives, school teachers, youth representatives, health workers and the IPASC team took the planned activities forward. Based on our sensitization discussions, the community decided to address the issue of inaccessibility of services by building a bridge over the river. This bridge would make transfers to hospital much easier. We then met with the Bunia district health authorities to discuss our health services.

Using antenatal care visits to discuss health problems
Bunia, DR Congox, Meso Ulola, 2008

Community meetings always provide solutions to community problems
Bembeyi, DR Congo, Meso Ulola, 2009

The community living library
Bembeyi, DR Congo, Meso Ulola, 2009

'We used to think only health workers could lead discussions on health. Now we know that we students make very good peer educators.'
Bunia, DR Congo, Meso Ulola, 2009

Several months in the year we couldn't reach the health centre when the river flooded.
So we made a plan to change the wooden bridge to a durable stone and cement bridge.
Bembeyi, Meso Ulola, 2009

The cement bridge will make it easier to get to services all year around
Bembeyi, Meso Ulola, 2009

The first bridge crossing to Bembeyi is complete and now the ambulance can at least cross. 'Thanks be to God for our lives,'
Judith, *Bembeyi, Meso Ulola, 2009*

Our review during and after the actions found that people knew more about HIV testing and treatment services and were more willing than before to test for and know their HIV status. The nearest voluntary testing and counselling centre was still about 7kms away and treatment had to be obtained at the referral hospital but the social barriers to using these services had fallen. The new bridge had significantly improved access. With more social dialogue on treatment taking place, people in the area were beginning to negotiate for service improvements.

Communities can significantly change attitudes and remove barriers to testing and treatment if organized to do so. Information is power. It offers an important entry point making it possible for communities to work together and address disabling conditions within the community. Our primary health care interventions need to invest in these social dimensions in an empowering way to make effective use of other resources in the health system.

Read more at: Baba A, Ulola M, Assea M, Ngule D, Azanda N (2009) *Acceptibility and accessibility of HIV testing and treatment services in Bembeyi, Bunia, North Eastern DR Congo,* EQUINET PRA paper, IPASC, TARSC, IHI: EQUINET, Harare at: www.equinetafrica.org/bibl/docs/PRA%20Rep%20IPASC%20May09.pdf

It is easy for a community to participate in an activity it was involved in planning from the beginning
Bunia, Amuda Baba, 2009

Right:
To peace and freedom
Bembeyi, Meso Ulola, 2009

Below:
Together, we are strong
Bunia, Amuda Baba, 2009

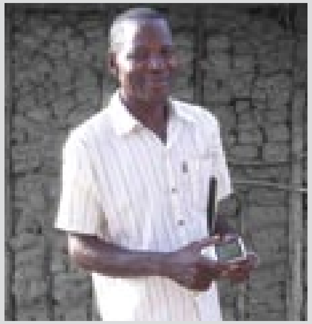
Bagamoyo

TANZANIA

We can do better: Improving the environments for health

Selemani Ally Joe, Mwajuma Masaiganah, Msichoke Seaweed Group and Cooperative Society

Although we live in a coastal region, our community faces problems due to the lack of safe drinking water. Communities have been resourceful in digging wells but these wells are often left uncovered, posing health risks to the community. People in our area are unaware of the dangers of waterborne diseases. Achieving the Millennium Development Goal on provision of safe water for all by 2015 seems to be just a dream.



Mwajumah Masaiganah (top)
Nairobi, R Loewenson, 2007
Selemani Ally Joe (bottom)
Bagamoyo, R Loewenson, February 2009

'A source of life-giving water or a hazard to children?'
A well in the middle of town where children play
Magomeni, Selemani Ally Joe, February 2009

‘This is my water source, and my place to wash and cool off’
Milingotini Bagamoyo, Selemani Ally Joe, April 2009

‘Why do people wash in a place where we all fetch water? They create puddles where mosquitos breed and destroy the environment around water sources.’
Bagamoyo, Selemani Ally Joe, 2009




We face other challenges to health in our environments, including poor housing and unsafe or absent sanitation. There is a danger that people just become accustomed to poor situations and accept the unacceptable. They see diseases as something they have to take to a clinic and not something that can be avoided by improving the environments we live and work in. Waiting to fall ill is risky, as our clinics lack medical supplies and health workers and patients may not always recover. And even if we manage to get treatment, we go back to the same conditions that made us ill.

Our work in the community involves initiating social dialogue through various approaches. We question situations that are hazardous to health and discuss what we can do about them.

Left page:
50 years after independence, what are we waiting for to improve our shelter?
Bagamoyo, Selemani Ally Joe, April 2009

Right:
'How did I get to this?'
Role play in community theatre for health
Bagamoyo, Selemani Ally Joe, April 2009

We discovered in the dialogue with communities that instead of changing our environments to improve health, many people turn to traditional healers. In some cases, this exposes them to further risks rather than helping them. Others turn to alcohol to escape the bad environments they live in, also further harming their health.

Traditional ritual: Prayers, thanksgiving and pardon. People put grass on a person to look like a hut, they tie a live black chicken behind his back to signal life and the ghost-like man leads the rest of the family members back to the village where they celebrate in the belief that ill people will be cured and saved from the evil spirits
Magomeni, Selemani Ally Joe, April 2009

Top and bottom right
Community role play about a situation where a woman has been diagnosed with HIV
Bagamoyo, Selemani Ally Joe, April 2009

Local brewery with alcohol in yellow canisters ready to be decanted into individual bottles
Magomeni, Selemani Ally Joe, February 2009

'Working at the brewery I also drink, and nap while I wait for the next customer'
Magomeni, Selemani Ally Joe, February 2009

There are alternatives. Through community meetings we have discussed how to bring about change. One starting point that we all agreed on is our children. It is essential that we educate them to expect a different life and to know how to create this. They should know that their health and living conditions can and should be a lot better than those of their parents.

'We should make our first priority education, our second priority, education and our third, education. We should look for an opportunity to make that a reality, because with education, we will achieve our goals to reduce, if not eradicate, poverty amongst our people.'
District Commissioner, Bagamoyo

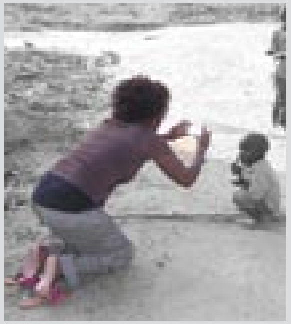
Community meeting in Bagamoyo with the district commissioner
Bagamoyo, Selemani Ally Joe, 2009

'It's a struggle to get the water out but I'm happy we have a closed well.
Next year we will make sure we have a tap'
Magomeni, Bagamoyo, Selemani Ally Joe, February 2009

A young girl looks to the horizon
Magomeni Bagamoyo,
Selemani Ally Joe, February 2009

Victoria Falls

ZIMBABWE



Maria Chigama (top) and
Dumisani Masuku (bottom)
Bagamoyo Tanzania,
R Loewenson, February 2009

Caring for orphans and vulnerable children

Dumisani Masuku, Maria Chigama, Holistic Child Support Initiative, Together for Children, Zimbabwe

Some children in Victoria Falls have difficult lives. They live in poor conditions and never have enough to eat. Those who are orphans, largely due to AIDS or migration, work in hazardous places to earn money and have no parental or adult support. Despite having to play adult roles to survive, when it comes to services, their views and input are often overlooked, particularly at the planning stage. Holistic Child Support Initiative is a Zimbabwean non-governmental organization that aims to support children and give them a voice.

We brought together community members, health workers and children to discuss the problems children face. We talked about improving communication between health workers, community members and children and we resolved to encourage children to participate in primary health care services.

Top right:
Limited choices, the only way to survive for now
Victoria Falls,
Dumisani Masuku, 2009

Bottom right:
But why?
Victoria Falls,
Maria Chigama, 2009

(Below top) And for how long will this continue?
Victoria Falls, Maria Chigama, 2009

(Below bottom) Somewhere to relieve myself
Victoria Falls, Dumisani Masuku, 2009

What about my right to food, shelter and education?
Victoria Falls, Zimbabwe Maria Chigama, 2009

Top: Don't underrate us – we know what affects us, and what we need, *Child participant., Chinotimba Township, Victoria Falls, Dumisani Masuku, April 2009*

Bottom: This is what we think. Child presenting at a participatory meeting, *Chinotimba Township, Victoria Falls, Dumisani Masuku, April 2009*

Right: Together as one – putting our heads together at a child rights workshop
Chamabondo Primary School, Victoria Falls, Zimbabwe Maria Chigama, April 2009

The community and the health workers saw the issues differently. The most significant contribution came from the children themselves. Children wanted organizations to complement one another rather than compete with each other. They wanted better communication between health workers, community members and children. Children felt that assistance from both the community and health workers was limited.

They highlighted that health institutions demand payment, disregarding reference letters from institutions like schools. They said that insisting that children can only be attended to at a clinic if they are accompanied by an adult was harsh and meant that some children were excluded from care.

Above:
Time to play – games in the sand
Chinotimba Township Victoria Falls, Maria Chigama. April 2009

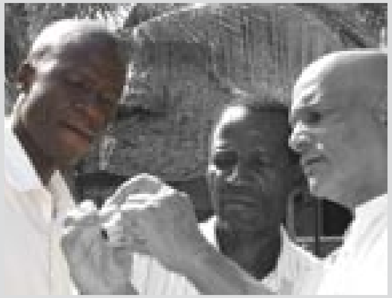
Left:
I love him so I try to give him the best
Victoria Falls, Zimbabwe Maria Chigama, April 2009

'I never knew that children knew all this information. In future we will make sure we involve children whenever we are planning.'
Health worker, Victoria Falls

The children pointed out that they are not involved in identifying their health needs or in the planning and budgeting for them. They felt that only a few centres were child friendly.

We are now in the process of identifying shared priorities for action among children, health workers and community members in a way that involves children and brings together the organizations serving their interests. We hope to strengthen primary health care services that are key to children's wellbeing. Initially, the process seemed complex but now that it is underway, it seems to be flowing smoothly, with everyone's involvement.

Kasipul



Jacob Ongala (top), Rachuonyo Health Equity, and Samson Juma (bottom), Rachuonyo Health Equity
R Loewenson, Bagamoyo, February 2009

KENYA

Responding to the needs of people living with HIV

Jacob Ongala, Samson Juma, Rachuonyo Health Equity,
Kasipul Division Home-based Care Stakeholders Group, western Kenya

'It is hard to walk long distances on foot to access medication at the local clinic, particularly on an empty stomach.'
Community member, People living with HIV

Kasipul Division Home-based Care Stakeholders Group is a forum of care providers that meet monthly to share experiences and lessons in coping with AIDS. It began in 2005 under the auspices of the Ministry of Health and now includes over twenty local organizations. It has established a multisectoral strategy for comprehensive community care systems to support people living with HIV.

Only 30 per cent of the estimated over 220,000 Kenyans in need were receiving antiretroviral therapy by 2006. Many areas have insufficient health workers to deliver treatment but access to treatment is just one challenge. Famine and drought have complicated treatment delivery in many regions of Kenya. Few people get the nutrition they need to support their treatment. People with HIV-related illnesses are less able to work and earn an income or produce food, further undermining their own and their families' nutrition.

Right hand page:
Distance
Kasipul, Kenya, Samson Juma, March 2009

Right:
Traders scramble for scarce food in local Kaisipul markets
Kasipul, Kenya, Samson Juma, March 2009

'Up to recently, I suffered a very bad sexually transmitted infection but could not share my situation with health workers because I was afraid they would quarrel with me.'

Person living with HIV in Rachuonyo District

'My own relatives are tired of me and no-one in the neighbourhood is ready to give me food but the food in the HIV clinic is issued only to thin people.'

Patient, Exit interview

Coping with HIV, the loss of my partner and poverty
Kasipul, Kenya, Jacob Ongala, 2009

Added to the stigma and negative attitudes people with HIV face, including from health workers, these barriers lead people to skip or abandon treatment. Health workers advise people to 'eat good food' before they take the drugs. Clients interpret this to mean 'eat big, expensive meals', draining their already limited income. Some exchange sex for food as a survival strategy, further increasing their risk of AIDS. Others default on treatment when they cannot meet their food needs.

Sucking a water tap trying to get water that doesn't flow
Kasipul, Kenya, Samson Juma, March 2009

'Please help! We've been trying to keep these animals out of the fields for hours now'
Kasipul, Kenya, Samson Juma, 2009

In 2008 and 2009 we implemented a participatory action research programme to support the voices of people living with HIV. We helped them to talk to health workers about their health and nutritional needs and to engage partners outside the health sector to support these needs. People talked about the problems they experienced in taking antiretrovirals on an empty stomach, as they were unable to obtain the costly food they believed health workers were advising. Health workers, in turn, expressed their difficulties with clients skipping drugs.

Producing food and raising livestock are major activities in the community, yet many felt that food was the root cause of people defaulting on treatment. This was confirmed through exit interviews at clinics. It is not only people living with HIV who have problems accessing food. Food security has declined in the whole community as harvests have fallen. However, clinics give food supplements only to people with low body mass indexes. Furthermore, people living with HIV feel compelled to share the food they receive with their families. Even extended family structures have insufficient food to support ill family members.

While communities have in the past provided support to vulnerable groups, people reported that these safety nets had weakened, leaving everyone more dependent on limited individual resources.

'I have eight people looking to me for food and up-keep yet I cannot effectively feed myself let alone them. My HIV infection has progressed to AIDS and I'm too weak to work. I do not have money to hire labour to work on my farms.'

Person living with HIV , Rachuonyo District

Right top:
Food market
Kasipul, Kenya, Samson Juma, 2009

Right bottom:
A boy prepares a meal for his siblings
Kasipul, Kenya, Samson Juma, 2009

Above:
(Top) Getting some start-up capital is a step towards milk production
Kasipul, Kenya, Samson Juma, March 2009
(Bottom) Not too old to produce
Kasipul, Kenya, Samson Juma, March 2009

Left:
We use what we have to meet the needs of our family
Kasipul, Kenya, Jacob Ongala, 2009

The people living with HIV team putting their views together
Kasipul, Kenya, Jacob Ongala, 2008

We observed that the Kasipul community has agriculturally productive land but farms are lying fallow. People don't have enough cash to buy farm inputs and illness is undermining labour and so weakening food security. We considered food supplements were a short-term intervention, an emergency response that could weaken the establishment of longer term approaches. The discussions established actions that would draw attention to the nutritional needs of people living with HIV. We wanted to extend the group support roles to include nutrition support and we resolved to break the isolation of people living with HIV. We included nutrition counselling in community health worker programmes to help patients make informed choices on available local foods, how to process them and prepare meals. Backing this, we organized support for production with self-help groups establishing kitchen gardens, poultry keeping and market gardening.

Our experience suggests that we need to embed our efforts to expand access to treatment within a wider framework of support, involving other sectors. People living with HIV should not be seen as disabled dependants of emergency support but people who understand and can address their nutritional needs through local food resources.

When we reviewed the actions we had taken, we could see an improvement in communication and a shift towards more locally-generated, longer-term strategies for nutrition support.

These health initiatives had wider production and market impact. For example, cooperation between an international and local institution led to the local production of yoghurt that was not only nutritionally beneficial to local people but also provided income to the community.

Read more at: Ongala J, Otieno J, Awino M, Adhiambo B, Wambwaya G, Ongala E and Rajwayi J (2009) *Intersectoral responses to nutritional needs among people living with HIV in Kasipul, Kenya,* EQUINET PRA paper, RHE, KDHSG, TARSC: EQUINET, Harare at: www.equinetafrica.org/bibl/docs/PRA%20Rep%20RHE%20Jul09.pdf

Left top:
Community meeting
Kasipul, Kenya,
Samson Juma, March 2009

Right hand page:
The community built a bridge for people to access the local market
Kasipul, Kenya, Samson Juma, March 2009

Above and right: Local day schools are working with parents and partners to provide lunch for children
Kasipul, Kenya, Samson Juma, March 2009

'This process has helped to remove power barriers that existed between us, health workers and other officials. I feel strong enough now to empower others.'
Person living with HIV, Kowidi

A moment of joy in an inch of water
Kasipul, Kenya, Samson Juma, March 2009

Kamwenge

Joseline Kabasiime Musigye (top), Kamwenge and Aaron Muhinda (bottom), HEPS Uganda
Bagamoyo, R Loewenson, February 2009

UGANDA

Community empowerment and participation in maternal health

Joseline Kabasiime Musigye and Aaron Muhinda with Paul Akankwasa and Moses Mulumba,
Coalition for Health Promotion and Social Development (HEPS)

Despite two decades of economic growth in Uganda, maternal mortality is still high at 435 per 100,000 births. Fewer than half the women deliver in health units and only eight out of every ten women attend antenatal care. Yet fertility rates are high in Uganda. About 1.2 million women become pregnant every year, of whom about 6,000 die from pregnancy-related causes and childbirth.

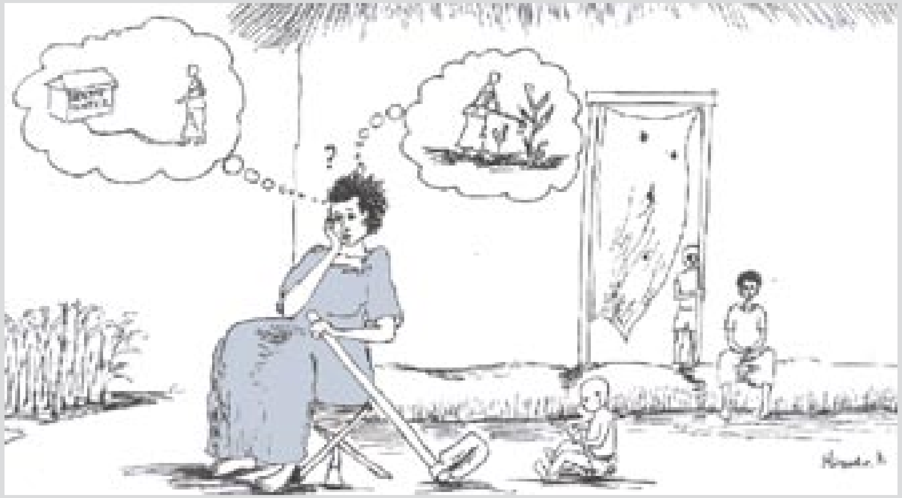
Kamwenge district, as a remote rural area, has even poorer maternal health statistics and a shortfall of health facilities and staff. Women find the services difficult to reach and are sometimes afraid of the health workers' attitudes. They seldom get support from their male partners. Health workers feel burdened by their heavy workloads which are due to understaffing.

Right-hand page:
'I have to finish my household chores before I can think about my health'
Kamwenge district, Joseline Kabasiime Musigye, June 2009

Right:
Children too have to help with chores or they do not get done
Kamwenge district, Joseline Kabasiime Musigye, April 2009

Using picture codes to raise discussion on maternal health

'The woman appears tired, yet needs to go to the health centre. She is in a dilemma since she has to either stay home and feed her family or go for care at the expense of her family. This definitely happens in Kamwenge.'



'The woman is being carried on a stretcher over a long distance. There is not enough support and people have problems with poor roads. This is also a problem in our area.'

'The mother isn't being attended to, though her case is clearly an emergency. She seems to have travelled a long way and this may be one reason for her current condition (miscarriage). This is common in Kamwenge; there are so few health workers, patients have to stand in long queues and emergency care is insufficient."

'The mother is worried about the bill she has received for care. This happens in both the conventional health centre and with traditional birth attendants. The woman's husband is in a bar drinking and not at the hospital clearing the bill.'

Between 2007 and 2009 we worked with community members, leaders and health workers in Kamwenge and Kiboga districts to increase the demand for maternal health services, improve access to these services and encourage people to use them. We used participatory methods to identify the most critical barriers to maternal health within the health services, the community and households. Community members prioritised those barriers that most needed attention.

Community members planned what actions to take and prioritised them. They included: training volunteer community trainers; sensitising health workers in communication skills and the rights of expectant mothers; providing suggestion boxes at clinics for feedback from pregnant women; and setting up public dialogue on maternal health through religious leaders, local radio stations and drama.

Could that be me? Watching the drama on barriers to uptake of maternal health services in Mulagi Sub-county
Kiboga, Mulumba Moses, October 2008

Communicating through drama the barriers to uptake of maternal health services in Kiboga district, central Uganda, Mulagi Sub-county
Kiboga, Paul Akakwasa, October 2008

Children too have to help with chores or they do not get done
Kamwenge district, Joseline Kabasiime Musigye, April 2009

Above and on right-hand page:
Valuing women's work and health: in our community women play an important role in ensuring food security at home
Kamwenge district, Joseline Kabasiime Musigye, April 2009

'The stress from overload makes health workers irritable and sometimes rude to expectant mothers who come to deliver without the necessities such as mama kits. Kamwenge is a remote place for health workers, without housing facilities or extra motivation, and not many well-qualified health workers are willing to take up a job in the area'
Health worker, Kamwenge

'During our weekly meetings, we agreed to treat poor expectant mothers differently. We don't force them to buy previously mandatory mama kits but rather encourage them to at least be prepared for labour.'
Health worker, Kamwenge Health Centre III


AFRICA
FIFA

After the initial intervention people noticed an improvement in maternal health awareness. There was better communication between the community and health workers – health workers and families showed more respect in supporting pregnant women. They were more aware of maternal health in the community and the actions they needed to take. The strongest positive changes were noted in communication between health workers and pregnant women. The intervention had the greatest impact in this area. The health information system showed that the use of antenatal services and deliveries at the clinic had increased in areas where we had implemented the programme.

Yet some barriers remained. The health infrastructure and road networks were still poor. Nursing staff received little support for local accommodation or for transport and uniforms. The procedure for handling complaints from the suggestion boxes remained unsatisfactory. Follow up of HIV testing and adherence to malaria treatment was still erratic. Men still had poor attitudes towards their partners and offered them little support when they attended maternal health services. We are now tackling the issue of male attitudes through our community leadership. We are also liaising through the district administration with central government to ensure that guidelines on health infrastructure, equipment and logistics are met in Kamwenge.

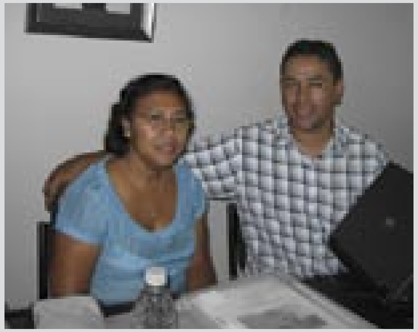
Our work continues.

Read more at: Muhinda A, Mutumba A, Mugarura J (2008) *Community empowerment and participation in maternal health in Kamwenge district, Uganda*, EQUINET PRA paper, HEPS Uganda, EQUINET, Harare, at: www.equinetafrica.org/bibl/docs/PRAheps2008.pdf

Left hand page:
I do what I can to ensure my wife gets the care
she needs during her pregnancy.
Kamwenge district, Joseline Kabasiime Musigye, April 2009

It's great to be alive!
Bagamoyo Tanzania
Aaron Muhinda, February 2009

Cape Town



Ashraf Ryklief and Dorothea Baatjies
Bagamoyo, R Loewenson, 2009

SOUTH AFRICA

Raising our voices, breaking our silence: Experiences in primary level health services

Ashraf Ryklief, Industrial Health Research Group, South Africa;
Dorothea Baatjies, HOSPERSA, South Africa

The culture of occupational health and safety in public sector health services in South Africa is predominantly that of neglect. It is characterised by minimal compliance with the law, by reactive rather than proactive prevention and by a reliance on compensation for injury. Employers, unions and health workers all reproduce this culture of neglect in various ways but health workers are its main victims.

Although there are policies for workers' occupational health, health workers don't know about them and unions don't take strong action to defend workers' health rights. When local clinics are overcrowded, community members struggle to get the attention they deserve. Health workers are also at risk from tuberculosis and other communicable diseases, due to the crowding at service centres.

Right page: Patients queue along the fence outside the clinic from as early as 4:30am until the clinic gate opens at 7:30am *Matthew Goniwe Clinic, Khayalitsha, Cape Town, Dorette Baatjies, March 2009*

Right: The queue grows along the fence *Matthew Goniwe Clinic, Khayalitsha, Cape Town, Dorette Baatjies, March 2009*

'How does one care for someone when we do not care about ourselves? Health care workers have kept silent for so long. Do you know what silence is? Silence is the absence of sound. Sound is when you make an impression and from us as nurses there is no sound or impression. That is why the government can make legislation without asking the health workers. The message of silence – it is "unagreed" but everyone accepts it as a YES. I appeal to everyone to consider your silence because if you don't want to say yes, raise your voice and say NO.'

Nurse, primary care clinic, Cape Town

Through our participatory research, we uncovered poor working conditions that dehumanise patients and health workers. We also uncovered real cases of workplace injury and illness that have been buried under a culture of ignorance, neglect and silence. We collectively took ownership of the issues and acted on them. We engaged the authorities as a group and as a result started to challenge the culture of neglect. By raising their voices and challenging patterns of power relations, participants also began to experience change within themselves.

Above:
Patients pushing against each other to get help that same day
Heideveld Community Health Centre, Athlone, Cape Town,
Dorette Baatjies, March 2009

Left and left hand page:
I come regularly to queue for my chronic medication – every time from 4:30am in the cold
Matthew Goniwe Clinic, Khayalitsha, Cape Town,
Dorette Baatjies, March 2009

While we were able to raise issues and deal with them at the clinics we worked in, what about all the other clinics? What about the way health services are delivered at that important level of interface with the community? An important challenge facing us is how to sustain and spread the action learning process that we have begun. One way we are doing this is through the Western Cape Public Health Sector Trade Union health and safety and HIV forum.

Read more at: Industrial Health Research Group (IHRG) (2006) *A PRA project report: Raising our voice, breaking our silence: Health workers' experiences and needs around occupational health services in Cape Town, South Africa*, EQUINET PRA Report, EQUINET, Harare, at: www.equinetafrica.org/bibl/docs/PRAihrg.pdf

In 2006, the Industrial Health Research Group and a small group of unionised health workers used participatory learning and research methods to investigate and intervene in these conditions. The process involved health worker discussions using participatory methods, workplace-based investigations and the dissemination of networking resources among health workers in the area.

A combination of workplace-based case investigations and critical reflection on interventions provided a very powerful action-learning experience.

'I think that what is important about this approach is that it helps us understand that we learn by doing. The emphasis is on learning through action. When somebody brings a case to you, you learn as you go along.'

Health worker, Cape Town 2006

Security guard's office
Matthew Goniwe Clinic, Khayalitsha, Cape Town, Dorette Baatjies, March 2009

'There is now better communication with management around health and safety. Myself and other workers will now also be going on health and safety training. They are eager to learn and to change their views on health and safety.'
Clinic health worker, Cape Town

Collecting cards from TB patients in an overcrowded waiting room – a health hazard for workers and patients
Matthew Goniwe Clinic, Khayalitsha, Cape Town, Dorette Baatjies, March 2009

Displaying my message
Matthew Goniwe Clinic, Khayalitsha, Cape Town, Dorette Baatjies, March 2009

Lusaka district

Community and health centre partnership

Clara Mbwili-Muleya and Idah Zulu Lishandu,
Lusaka District Health Team and Equity Gauge Zambia

Idah Zulu Lishandi (top),
Lusaka District Health Team
Clara Mbwili Muleya (bottom),
Lusaka District Health Team
Bagamoyo, R Loewenson, February 2009

ZAMBIA

During the most recent health reform in Zambia, we developed policies to achieve the health vision of providing equity of access to cost-effective quality health care as close to the family as possible. The changes focused on leadership, accountability, partnerships and sustainability. We set up neighbourhood health committees to enhance accountability and participation. Despite this, implementation has not gone as smoothly as we expected.

Poor communication and limited information exchange between district authorities, health workers and local communities have led to misunderstandings, loss of trust and less participation. These shortfalls have limited the effectiveness of our actions in preventing and managing health challenges such as the cholera epidemic, which is caused by the lack of safe water and sanitation facilities in some communities.

Right page:
Cholera patients in the recovery tent of the Cholera Centre
Matero Ref. HC, Zambia, Idah Zulu, May 2009

Right:
A Cholera Centre – a village of hope in a cholera epidemic
Matero Ref HC, Zambia, Idah Zulu, February 2009

Between 2006 and 2009, a team from Lusaka District Health Board and Zambia Equity Gauge worked with EQUINET. With support from the Training and Research Support Centre, CHESSORE and Ifakara Health Institute, we used participatory reflection and action approaches in Lusaka city and rural Chama districts to strengthen community and health centre partnerships and accountability. We facilitated dialogue between health workers and communities about their experiences, issues, health priorities and areas for change. We facilitated the implementation and regular review of a joint plan to strengthen partnership and action on the shared health priorities.

We began to see the change in the partnership as the process unfolded. We spread the process to new clinics and areas in 2008, through the teams built in 2006 and 2007. The process uncovered simmering tensions between communities and health workers.

As the process progressed, both groups began to articulate a mutual appreciation of each others' roles in achieving shared goals. They acknowledged the importance of communication and the need for affected communities to be involved in the planning stages of activities. Activities were planned to integrate community inputs into the 2008 planning cycle and to jointly discuss the use of health centre revenue with communities.

People in households affected by cholera often feel stigmatised
Matero Compound, Zambia, Erick Chipita, March 2009

Right page:
Mothers jostling each other to get their babies weighed at a community growth monitoring point
Nazerene Church, Chunga Lusaka, Zambia. Idah Zulu, 2009

'The notice is short and the health centre staff start informing other people verbally. The NHC chairperson calls people nearby and not everyone is involved!'
Community member

'Should communication always start from the person in-charge, why not from the NHC chairperson?'
Community member

'The person in-charge should be aware of what is happening because you can't work in isolation. It depends on the information. Community members may have the information they need to work together. The person in-charge is the entry point for things to move smoothly.'
Health worker

(Top) Community volunteers disinfecting and contact tracing during the cholera outbreak leave no water pools to chance
Matero Compound, Zambia, Idah Zulu, February 2009
(Bottom) Team work. Community volunteers gather stones to patch up the road to the health centre
Matero Ref. HC, Zambia, Idah Zulu, April 2009

(Top) In a partnership between Medicin Sans Frontiere, the health centre and the community, an incinerator for waste products at the clinic is almost complete
Matero Ref., Zambia, Idah Zulu, March, 2009
(Bottom) A women's community group volunteer to clear the health centre surroundings
Matero Ref. HC, Zambia, Idah Zulu, February 2009

Talking health is also entertaining! Peer group doing drama on AIDS
Mumbwa, Zambia, Clara Mbwili-Muleya, May 2009

'We have seen better interaction between community members and health workers [since the participatory reflection and action intervention].
They are able to express themselves even in areas where we used to think they couldn't comment. Health workers are seen participating in planning. This time they didn't need guidance and they were even guiding.
We have appreciated their inputs.'
Sister in Charge,
Chipata Health Centre

We discussed and reviewed the work with the health workers and community members, using progress markers. The review found that interaction between health workers and community members had improved. Community members had more confidence so were more able to make an input in the planning processes. Community plans were now included in the overall plans and most activities community members suggested were incorporated into the ongoing health centre programme. We used participatory tools to resolve any emerging issues and other centres had become interested in the process.

Communication between health workers had also improved, with a more open-door approach from departmental heads and the health centre person in-charge. As one health worker said:

> *'I used to fear being called to the person in-charge's office but after the participatory reflection and action process, I know every problem has a cause and therefore can be resolved.'*

'Sometimes it takes too long to notice change, while at other times change is seen immediately. So you can build on even a little change.'
Health worker at Chipata health centre

Right top:
I could be a health worker when I grow up.
A school health visit, Mambilima School
Lusaka, Zambia, Idah Zulu, April 2009

Right bottom:
Who feels it knows it. Women volunteers doing their part to mend the clinic road to make it easier for patients, especially pregnant women, to reach the health centre
Matero Ref. Health Centre, Zambia, Idah Zulu, May 2009

'The relationship has strengthened especially now that health workers attend community meetings. Nurses used to think that only health workers should participate in planning.'
Health worker, George Health Centre

Volunteers helping at a cholera centre, taking a hard-earned break
Matero Ref. HC, Zambia, Idah Zulu, April 2009

Marching on Women's Day
Lusaka, Clara Mbwili Muleya, March 2009

Right:
A shared goal for health workers and communities: healthy children
Lusaka Zambia, Idah Zulu, April 2009

Right hand page
Women involved in a community project
Lusaka, Idah Zulu, 2009

'There's a big change since we started and I am part of the change. I am a voice for the voiceless'.
Health worker at Chipata health centre

We now want to sustain these changes and scale up the process by institutionalising it in mechanisms and meetings. We are advocating that the participatory processes be included in the guidelines and orientation for local leaders and new health workers at the health centres. We aim to ensure funding for planned activities and to disseminate information on the outcomes more widely within the system. We have learnt that it is possible to scale up the processes by spreading them horizontally, with teams supporting each other. The changes take time and need continuous mentoring and resource support in the early stages. They need to be integrated into routine work with the support of the authorities. But we also see that if we do not invest in this, disharmony between health workers and communities will persist, undermining the functioning of our health systems.

Read more at Mbwili-Muleya C, Lungu M, Kabuba I, Zulu Lishandu I, Loewenson R (2008) *Consolidating processes for community–health centre partnership and accountability in Zambia*, Lusaka District Health Team and Equity Gauge Zambia, EQUINET PRA project report, EQUINET, Harare, at: www.equinetafrica.org/bibl/docs/PRAzambia.pdf


IN GOD WE TRUST

AFTERWORD

After the round of work and the exhibit that produced the photos shown in this book, we reflected further on the process as a group.

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

Generally we are 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 and this motivates us to act.

The photographs make you realise how much women do in the community, often with no recognition and sometimes at the cost of their own health. This is not just about burdens. The images show the many ways that women make a real difference to health but also how they are restrained by lack of time and resources.

Many of the photographs show the ways communities can and do act to protect their heath. Often this is 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.

> *'We are not outsiders. We are members, health workers and health activists in the communities that we were photographing.'*

While our work in health in the communities meant that people did not see the photographers as outsiders, there were challenges.

Bagamoyo, Selemani Ally Joe, February 2009

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 this and to open new dialogue and interaction within the community.

The exhibitions we held further demonstrated the power of images in communicating, even to a wide range of social groups. While locally the images promote dialogue on the realities shown, they also give new power to community members to more widely communicate the often hidden realities, without the limitations of language. The images produced a lasting effect in people's minds.

For the community photographers, the process built skills and provided the space to be creative. It gave an opportunity to discuss each other's work, engage with others about it and to 'relook' at work underway. As one of the community photographers said after the nine months of the process,

> *'I feel free – I am liberated by this new skill – I am now able to communicate my world.'*

'From other sources of evidence, I imagined reality. From the photos, I saw reality.'

Researcher, EQUINET conference, 2009

Photographs speak louder than words. This book presents photographs taken by community photographers in seven east and southern African countries, namely: the Democratic Republic of Congo, Tanzania, Zimbabwe, Kenya, Uganda, South Africa and Zambia.

We called our photographers the 'Eye on equity' team because the work was part of EQUINET's participatory action research work. Implemented through institutions in east and southern Africa, this work investigated, documented and implemented actions to understand and promote equity in health. We added photography as another tool to build and strengthen people-centred health systems and people's empowerment in health.

The book presents images of equity in health and of actions to improve health. These are the stories of insiders: of members, health workers and health activists in the communities that are shown in the photographs. The photographs are being used to stimulate discussion of health issues and actions. The book thus introduces both the realities and the work underway. It opens discussion on community photography as a means of keeping an eye on equity and as a tool for change.

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'I feel free – I am liberated by this new skill. Now I am now able to communicate my world.'

Community photographer, 2009