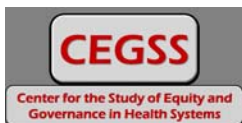


Experiences of participatory action research in building people centred health systems and approaches to universal coverage

REPORT OF THE
SESSIONS AT THE
GLOBAL SYMPOSIUM ON
HEALTH SYSTEMS RESEARCH,
MONTREUX, SWITZERLAND
NOVEMBER 2010



Training and Research Support Centre,
Regional Network for Equity in Health in East and
Southern Africa (EQUINET),
Centro de Estudios para la Equidad y Gobernanza en
los Sistemas de Salud (CEGS),
and SATHI-CEHAT



With support from Open Society Foundation, IDRC,
WHO GSHSR, Doris Duke Foundation

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Cite as: Loewenson R, Flores W, Shukla A, Kagis M, Baba A, Ryklief A, Mbwili-Muleya C. Kakde D (2010) TARSC/ EQUINET, CEGSS, SATHI-CEHAT, Experiences of participatory action research in building people centred health systems and approaches to universal coverage: Report of the Sessions at the Global Symposium on Health Systems Research, Montreux, Switzerland, TARSC, Harare

1. Background:

A universal health system values and entitles all citizens, so that everyone within a country can access the same range of services on the basis of need and pay for these services on the basis of their income. While this is achieved through redistribution and cross-subsidies, it also includes efforts to widen geographic access, to make public services more acceptable, to enable social empowerment and to promote health through the actions of other sectors that influence health outcomes, including agriculture, trade, industry, education, communication and so on (Gilson et al 2007; WHO CSDH 2008).

Knowledge is necessary, but not sufficient, for achieving universal coverage. The systematic processes that produce marginalisation and inequality also need to be challenged. Health systems are complex social systems that reflect and affect social values, and that may exacerbate or reduce inequity. The production and use of knowledge informs public health policy, but also influences the political processes that shape policy and intervention.

In the health sector, experiences such as that of Thailand showed that three groups of actors have played important roles in achieving Universal Health Coverage (UHC): national politicians for their political decisions, leadership, allocation of resources and legal reforms; researchers for the evidence and inputs to the design of the system; and constituencies and civil society for the pressure exerted to ensure delivery on policies and technical options. All had different strengths and acted as critical factors at different times: to catalyse the process; to provide political leadership for it; to inform and make it technically feasible and to maintain pressure for its implementation. No single body of knowledge was pivotal, but different sources and sets of knowledge and evidence were generated at different periods of time to stimulate and support the policy adoption and implementation (Jongdomsuk (2010) in Loewenson (2010)).



Health systems research produces knowledge to inform pathways and policies for building universal coverage. Operational and implementation research can strengthen capacities for implementation of knowledge. Participatory action research (PAR) has possibilities of making a more direct connection between the public actors and political forces that shape public policy. It involves the participation of citizens in the production of evidence, strengthens legitimacy of research findings and may be an entry point to generate action. Participatory action research (PAR) can generate social action and power, by more directly connecting with political forces, challenging power imbalances and opposition, organising citizen, health worker experience for knowledge and linking knowledge to action.

PAR methods systematise local experience, identify problems, organise shared collective reflection and analysis on relationships and causes of problems within groups with common experience (homogenous groups), link analysis to action and review of its effects and organise common experience and perception to generate new learning (collective validation) and knowledge from the process. PAR enables participation of affected communities in generating new knowledge, putting them in a stronger position to question existing, sometimes disabling, power relations (Chambers 1994; Laurell et al 1992). As with other areas of research, PAR has limitations and challenges both in design and application. It needs to be triangulated with other sources of evidence. Further, empowerment and dialogue are not automatic outcomes of the application of participatory methods and tools. It depends on the context, the continuous process of social analysis and action and the values

that drive it. Individual participatory tools have been used in development processes to encourage participation without creating social power or challenging the underlying power relations that marginalise people.

This report presents different experiences of using PAR in health systems from India, East and Southern Africa, Guatemala and Canada. These experiences are used to explore and discuss the learning on methods, on the knowledge generated and the implications for health systems, and what this means for the profile and practice of PAR. The report outlines the presentations and discussions from two sessions on participatory action research convened by the authors at the first Global Symposium on Health Systems Research in Montreux Switzerland, November 16-19 2010.

2. The Symposium Sessions

The sessions drew on experiences with PAR in health systems in four different contexts, ie Latin America, Africa, Asia and North America. In a roundtable in the first 90 minute session in the Symposium, the case studies from the four regions were presented and discussed to examine and reflect on the methods and shared learning on health systems derived from PAR; the unique contribution of PAR to universal coverage of health systems, why PAR approaches are not often used or heard and the recommendations to the symposium. Following the presentations a 'marketplace' approach was held with the approximately 50 people attending the session using three flip charts with statements on them inviting delegates to write their responses and inputs, debates to the statements on the flipcharts and debate them at the stand, before moving to the next flip chart (or returning to an earlier one). The statements on the flip charts were:

- FLIP CHART 1: PAR makes a unique contribution to universal coverage of health systems because.....
- FLIP CHART TWO: People don't use PAR approaches in building knowledge on health systems because....
- FLIP CHART 3: At this global symposium should make a difference to the future use of PAR in HSR by

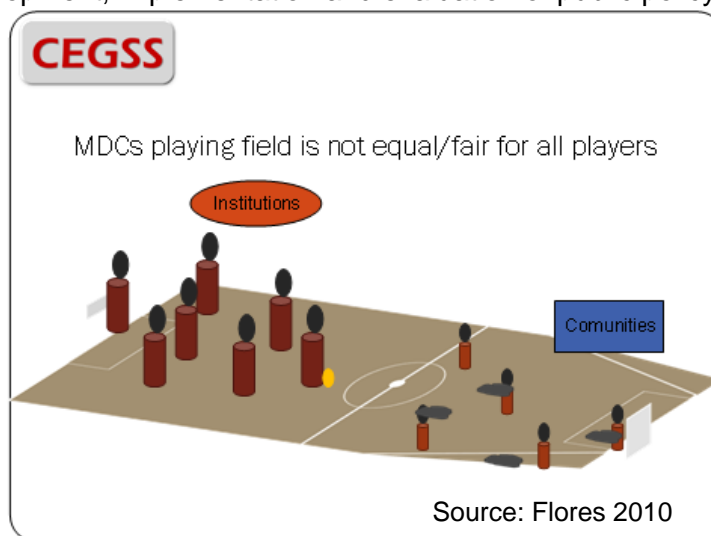
In a follow up two hour session convenors presented the major issues and debates raised in the flipcharts, presented further experience through video clips of the research from a community lens in India, heard experiences from other delegates on their PAR work on relation to the issues raised and drew conclusions on the implications for future participatory research on health systems, for approaches to organising community evidence as knowledge for health systems development, and for follow up action to build a learning network on PAR.

3. Presentation of the PAR work

3.1 Engaging citizens and front line health workers to influence health policy in Guatemala

This was presented by Walter Flores, CEGSS. Guatemala is a country of contrasts. Despite being a middle-income country with a strong agro-export sector placing the country among the top five world exporters of coffee and sugar, the country presents some of the worst health and social indicators in the Latin American region. Guatemala's indigenous population experiences high avoidable infant, child and maternal mortality and lots of extreme poverty. Changes to improve equity and reduce social exclusion of indigenous population are slow due to complex power relations reflecting the politics of health. Moreover, inequities in health are the result of historic inequities of power.

Since the beginning of the democratic era (1989) and more after the signing of the peace accords (1996), the country has been implementing social reforms; however the benefits are still concentrated in the large urban areas and better-off populations. Benefits for rural populations (about 60% of the total population) are still very limited. The country has also implemented some progressive laws that recognize the right to health and promote the participation of citizens in the development, implementation and evaluation of public policy. Although the above legal framework is a major step forward, the effective participation of citizens, particularly those affected by inequity and social exclusion, is very limited due to several barriers that stem from rural families living further away (transportation costs and travel time), have less formal education and speak languages other than the official language of mainstream business (Spanish). These barriers deny indigenous citizens from actively engaging in the deliberation of public policy and influencing the allocation of public funding towards services that can benefit them.



In this context, a civil society coalition (community based organizations, non-governmental organizations and a research center) have implemented a systematic process based on participatory action research aiming to bring changes at the municipal level. The main hypothesis was that empowered rural citizens can affect the power balance in public decision making and lead to pro-equity public policy and resource allocation. The joint efforts started in the year 2007 and have been implemented in several phases that are described below.

In phase one, the team carried-out a baseline study that involved in-depth analysis of the context in which we were working. This included not only the collection of key indicators of equity of access and resource allocation, but also applying rapid ethnographic techniques (e.g. social mapping, document analysis, participant observation and in-depth interviews to key social actors) to analyze and understand the power relations, social determinants of health and the perception of key social actors (community leaders, local health authorities, representatives from municipal governments) on the barriers to participation in public policy dialogue and debate .

Based on the findings of the baseline study, a capacity building process (phase 2) was designed and implemented. This process included training workshops in which community representatives and front-line health care workers, acquired knowledge and skills around the legal framework for health and social participation in Guatemala, participatory planning, monitoring and evaluation.

Phase 3 involved designing, field testing and implementing a participatory system to monitor whether public polices and resources at the municipal level were addressing and resolving the access to health care problem. For the monitoring system, two different type of instruments were developed:

a) health care facility surveys to assess availability of essential drugs, medical equipment/supplies and availability of human resources and

b) a topic-guide to interview families that faced a health care problem, assisted to a public health care facility and did not receive adequate care. The purpose of adding family interviews was to demonstrate that the inability of public health care facilities to solve the basic health care needs of families is having a negative impact in their survival since they had to use scarce resource to pay for medicines, transport to a central hospital, and also endure working days lost to illness. Community leaders were trained to apply the instruments and to carry-out the analysis of collected data.



Community team surveying drug availability at a health care facility, Flores 2010

Community leaders presented the analysis to local health and municipal government authorities. They accompanied the presentation with specific demands to improve the situation. Although the process is still very recent, there has already been some achievements: municipal government have accepted to increase the allocation of funding to buy petrol for the local ambulance during emergency transport (families were paying it before), two subcontracted providers of immunization and other basic health care services had their contracts terminated due to corruption (revealed by the monitoring work of communities) working hours of health care facilities have been extended and complains by indigenous families that have received disrespectful treatment by medical doctors have been taken seriously.

The above achievements have resulted in a tremendous boost for the self-confidence and motivation of community leaders. During a recent project evaluation, a leader stated: *"I feel this is awakening for all of us, we know now that it is possible to demand our right to health and we have seen that a change is possible"*. Other female community leader stated: *"Through the training and the monitoring system, we are now capable of discussing with the doctors and municipal authorities the problems with medicines and personnel in the health center and health posts. Before that, we had to accept that services were almost never there and we thought nothing could be done about it"*.

Up to now, the partnership of rural citizens, health care workers and researchers is demonstrating two important lessons:

- a) Through a participatory action research approach, citizens affected by inequity in health can become research partners and actively participate in the monitoring of public policies,
- b) Demanding actions from local governments, parliament and the executive branch are also valid and relevant interventions to promote health care equity.

The experience is expanding to new municipalities in Guatemala and community leaders who have been actively involved in the initial six municipalities are serving as the key facilitators to the expansion work in new municipalities.

3.2 Community based monitoring of health services in Maharashtra, India

Abhay Shukla and Dhananjay Kakde presented the experiences of SATHI in India. In India, the National Rural Health Mission (NRHM) was announced in April 2005. It was launched with a view to bring about improvement in the health status of the rural population, mainly by strengthening the public health system with strong focus on the primary health care. One of the most significant policy initiative under NRHM has been introduced in the form of a comprehensive framework of community based monitoring (CBM) and planning at various levels of the public health system. At the core of Community Based Monitoring is the act of tracking, recording and reporting the state of public health services in villages, as experienced by the people themselves.

There are several key processes in CBM:

i. Building people's capacity to publicly rate health services – a process of raising awareness of community members regarding their health entitlements and the significance of community monitoring was carried out in all villages, where CBM was implemented. In this phase capacity building of Village Health Committees and monitoring committee members was done through training. The strategic objective of the VHSC training was to inform and empower VHC members to perform the monitoring by collecting health care related information at the village level and also to motivate VHSC members to play a proactive role in the monitoring and planning of health services.





ii. Data gathering and filling report cards at village, PHC, Rural Hospital levels-Almost all indicators for collection of information are based on the services guarantees stated in the NRHM implementation framework. In each monitoring cycle at the village level two group discussions were planned. Similarly at the PHC level, exit interviews of the out patients, PHC facility survey and interview of the PHC Medical officer was also conducted. Slightly complex tasks like facility surveys and medical officer interviews were mainly conducted by representative of the Block nodal non government organisation (NGO). The report cards marked health services using 11 indicators, with each

rated good, partly satisfactory, or poor. All indicators used a three month recall period.

iii. Based on report cards, dialogue with health functionaries- Findings from the filled report cards were presented in the public hearings or mass dialogue with functionaries. Around one hundred health related have been organised in the state of Maharashtra at various levels of the public health system so far. These events for public accountability have contributed to a number of improvements in all CBM districts and blocks and this process has led to increased dialogue between people and public health providers.

iv. Involvement of Media- One of the key strategies of CBM has been involvement of the media in creating public opinion about the state of the public health system and also to positively influence decision makers. Till date a total of over 225 news items have been published in the national, state and regional level news papers. Similarly events like public hearings and the state review workshop were significantly reported in the electronic media.

सुल्या गटाच्या गटचर्चेमध्ये विचारायचे प्रश्न
३. साथीच्या आजारांवर गावात केल्या जाणाऱ्या उपाययोजना

प्र.क्र.	प्रश्न	प्रतिसाद (पर्यायावर खूण करा)
१	 <p>मागोल तीन महिन्यात ताप आलेल्या प्रत्येक व्यक्तीचा तपासणीसाठी वोटानुन रक्ताचा नमुना घेतला गेला का?</p>	<p>प्रत्येक व्यक्तीचा - <input type="radio"/> <input type="radio"/></p> <p>काही जणांचा - <input type="radio"/></p> <p>कोणाचाही नाही - <input type="radio"/></p> <p>तापाचा रुग्ण नाही - <input type="radio"/></p>
२	<p>गेल्या महिन्यात गावातील पिण्याच्या पाण्याचा नमुना तपासणीसाठी किती वेळा घेतला गेला ?</p> 	<p>दोन वेळा - <input type="radio"/> <input type="radio"/></p> <p>एकदा - <input type="radio"/></p> <p>एकदाही नाही - <input type="radio"/></p>
३	<p>मागोल तीन महिन्यात साथीच्या आजारांचो माहिती घेण्यासाठी एम. पी.डब्ल्यू.ने /नर्सबाईनी घरभेटो दिल्या का ?</p> 	<p>नियमित - <input type="radio"/> <input type="radio"/></p> <p>कधी कधी - <input type="radio"/></p> <p>कधीच नाही - <input type="radio"/></p>
४	<p>एम. पी. डब्ल्यू.ने गेल्या महिनाभरात गावात किती वेळा भेट दिली ? (संदर्भासाठी गाव आरोग्य कॅलेंडर वापरा)</p> 	<p>दोन वेळा - <input type="radio"/> <input type="radio"/></p> <p>एक वेळा - <input type="radio"/></p> <p>भेट दिली नाही - <input type="radio"/></p>
एकूण भाक-यांचो संख्या		

इतर मुद्दे -

चांगली परिस्थिती ६ ते ८ भाक-या
 काहीशी समाधानाकरक परिस्थिती ४ ते ५ भाक-या
 गंभीर परिस्थिती ४ पेक्षा कमी भाक-या

किंचा

तापाचा एकही रुग्ण नसेल तर पुढील प्रमाणे गुण द्यावेत...

चांगली परिस्थिती ५ ते ६ भाक-या
 काहीशी समाधानाकरक परिस्थिती ३ ते ४ भाक-या
 गंभीर परिस्थिती ३ पेक्षा कमी भाक-या

परिस्थिती प्रमाणे रंग भरावा

Community monitoring forms, Shukla and Kakde 2010

- v. State level conventions and dialogue- Until the development of CBM there was no regular forum for community level groups to raise issues at the state level in ways that could elicit action. Under CBM, there are now officially mandated dialogues between the state and civil society every two to three months. These dialogues help to address issues that have not been resolved at lower levels and reinforce the commitment of the entire health department. They have proven instrumental to the development of CBM. One element that makes these meetings particularly fruitful is the simultaneous presence of state, district and block level health officials. Elected village leaders (village headman) in the first two years ignored the PAR activities. After the changes were achieved, the village head man showed interest and wanted to take credit for the achievements. They were therefore pulled into the PAR process.

Three rounds of collection of information and grading of services have taken place between mid- 2008 and end-2009, and in the second session a film was shown of this work and the community sessions in completing and using the monitoring to hold local health providers and authorities accountable. The SATHI video clips showed the use of the community based monitoring (CBM) tool at village level and community completing, discussion, analysis, reporting and public display of the report card, and the community participation in public hearings. CBM and quantitative data on spending in 4 districts of 200 villages were mixed, with findings on use of funds. The CBM tools are simple, usable, objective, capture the nuances of services and the quality of services.

In the 220 villages spread over five pilot districts, the first, second and third rounds of CBM data collection took place between July 2008 to December 2009. At the beginning of CBM process, villages rated their health services 'good' at an average rate of 48%. This has increased by 13 percentage points to 61% in round two, and by round three it increased by an additional 5 points to 66%. The average percentage of services rated 'bad' by villages decreased from 25% to 16% to 14% over three cycles of monitoring. Specific indicators like immunisation improved by 21 percentage points from 69% 'good' in round one to 90% 'good' in round three. Between rounds one and three Anganwadi services and use of untied funds improved by 33 and 31 percentage points respectively. Regarding the PHC health services (like 24 hr delivery care, indoor care, laboratory and ambulance services etc) significant improvement took place, rising from 32% in the first round to 74% in round three.

3.3 Using PAR in strengthening people centred health systems in east and southern Africa

Rene Loewenson, TARSC, EQUINET described how between 2006 and 2009 a multi-country participatory action research programme was implemented in east and southern Africa through Training and Research Support Centre (TARSC) and Ifakara Health Institute (IHI) in the Regional network for Equity in health in east and southern Africa (EQUINET), implemented with institutions in each country that work in or with communities and local health systems. The programme explored several dimensions of 'people-centred health systems', including on health worker communication with communities and on PHC oriented approaches to HIV and AIDS.

Each country site used participatory action research (PAR) methods to explore and act on an issue identified by the participating lead organisation in dialogue with communities and local government and health authorities. At a training workshop on participatory methods for health research TARSC and Ifakara Health Institute built skills in PAR, and supported facilitators from community or primary care level actors in state and non state institutions to design protocols for PAR work on the priority area of health worker- community interaction identified. The design and tools were peer reviewed and the implementation mentored by TARSC and IHI to ensure consistency of the broad steps of the research, its implementation and the recording of findings across all sites. Studies obtained ethical or authority clearances and consent from community leaders and participating community members. In all cases the work was implemented with relevant community structures. All the studies followed steps of problem identification; a baseline assessment of perceptions of the current situation through a questionnaire survey with affected community members and health

workers and PAR processes with range of tools to organise evidence and perceptions from communities, health workers and others on the chosen issue. Following this actions were planned and planned interventions implemented, with progress review within communities using progress markers set by health workers and community members.

A follow up assessment and review was implemented when the interventions had advanced after a period of about 6 months to a year to assess change in the determinants and outcomes under study. The individual reports were peer reviewed by two peer reviewers, published and made available at local level for ongoing dialogue between communities and health workers and relevant authorities. An analysis of the learning across the seven studies using a shared conceptual framework for the work developed at the initial training. Comparable methods across the sites provided a framework of key themes for sharing findings and building common learning and process of collective validation using these shared analytic themes was used in building the learning across sites. A network and '*pr4equity*' mailing list provided a communication channel for exchange of findings and for dialogue on lessons learned. A learning network was established and a follow up meeting held involving all teams to review the evidence and experience using the shared analytic categories below and a synthesis paper is being finalized based on the outcome of that process. In the meantime a further phase of work was implemented in 2009 to use community photography in communicating the process, actions and learning, and as a tool for further PRA work.

Case studies from this participatory action research work were presented:

3.4 Overcoming barriers to AIDS treatment in DRC

Amuda Baba, IPASC, described how, in the context of 7.5-19% adult HIV prevalence in Bunia, in north eastern DRC, communities faced numerous barriers to access prevention, treatment and care services. This study was conducted in Bembeyi, a rural community, located at 10 km east of Bunia. Apart from that, two rivers lay between the community and the referral hospital that the ambulance was not able to cross in the rains. Stigma and discrimination were also considered as barriers in using testing and treatment services. This study used a mix of PRA and quantitative approaches. A quantitative survey with 80 respondents from the groups noted above was carried out before and after a PRA process that explored causes of stigma and barriers to testing and treatment services, and identified and implemented shared priorities for action on these causes. The implemented action plan was monitored monthly by a local committee, using progress markers of what the community groups felt they (i) must and (ii) would like to achieve. A post intervention questionnaire administered to the same individuals as the baseline survey assessed changes on the proposed outcomes, and an evaluation meeting was held with the PRA team and selected community groups to review the process, assess outcomes through PRA approaches and define next steps.

The Participatory Reflection and Action (PRA) work explored the barriers and stigma associated with HIV testing and treatment services with women and men living with HIV (20-49 yrs) male and female adolescents (15 – 19 years), community leaders and community health workers. This work identified that social barriers to use of services - lack of knowledge, fear and stigma - add to poor availability, and that even for those who reach services, health workers are perceived to communicate poorly. As a result people leave treatment to late stages when they are ill, but find the long journey more difficult at that stage.

A three month plan was developed by communities to act on these issues through community led sensitisation and encouragement of early HIV testing, shaped and implemented by the community. The community also decided to address the inaccessibility of services, by making a bridge over the river to enable transfers to hospital during the rains, first using wood and then, after participatory dialogue, through a stone and cement bridge, supported by UNDP. The process was found to have reduced stigma, raised awareness, and raised community capacities and organisation to address social barriers. PRA and the social processes can stimulate organisation and cohesion for infrastructure and service changes. It appears that PHC services for AIDS that do not invest in these dimensions in an empowering way undermine the effective use of other resources and the necessary synergy between communities and health services needed to manage a chronic condition such as AIDS.



Barriers to access to services, Bunia IPASC 2010

3.5 Recognising health workers' health problems in Cape Town, South Africa

Ashraf Ryklief, IHRG, outlined the work with health workers in South Africa. Occupational Health & Safety (OHS) is a public health Issue as Health Care Workers (HCWs) are a community with public health needs. Workplaces should have preventive OHS programmes and participation of HCWs in workplace OHS programmes can raise awareness of links with patients' illnesses and patients workplace exposure. A PAR process was implemented with seven unions in the "Public Health Sector OHS/HIV Forum" , a union network facilitated by IHRG on Health worker experiences with occupational health services in Cape Town. It involved HCW (elected H&S and shop stewards) working in primary health care facilities. The PAR found that OHS was neglected in the public health institutions, with a perception in workers that management nor unions were taking it seriously, and workers were not claiming their rights, contributing to the neglect. HCWs were thus adapting to deteriorating conditions in which they work and provide care, including as a result of staff shortages, patient load & poor working conditions. HCWs are also in the frontline of community frustration and anger with poor health care services. The findings from the PAR investigations were used to raise and challenge management practices. Diseases, injuries and outcomes were identified (TB, latex exposure, incapacity dismissals) and raised for action, and OHS policies and procedures reviewed. The participants challenged their trade unions to address their OHS problems, and raised issues improvements they sought in OHS

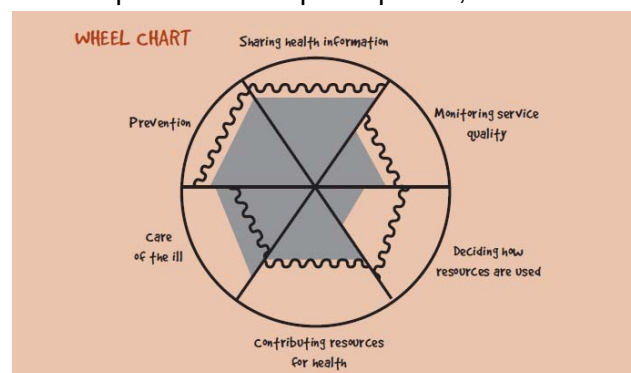


Presentation on the IHRG work 2010

conditions. The PAR approach can facilitate and sustain learning in unions and health institutions but needs trade union organisation to support and institutionalize it.

3.5 Strengthening mechanisms for dialogue on planning and budgeting at primary care level in Zambia

Clara Mbwili, of the Lusaka District Health Team, described how in the early 1990s Zambian government health reforms aimed at enhancing the health system at all levels. This included providing equity of access to cost effective quality health care as close to the family as possible', based on leadership, accountability, partnerships, sustainability. However misunderstandings between health workers and community members on resources have arisen. These arise as the conventional training of health workers assumes that clients are not knowledgeable on health issues and as community members are not engaged in planning, budgeting and implementation. One result is a mismatch between policy and practice in health services delivery and outcomes. The team in Zambia hypothesized that PAR could be used to improve relations between health workers and community members within a public health system, complementary to the quantitative methods that provide evidence for health system strengthening. In 2006/7, PAR was implemented in two Zambian urban Lusaka and rural Chama districts at health centre level, to strengthen information sharing for planning, budgeting, resource allocation and activity implementation (PIB); involve health worker (HW) and community members (CM) at health centre level and tools to identify needs, proposed actions, systems barriers and changes needed for PIB. In 2008/9 in Lusaka we again used these methods to assess feasibility of scale up to new health centers, while consolidating and building capacities for institutionalizing the approaches in existing centers. Both intervention studies used an iterative spiral model of participation, reflection and action carried out by health workers and community members involved in health activities at the selected health centres. Experiences, issues and areas for change were obtained using participatory tools during combined workshops of health workers and communities, followed by an implementation phase of the activities planned. Regular review meetings were held to reflect on activities and outputs achieved, followed by identified further necessary action. A pre and post intervention questionnaire was administered to participants to assess change.



Presentation on the IHRG work 2010

In 2006, following the PAR process outlined in the regional programme earlier, the research identified blocks in joint planning, including fear of the unknown; poor communication between and among health workers and community members, poor understanding of roles; health workers perception that community members have low knowledge on health issues; and community members feeling powerless and unappreciated by health workers. There were also system level barriers, with few fora or resources for health workers and community members to exchange as equal partners. The PAR itself, the shared identification of factors and the dialogue it build across health workers and community members on actions to remedy problems had a direct impact on the system.

Information sharing between health workers and community members increased, community members were able to approach health workers for information more confidently, and health workers provided information to community members on planning and resource allocation. The process led to a change in perceptions, understanding of constraints and behaviours around the planning process and increased the mutual respect between health workers and community members.

The 2006 project showed that the participatory methodology improved communication and interaction between community members and health providers, and strengthened the inclusion of community and primary care workers priorities in health plans. The follow up work found that sustaining participatory approaches progressively de-mystify and increase community involvement in planning and budget processes, strengthen dialogue and resolve issues in the interface between communities and health workers. When the PAR was scaled up to new areas of Lusaka in 2008/9, it was found to build communication, trust, transparency and accountability. It did not require significant resources, but did need to be encouraged by feedback and strategic review. It can be scaled up and sustained in district health systems through horizontal capacity building, mentorship as part of routine duties. This takes time and leadership support. Institutionalizing the process calls for mentoring and resource support in early stages, and for integration within routine work, support by authorities, and orientation of new health workers.

3.6 Learning across the PAR sites in east and southern Africa

The work collectively shows how participatory inquiry exposed issues for health workers and communities that are barriers to universal coverage, and addressed differences between communities and health workers in perceptions of the problems and solutions needed.

The evidence from across the sites showed that communities prioritise causes of ill health at a more structural level than health workers, and that the social, cultural, family, partner relations identified have important and underserved influence on health actions. Health services have high legitimacy but weak capabilities for social roles, but limited action on barriers and facilitators to uptake and adherence leads to resource inefficiencies and vicious cycles of ill health. We found that as peoples power over their health improves, so their expectations for health and from their health services also increase. From the PAR work, it was found that participatory approaches enhance the conditions and processes for communication, respect, trust in health systems. They provide a means for recognition, early detection of, strengthened demand on buried health problems and social determinants and shared analysis and shared power between primary care health workers and communities, to the benefit of both. The process builds positive cycles of knowledge, local self determined plans and action, review and reflection within communities and local levels of health systems.

Nevertheless, PAR approaches face challenges: The methods are not well known and the core method for knowledge production, ie collective validation by homogenous groups – is often not rigorously applied. The findings are specific and there is limited meta-analysis across sites of PAR, affecting the scale and generalisability of the findings. Those involved face challenges in reporting knowledge in peer reviewed journals. The work takes time and mentoring. It often points to structural determinants that demand action at higher levels of authority than those within communities. These findings raise issues for how to institutionalising participatory research and practice.

3.7 Effecting health services change in Canada

Majja Kagis of Canadian Association of Community Health Centres outlined how in Canada, PAR broadly defined, contributed to the part of the growth of a movement that supports universal health coverage. When physicians were opposed to the initial introduction of universal health care, citizens mobilized. Through PAR within a political-community development process, community members ensured funding for Community Health Centres (CHC's). CHC's are community based institutions that deliver comprehensive primary health services to geographically defined communities. The process in this example was politically driven, open and simple, but required the support of a few professionals who were willing to work in the centres. It made available to funders information that had not been previously documented.

A second example is that of a health centre that grew out of the community. Poor women in a public housing community did not have access to health services, particularly for their young children. The tendency was to use the hospital emergency services, for which the transportation could be charged to social service. Women initiated the issue and questions, which were further developed by researchers and social service staff. A PAR process was used to jointly put together the evidence for an argument to develop a community health centre. The convincing argument in this case was a financial one: less funding would be required to start a small CHC than to continue the use of taxis and of emergency services. A hospital based, operational research project would have examined use of professionals within the hospital setting, improving triaging and so on. However the PAR work born from cooperation between clients, social development and health workers led to the support for community health centres. .



Example of a community Health Centre, Kagis 2010

In a third study, users and physicians in a CHC cooperated in order to examine medication need and use. Physicians noted that cost was an impediment to purchase of needed drugs. A small research project was designed, approved by the board of the CHC. Even before the essential drugs list appeared at WHO, 100 of the most common generic drugs began to be carried by a CHC pharmacy. This project formed one of the bases for a provincially instigated drug plan. It involved the users, the board and the physicians at the centre.


Maija compared these programmes with others that were less successful, and pointed to the fact that this was because the community was not involved, because the board didn't understand the project, and because funding mechanisms at national levels were not flexible enough to do the kind of community preparation that real participatory action research demands. The case examples suggest that in PAR, it is important to have a community elected board that not only comes from the community, but can mobilized and draw upon that community when particular questions arise, and that can further take any new knowledge back into the community. The issue of local knowledge translation becomes a moot point, since it is the very community that has created its own knowledge. There does remain the issue of knowledge translation upwards, but a mobilized community has more influence in terms of policy development and politicians than a single researcher.

4. Discussions and delegates experiences with PAR

4.1 Delegate experiences

Delegates in the symposium sessions raised their own experiences of using PAR. These highlighted further issues complementing those raised by in the case studies:

- i. In South Africa, the work has shown that values embedded in the community are not included in mainstream research, and PAR can bring out those community values and raise them within the health system as part of an empowerment process.

- ii. An experience of 30 years of research with trade unions indicates that unions present an important entry point for PAR. This has shown that PAR is hard and takes longer, and is cost-effective. Social epidemiologists value the methodology. For example PAR conducted for the International Transport Workers' Federation (ITF) was implemented to investigate if concern about a spike in fatigue amongst civil aviation workers is perception or reality. The use of a PAR approach to gather and reflect on the subjective experience of fatigue, triangulated with other approaches, was essential for this work and to cover the scale of those in the industry globally. It produced a 67% response rate and highlighted trends between 2000 to 2007 that linked a downward spiral in working conditions with workers' health and fatigue.
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- iii. An experience of work with a slum dweller community in Bangalore was recounted where evidence was collected by the community on the water supply of slum dwellers compared to water supply of another community. This was related to the levels of water-borne disease. The community recorded evidence regarding the frequency of water supply, quantity supplied, recorded incidence of disease, collected mid-month water samples for laboratory analysis. The water quality, supply evidence and record of ill health showed the relationships and were raised with the authorities, although it has still been difficult to produce the change.
- iv. In an experience of using PAR in Lesotho, Zambia and South Africa, the work focused not only on identifying needs but also mapping of assets within the community for health to stimulate partnerships for health around hospice care. The impact is enormous and has led to more funding to continue/grow work, build capacity of hospices to play a critical role as intermediaries.
- v. An experience in Malawi was of use of PAR in understanding the delays in using maternal-child health care services. Traditional health care attendants were banned and only western services promoted. This was investigated using PAR methods to assess evidence on outcomes of care from different providers, directly involving the women directly in research.
- vi. Women with HIV and commercial sex workers in Zimbabwe were trained to be researchers and conducted focus groups. They developed an inventory of reproductive health needs. The women presented this work with significant impact to doctors in district meetings. The co-ordinator acted as go-between the women and the health workers, to help the latter understand the difficulties faced and take action to include women in their meeting discussions.
- vii. In Egypt injecting drug users were involved more directly in surveys on services provided by comprehensive care centres after 2 years to answer if centres were meeting the needs, determine what is missing / additional services needed, and investigate the experiences of the service providers. The community's own researchers collected information from injecting drug users. This was the only means to collect reliable and unbiased information and gave valuable feedback to the services on what was working well and what required attention / improvement.

Delegate discussions at the symposium 2010

- viii. In Rosario Argentina the implementation of the decentralisation policy was noted to result in fragmentation with problems for health services. Reforms required delivery of primary health care to be delivered by general practitioners. Through PAR approaches health care workers were empowered to raise the impact of this and the possible changes towards comprehensive primary health care, making the changes possible.
- ix. PAR methods have been combined with other methods, such as with the CHAT (qualitative) method and quantitative mediation tools that brings benefit of triangulation. PAR can be enhanced by other methods. This enriches the research evidence for policy.
- x. Experiences of eight schools of medicine across Australia, Cuba, Venezuela, South Africa, Northern Canada, suggest that PRA methods should be triangulated with other methods, developed in collaboration with community and health sector. The approaches yield valuable information– but the experiences of PAR is not known because users are not publishing their experiences.
- xi. 20 years of practising PAR in India has shown its value for mobilising communities for change Knowledge creation more directly amongst participants makes a more direct connection between knowledge and experience, not influenced by researcher.
- xii. Communities can also take over the research agenda, for example in Northern Cambodia, local people have established a community research centre and more directly set and implemented their own research agenda.



Delegate discussions at the symposium 2010

4.2 The Public Health Watch programme

Cynthia Eyakuze of A Open Society Foundation (OSF) Public Health Watch (PHW) programme outlined the programme focus on health rights. OSF sees a growing demand from activists for these kind of methods, especially for work with extremely marginalised and highly criminalised communities such as sex workers, harmful drug users. This type of community generated knowledge / evidence is often called / dismissed as anecdotal evidence. PHW does monitoring to take action and looks at what difference activists wants to make. This has led to challenges in working with academic partners and means that these approaches are often better understood by advocacy advocates. In this it is important to set outcomes appropriately, especially in the marginalised and highly criminalized communities OSF works with. This calls for a learning network, as a means to share resources, methods and experiences.

5. Key themes and issues emerging from the PAR work

The convenor and delegate experiences raised suggest that there is a rich experience in PAR, and far more practice taking place than is being documented. We need to find ways of systematising these cases / experience. The cases also highlight the need to go beyond the health system and formal information system to know what is happening in the interface between systems and community practices were not interacting. There is often a huge gap between what was happening and what health information system was collecting, that demands more community based research approaches including PAR.

There is a spectrum of these approaches: Some involves community members in collecting data using traditional tools, others use monitoring to record community perceptions and experiences, others systematise communities' knowledge through collective processes for systematising and interpreting knowledge. There is need to be clear on where the control is in these processes, and the opportunity costs, barriers, challenges and the responsibilities this raises. Communities complain of taking unfair burdens and in this work also the roles and responsibilities need to be clear, so that control is not equated with unfair burdens. It is important that the work not only raises needs and assets, but that there are also examples of work that analyse the link between outcomes and determinants of health. The examples further highlight the role of intermediaries and bridging organisations to move from local to wider level inquiry and action. Trade unions are raised as an example of this.

In the market place discussion the responses to the three themes identified the potentials, challenges and areas of possible follow up action. These are shown within the summaries of the points raised within each of the three statements debated:

5.1 PARs unique contribution to universal coverage of health systems

In the market place delegates identified that PARs unique contribution to universal health systems is that it can

i. Support social empowerment

- Strengthen collective power in affected communities (including health workers)
- Change the power dynamics that perpetuate inequity, confront power differentials and redistribute power
- Build shared interests and perceptions across groups
- Organise and provide people with the means to articulate their thoughts and experience
- Empower people to demand the health inputs and services they need

ii. Strengthen local levels of health systems

- Provide local level contextual evidence
- Give communities voice as the best actors to raise the social determinants of health
- Strengthen local capacity and demand for resources to prioritized areas
- Support ownership and involvement of people in health systems and devolution (ie involvement in decision making)
- Enhance the work, effectiveness of health workers, dialogue within the health system
- Reach people excluded or difficult to reach with formal systems (eg insurance etc)
- Align competing top down agenda's to local demand and reduces resource wastage
- Provide down to earth examples to inspire policy support/change

iii. Strengthen demand for services prioritized by communities

- Organise and strengthen people voice so it is heard
- Raise social awareness, demand and uptake of local services and health actions
- Provide a more sustainable basis for demand and uptake than incentives

iv. Strengthen links between knowledge generation, translation and action

- Involve those affected in the knowledge generation
- Facilitate multiple voices and perspectives
- Remove the elitism from research
- Bring out the knowledge and evidence from the community itself

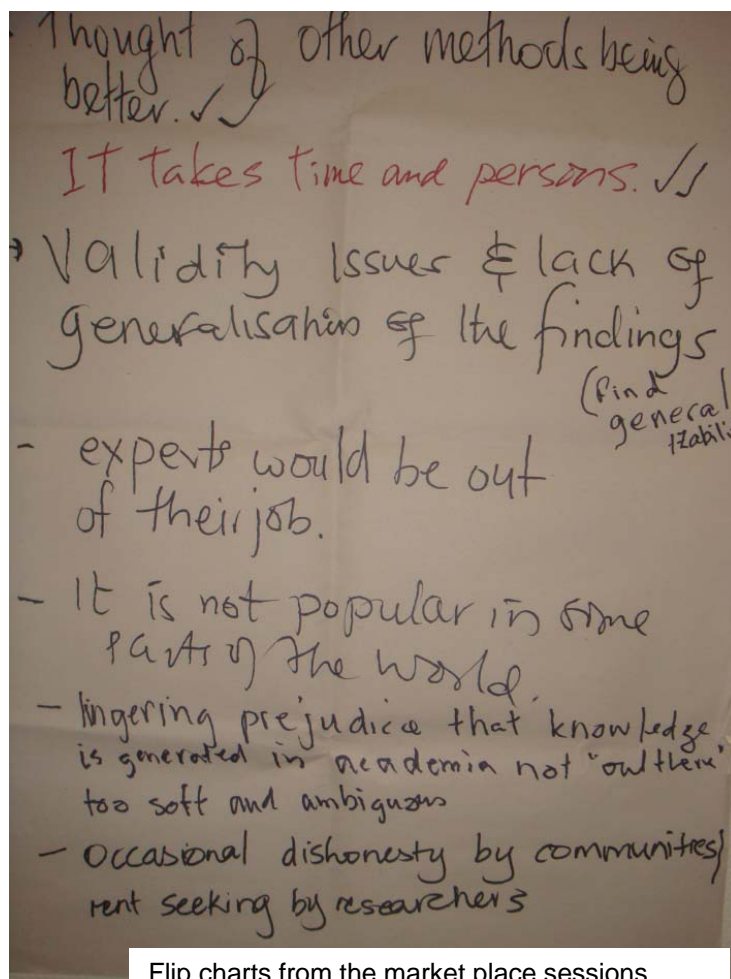
5.2 Limits to use of PAR in building knowledge on health systems

In the market place delegates identified the limits to use of PAR approaches in building knowledge on health systems as

i. Perceived / prejudged to be an 'inferior' approach to research knowledge

- Not real science- knowledge is generated in academic institutions.....“Methods don't look scientific enough”
- Not taught in medical or health science courses or popular in some parts of the world

- Prejudice in the scientific community – scientists, academics know better than the people/ discount peoples knowledge ...”Experts would be out of their jobs”
 - Dominant paradigm not “ready” for this- need to engage on this
- ii. Perceived challenges when tested against traditional scientific criteria**
- Based on subjective evidence
 - Issues of validity and generalisability of knowledge-
 - Lack of understanding (and implementation) of the methods for analysis and rigour
 - Ambiguity of methods
 - Vulnerable to community / researcher dishonesty
- iii. Is demanding to implement**
- Takes time, people, patience, resources
 - Outcomes are not predictable”and funders do not like that”
 - Demand to overcome apathy
- iv. Has not addressed how to move from fragmented local experience and knowledge to national health systems**
- Peoples local knowledge and perceptions one but not the only source of evidence
 - If not scaled up seen as limited and with small impact
 - The conceptual model to replicate PAR is not well understood
 - National level can become a series of local sites (vs a unified system of knowledge and action)
 - If systems do not support upstream action can lead to wasted time and effort
 - May not identify and challenge real power inequities”where is the power”



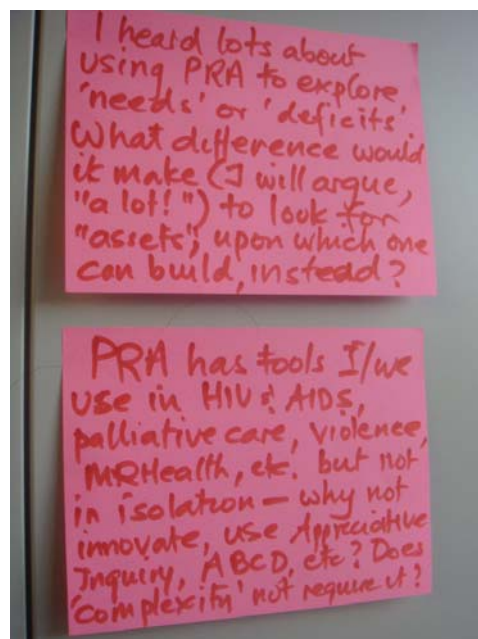
Flip charts from the market place sessions

5.3 Recommendations for the GSHSR on the future use of PAR in HSR

Delegates make recommendations for the GSHSR on the future use of PAR in Health systems research as to

i. Make clear links between PAR and the SDH and health equity agenda

- Recognise communities as best placed to raise and act on the social determinants of health
- Recognise the role of PAR in promoting equity, inclusiveness and raising voice and agency of vulnerable groups ...eg “people with disability”
- Recognise the role of values and the need to address democratic deficits in health systems
- Recognise the role of different forms of evidence in health systems



ii. **Develop ways of embedding PAR approaches in HS planning, implementation and evaluation**

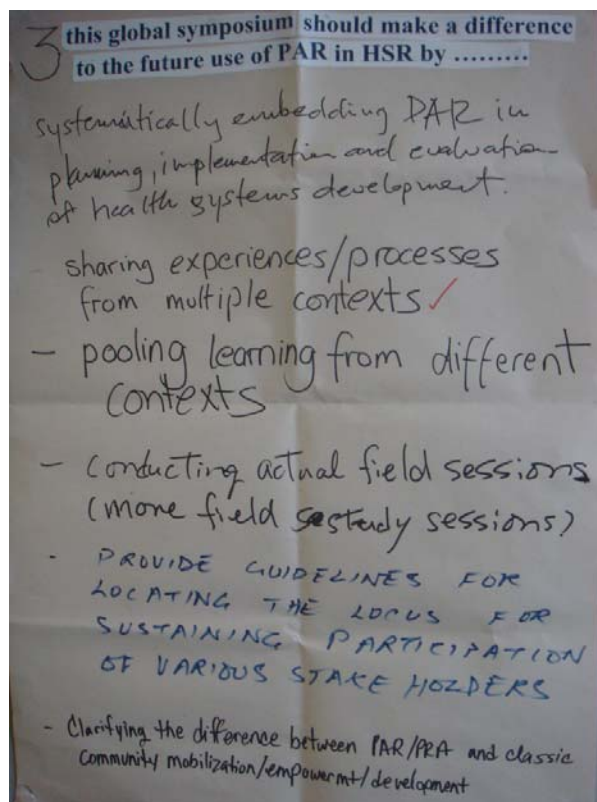
- Recognise the role of PRA in identifying assets for health systems (beyond needs and deficits)
- Provide guidelines for how to move from project/ site specific work to sustained programme, institutional approaches
- Make links in processes between communities and state actors and existing mechanisms for planning and accountability
- Integrate PAR in routine monitoring (eg of “quality of care”)

iii. **Embed PAR approaches with other research methods**

- Raise understanding of PAR as a source of evidence as in other types of research
- Link PAR approaches with other forms of knowledge generation
- Recognise the relevance of PAR in understanding complexity in health systems
- Include in medical, science, nurse and research training at undergraduate level

iv. **Provide opportunities for exchange and learning on PAR**

- For sharing experience, processes, methods, pooling learning from different contexts
- Build conceptual models to replicate PAR, ie what works, when and how
- Clarify common issues and differences between different participatory approaches (PAR, Community monitoring)
- Widen methods used, eg Appreciative inquiry, “ABCD”
- Clarify roles in and differences between PAR and other social mobilisation approaches
- Make connections between PAR and other research communities



In the concluding period of the second session through small group discussions suggestions were made for the way forward in terms of what support people would find useful in their work, and what they could contribute to wider exchange and learning.

6. Proposals for follow up

There was general agreement on the need to widen the learning network on PRA so that it is inclusive of all sites of work internationally (at present there is a learning network in east and southern Africa). Delegates were keen to obtain information to support their work on

- Concepts, meanings and standards of PRA knowledge
- Methods in different contexts
- Resources, guidelines
- Collaborative, networking, experience
- Training of trainers, sharing of capacities
- How to use PAR evidence to influence national programmes and policy

One group identified ‘ten points’ for a future learning network

- To influence local and national
- Learn from experiences in different settings

- Learn from different methodologies with organising this PAR. Interaction of community of practice of what they did and the outcome
- Resource guideline and training, e-learning, seminars, learning by doing
- Mentoring of these of these practices, familiarity, guidance to practice,
- Collaborative voice to ask questions, when considering what to do
- Webpage tools to put it all together as a repository, our community of practice
- Drawing up on sources of support such as funding from a sympathetic institute, foundation, academic department, advocacy (e.g. Open Society Foundation).
- Train the trainer, i.e. misconceptions
- Access to best practice – actual models, when constructing and designing a PAR, what does this society of “K” (knowledge?) disseminators consider as “good enough” as an acceptable standard

A learning network that supports this was thus suggested that would provide

- a communication channel through a mailing list
- A website portal for resources and links to members websites
- a repository of resources, photos, case studies, methods
- use of flickr as a tool or sharing photographic materials
- an inventory of networks, sites working with PRA
- opportunities for face to face meeting, exchange, including on the ‘ten points’ above.

It was noted that this would need a home / host / hub/ co-ordinator and moderator.

As a follow up to this the convenors (EQUINET (TARSC and others in the PRA network); CEGSS; SATHI) working within and across their networks committed to

- make input to the final plenary of the GSHSR (this was done and participatory action research was raised in three different presentations at the final session)
- Widen the EQUINET pra4equity mailing list to subscribe all those at the symposium wanting to be involved in the follow up as an interim tool for shared communication across those involved
- produce a summary report / paper on the proceedings of the PRA sessions at the GSHSR to profile the work
- Dialogue with Ellen Roskam from WHO on the offer to edit a book of case studies on PRA including experiences from the GSHSR
- Dialogue with MEDICC review to include papers on PAR in future issues
- Upload materials on the searchable EQUINET database www.equinet africa.org to allow for exchange of materials until a more formal website platform is developed. Follow up dialogue is being held on this with support from WHO
- Develop a proposal for activities, website and meetings for the learning network

Emphasis was given to find a means to reflect the independent identity and contexts of participating organisations from all continents in a learning network, while also creating opportunities for exchange, dialogue, learning, for enhancing public dissemination, scrutiny and feedback, and for development of cross cutting learning on methods, on the science and art of PAR and on the implications for health systems.

In the two sessions there was a clear consensus expressed that politics and evidence need to combine for universal health coverage, as both an expression of values and a set of technical options, to be achieved. This is not simply about health care- the social determinants of health also need to be addressed, as do the social inequities that act as barriers to universal coverage. This calls for a shift in mindset to make more effective connections across geographical regions, disciplines and constituencies. Research, in the sense both of the generating of new knowledge and the reinvestigation of realities with new eyes offers an opportunity to do this. Participatory action research offers the opportunity to do it more directly with the communities involved, in ways that bring people to the centre of knowledge generation, that raise the realities, determinants and proposals for policy and action as seen by those most affected, and that integrate action within the process.

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Acknowledgements:

The work described in the Guatemala case study was financially supported by the International Development Research Centre (IDRC) Canada. The work described in the African network was financially supported by IDRC Canada and SIDA Sweden. The work in the India case study was financially supported by the National Rural Health Mission, Government of India and in the Canadian Case study by Canadian Cooperative Association, the Saskatoon Community Health Clinic, and the City of Ottawa. Thanks for conference delegate support from the conference organisers, Open Society Foundation and Doris Duke Foundation, and many thanks to the delegates who participated in the session and contributed to the discussions reported in this article.