Participatory action research in people centred health systems

International Workshop Report

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Regional Network on Equity in Health in East and Southern Africa (EQUINET)
Training and Research Support Centre and the pra4equity network
with Asociación Latinoamericana de Medicina Social (ALAMES)

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1. Background

There is a growing demand to channel collective energy towards justice and equity in health, and to better understand the social processes that influence health and health systems. Communities, frontline health workers and other grass-roots actors play a key role in responding to this demand, in raising critical questions, building new knowledge and provoking and carrying out action to transform health systems and improve health. There is a widening array of methods, tools and capacities – old and new – to increase social participation and power in generating new knowledge through participatory research to achieve social transformation.

Immediately following the 2014 Global Symposium on Health Systems Research, a one day workshop was held, convened by Training and Research Support Centre (TARSC) (www.tarsc.org) and the pra4equity network in the Regional Network for Equity in Health in east and southern Africa (EQUINET) (www.equinetafrica.org) with Asociación Latinoamericana de Medicina Social (ALAMES) (http://www.alames.org/). The workshop was held to deepen the discussion on the use of participatory action research (PAR) in health policy and people centred health systems, including in acting on the social determinants of health. While there are many forms of participatory research, the workshop specifically focused on PAR, that is on research that transforms the role of those usually participating as the subjects of research, to involve them instead as active researchers and agents of change, where those affected by the problem are the primary source of information and the primary actors in generating, validating and using the knowledge for action, and that involves the development, implementation of, and reflection on actions as part of the research and knowledge generation process. PAR seeks to understand and improve the world by changing it, but does so in a manner that those affected by problems collectively act and produce change as a means to new knowledge.

The one day workshop was open to delegates from all regions globally to foster cross regional exchange and to include people from the pra4equity network in east and southern Africa. It aimed primarily to bring together people involved in PAR, using it in various health system processes, but included also some delegates involved in other forms of participatory research.

The workshop aimed to exchange information, experience and build learning on and capacities in PAR, and specifically on

- The background to and motivations for the emergence and use of PAR in health policy and health systems across different regions
- The key features of PAR and their implications for research in health and health systems
- Experiences of applying the processes and methods of PAR in people-centred health systems,
- Ethical Issues in taking forward work on PAR, and
- Learning networks and communities of practice in building capacities for, exchange on, documenting and reporting PAR


The reader promotes understanding of the term ‘participatory action research’ (PAR) and provides information on its paradigms, methods, application and use, particularly in health policy and systems.

The meeting gathered 48 delegates from all regions globally (See delegate list in Appendix 1). The meeting process involved a mix of presentation and participatory processes (See programme in Appendix 2). The meeting was supported financially by IDRC Canada with further support for travel and board costs of some east and southern Africa (ESA) participants from Cordaid, and TARSC and delegate contributions to travel and accommodation. This report summarises the main inputs and exchanges at the meeting. Following the one day meeting the delegates from ESA countries involved in the regional learning network on PAR continued with a two day follow up workshop to deepen the exchanges and learning, specifically drawing on and for the work in the ESA region. This is separately reported.
2. Welcome and opening

Rene Loewenson from TARSC/EQUINET welcomed delegates to the meeting, appreciating the cooperation with ALAMES in organising and holding it. She noted that it followed organised sessions and papers on PAR in the Global Symposium for Health Systems Research (GSHSR) and gave an opportunity to explore PAR concepts a bit more deeply. It still faced the constraint of what could be done in a single day. EQUINET (www.equinetafrica.org) is a consortium of different institutions in east and southern Africa that works from local to regional level in ESA countries, and engages globally from self-determined perspectives derived within the region. EQUINET’s work is organised in themes and covers many aspects of equity and social justice in health, from wider social and economic determinants, such as food and nutrition, to health system issues, such as fair health financing or HCCs, as well as how these issues are engaged on globally, such as to secure medicine production and access in trade systems. EQUINET has since 2005 built a learning network – the pra4equity network- on participatory research on key areas of work on health justice and builds links across its different areas of work and processes, including in engaging in regional policy forums and with other networks that also seek social justice in health, such as in the south-south networking with ALAMES.

Mauricio Torres Tovar from ALAMES also welcomed delegates and the co-operation with EQUINET in organising the meeting and appreciated the opportunity to engage with colleagues from Africa and other regions on participatory action research. ALAMES (www.alames.org) emerged 30 years ago from the confluence of critical thinking in health and the struggles of the Latin American peoples in defense of their health. Several centres located in universities, social organizations or working in health systems formed this partnership with the aim of uniting efforts, and ALAMES has now extended to many Latin American countries. It has theme networks and through its members is involved in training in universities, in social movements and civil society organizations in defense of the right to health, and in promoting public and universal health systems.

Delegates introduced themselves and their institutions and countries as shown in Appendix 1.

The Methods Reader on PAR was distributed to delegates and Rene noted that some of the issues being discussed in the workshop or that could not be addressed in the day were more fully discussed in the Reader, with references for further reading drawn from all regions. The reader structure is shown in Box 1 below. She recognised the presence of some of the co-authors of the reader and of reviewers in the workshop and acknowledged authors that were not present but had key input to the Reader.

Box: The Methods Reader on Participatory Action Research in Health Systems

The reader is organized in five parts. This first section introduces the reader and its aims.

Part one: Concepts gives an overview of the key features and the historical roots and drivers of PAR and the paradigms used to generate knowledge. It explores the role of power and participation in health systems as a context for PAR.

Part two: Methods introduces the processes and methods used in implementing PAR. It raises also the opportunities in new information technologies for PAR and the experiences in institutionalizing PAR in health systems.

Part three: Issues & challenges raises various issues that arise in applying these methods in PAR, including in how questions of validity, bias of and generalization commonly raised in research are differently addressed in PAR. It examines the ethical issues and logistic challenges in PAR.

Part four: Evidence & action discusses options for and experiences in communicating and using evidence from PAR, and explores the role of learning networks and communities of practice in supporting and developing PAR methods and practice.

Part five: Empirical papers reproduces twenty-one published papers that are referred to in different parts of the reader and that provide examples of thinking on PAR, its features, aspects of and challenges.
3. Experiences of participatory action research across countries

Following the introductions, delegates heard the experiences of using participatory action research in diverse regions. Rene moderated the session and between the presentations people in buzz groups discussed the key issues emerging from them and wrote questions that they had on cards.

3.1 PAR experience in Latin America

Mauricio Torres Tovar and Jaime Ibacache of ALAMES presented the conceptual and ideological bases of PAR from Latin America and its use in Chile and Colombia. Mauricio explained that ALAMES has been involved in many change processes happening in Latin America both in the social and health areas. Their main challenge has been promoting and sustaining the construction of integrated public and national health systems and that ALAMES works in social medicine or collective health.

The development of PAR processes and experiences in Latin America has grown side by side with many other important social transformation processes originally linked to ecclesiastical communities and national liberation processes, such as popular education. Two important mentors for PAR have been:

• Orlando Fals Borda (1925 – 2008) Colombian sociologist and researcher, whose critical thinking contributed in academic and political processes and who founded PAR.
• Paulo Freire (1921-1997), who wrote pedagogy of the oppressed, with work that transmitted pedagogy of hope. He influenced the new liberating ideas in Latin America, liberation theology and teaching innovations.

Mauricio explained that PAR allows the breaking-away from traditional research methodologies, techniques and operations. It’s an ongoing renewing and construction process that uses systemization as an important tool to analyse experience:

• Epistemologically: breaking the classic pairing of subject and object in research, and recognising that the knowledge and experiences of community members have value in the creation of knowledge.
• Politically, associated with processes of social transformation, and
• Methodologically, developing different techniques to assess the causes of problems, and concrete and achievable strategies for planning and transforming reality.

PAR in Latin America has thus been linked to processes of social transformation. It breaks and questions concepts and methods commonly used in traditional research, with its own theoretical and methodological perspective. PAR is a process in permanent construction.

Jaime Ibacache ALAMES Chile described the PAR work in Patagonia in the south of Chile, within the Mapuche and Chono-Williche communities. Indigenous groups have perceived health and disease in very distinct ways, yet, since the 1960s, epidemiological profiles/health models in Chile have not only ignored cultural factors but also the politics of health in their implementation. Development models implemented in Chile have been models that have stripped the land, knowledge, and practices of these dynamic cultures and generated a sense of paternalism and dependence on an exogenous-foreign biomedical model. A trans-disciplinary team of physicians, anthropologists and community members have since the 1980s developed participatory methodologies in the territories to improve comprehension and understanding of the reality (“Kelluwam” from Mapuche) and to produce inclusive, intercultural and dynamic knowledge (“Wekimun”), generating self-organization to end colonialism and dependency. Linked to this the hospital is managed by the community, and the treatment models are inclusive and collective and embrace both Mapuche & Biomedical approaches, as in the example shown in the figure. The Boroa Filulawen Health Centre is managed by the community and communities contribute towards a socio-cultural epidemiology, starting in their homes as places to share knowledge and treatments.
Jaime explained that this experience has faced challenges. Funding from the Ministry of Health has been linked to biomedical goals and authorities and universities in the territories have adopted a biomedical and neoliberal health policy and culture that focuses on why people get sick and not also on why/how they remain healthy.

Mauricio recounted work with PAR in Uraba Region of Colombia on the work and health conditions of Banana Workers, using the Italian worker model. This model, also explained in the Reader investigates working conditions and their impact on health where the participation of workers and is a central component. It is guided by principles that:

- The knowledge of the workers is valuable
- Health at the workplace is a collective issue and cannot be delegated or exchanged for money, and that
- Damage to health is not a “natural” process but a consequence of work.

The research thus provides the basis for action to protect health at work in a process shown in the adjacent figure. Homogeneous groups, consisting of workers exposed to the same working conditions, answered collective surveys, and identified factors that were harmful or beneficial to health in the work environment, and interventions to transform the conditions. The workers disseminated the information about the findings to other banana workers using Primers and videos. The PAR enabled the banana workers to expose issues in the banana sector that jeopardized their lives by constantly exposing them to dangerous elements such as long working hours. The logic of obtaining high earnings by business owners, imposes a high pace of work, long working hours, piecework and specialization of a task for each worker. The main health problems found were skeletal, optical, mental, respiratory, gastric and skin related. The workers also developed better understanding and awareness of their rights within the working processes -including their right to health - and thus made proposals and facilitated interventions through the workers’ trade union to improve their conditions.

In general, Mauricio explained, PAR generates a strong link between people and researchers by breaking the divide between subject and object in research, and by addressing the power imbalances. It demystifies positivist research methods and recognizes the use of collective and popular methodologies. For social movements it has facilitated collective action and reflection, to acquire autonomy in the process of analysis and understanding of reality. He argued while methodological improvements need to be made, this must be done within social processes and movements, without isolating the issue as an academic phenomenon. The link between participation and power is central for PAR. It is important to further explore how PAR can contribute to the creation of resources of power for those who do not have it, and the role this plays in order to advance social transformation. Finally he commented that PAR implies action and social transformation as inherent to its origins and identity. He questioned whether it can be part of a traditional scientific community.

### 3.2 PAR experience in east and southern Africa

*Kingsley Chikaphupha REACH Trust* presented his first experience of working with PAR in Malawi in Southern Africa. React Trust started its work with communities in 1999. And in 2007 he joined the pra4equity network in EQUINET, building skills as a part of a group exploring how the roll out of HIV and AIDS services could take primary health care approaches that were more responsive to specific communities. HIV prevalence in Malawi at the time was at 12% of adults and about 70% of commercial sex workers [CSW] were HIV positive. While CSWs were thus a key group for access to treatment, they had limited access to HIV prevention, treatment and care programmes and the programmes did not
address their situation. REACH Trust works with communities and health services and both had raised the issue of CSW treatment. The work thus sought to raise visibility on the experience of CSWs in Lilongwe and to raise and address barriers to their access to and use of HIV prevention and treatment services. The work used PAR approaches with the CSWs as well as a baseline and follow up assessment of change by CSWs and health workers (HCWs) and key informant interview with community leaders. The facilitators’ team included CSWs and local community organisations and health workers, as well as people from REACH Trust. Kingsley described the steps for bringing CSWs into the work, which was challenging given the nature of the group. Community organisations, CSWs and ex-CSWs helped to identify CSWs through ‘snowballing’, noting that involvement was voluntary. The process was organised in meetings with social mapping (as shown adjacent), ranking, problem tree, market place, wheel chart and Margolis wheel, used to gather experiences on health and use of care, identify priority problems and their causes and to identify possible changes in services to address them. The CSWs identified various barriers, including gender based violence from healthcare workers, the community and their male counterparts. These experiences were raised with health services.

The process itself raised CSW demand for information on services. The social mapping identified close to community counselling, testing, prevention and treatment services and the services provided outreach counselling, sugar, salt, soap and mobile clinics to reach CSWs in community sites. There was improved uptake of these services and those for HIV and STI testing and treatment by CSWs. Although time intensive, the process was effective in drawing out and validating experiences of the CSWs and highlighted their problems with services. At the same time the process brought out the different and shared perceptions of healthcare workers and CSWs and allowed for the identification of shared priorities and creation of joined actions that improved uptake. Kingsley noted: “In the short time frame of the initial process, we did not expect to address all the issues. Many are structural and deeply rooted and need longer term processes. The process raised issues of gender violence and abuse that CSWs face (including through attitudes and practices in health care services) that dehumanize them, and perpetuate their own harmful behaviours.”

Barbara Kaim TARSC expanded on the Malawi experience to talk about EQUINET’s pra4equity learning network in East and southern Africa. This is a learning network of PAR practitioners - researchers, health workers, academics, CSOs, and community leaders - from 16 countries in East and Southern Africa. The network aims to advance and realize equity values and social justice in health. “We use PAR for transformation”. She raised that through PAR we have been able to critique the inequities and the social structures in which we live, and take actions on health. While EQUINET is nearly 20 years old, the pra4equity network is 10 years old next year and since 2005 has undertaken 30 sites of PAR work on areas such as health worker and community interactions, on HIV/AIDS and primary health care (PHC) responses, on social determinants of health and on strengthening the resourcing and functioning of PHC. The network has embedded PAR in other programmes including health literacy, sexual and reproductive health and other programmes aimed at strengthening rights and improving public health. The processes have been documented and shared in reports, books, through mailing lists and during online dialogues and the network has provided a platform for review, learning and sharing of experiences.

PAR processes have strengthened the social voice and community power and brought increased recognition and early detection of health problems and needs and changes in the culture and performance of health systems and in the use of local resources for health in response to social priorities. There have been important social outcomes, in many, but not all of the processes, including in
analysis of causes and awareness that systems can change, in demand, including from marginalised
groups, and in shared dialogue in planning on local health needs and self-determined action by
communities and frontline health workers, with monitoring and strategic review. The regional learning
network has helped to spread PAR beyond borders, sharing of values, resources, planning collective
action, strengthening and unifying the marginalized voices. There have also been many challenges that
have been raised in the network, including in how we sustain and institutionalize the practices, how we
report and use the processes for learning and address deeper structural determinants and the global and
national processes that impact the community level.

3.3 Conditions leading to PAR in Brazil and Pakistan
These experiences suggest the importance of the political, social, cultural contexts for PAR, that create
conditions for it and struggles over knowledge that affect the form and process of PAR.

Vera Coelho, CEBRAP Brazil described how during the Brazilian dictatorship in the 1960s and 1970s,
the health movement was initiated to mobilize and motivate people to demand their rights to health,
including through a universal health system (SUS, Sistema Unica de Salud ) and to participate in policy
processes as enshrined in the 1988 Brazil Constitution. This created spaces and structures for social
participation in health processes that were also formalised. While these mechanisms are themselves not
PAR processes, she outlined how they have created wider contexts for social power in health systems.
For example the federal government can only transfer money to states/municipalities where previous
and future health budgets/plans have been approved by local functioning health councils. This created
top down and bottom up political powers. Health Councils comprise a mix of half of the representatives
from civil society and half from and health professionals and workers. They bring information and
learning from federal, to state, to municipalities and vice versa. She also noted the challenges: There is a
normative adherence to principles of participation but low enforcement and variable implementation. In
areas with stronger backgrounds of mobilization there are more vivid and conflictive debates, more
inclusion of women and marginalized groups.

The work highlights challenges in institutionalising participation, even more so for PAR. She noted that it
has reinforced the importance of building a broad coalition that connects diverse actors in different
political spaces and levels of the Brazilian federation, and the necessity of training public officials to
support citizen engagement as part of government routines. It raises issues of investing in preparing and
bringing together in a coherent way the recommendations produced by the myriad of health councils.
As social mobilization is key, this and the learning from the processes implies building broad progressive
councils that occupy different political spaces and places in the community and government, and that
fully embrace participation and inclusion. There are more than 90,000 people working in councils who
produce myriad of innovations, but this has not yet been well documented and systematized to show
what is happening; calling for tools that can prepare and bringing together, in a coherent way, the
recommendations produced by these health councils.

Kausar Khan, Agha Khan University Pakistan outlined how in the last few years many public institutions
have collapsed and that the private sector is emerging in health. In health sector research, the positive
paradigm dominates, although the School of Nursing has become stronger in qualitative research; Social
scientists are weak and they are dominated by economists. Pakistan has a lot of experience in the use
of PAR. Originally called participatory rural appraisal or participatory reflection and analysis, the
methodology was adopted from Paulo Friere’s framework of transformation to support & validate action
research. PAR has been used widely but there is still no institution pulling together this work and
experiences systematically. Even in the government, the Planning Commission had a poverty
assessment that recognized the real experts of poverty as the poor themselves, although their input was
not recognised as ‘research; Kausar raised A Chinese philosophy suggests that there are two types of
people, those who think and those who act: Those who think but do not act are boring, and those who
act but do not think are dangerous. There is need to bring these two elements - action and thinking -
together, to create a balance when using tools for PAR, to not let tools take control but instead use them
better to ensure there is enough mobilization of people, enough skills development, enough
documentation, thinking, analysis and linking with the broader conceptual base of rights, equity, social
transformation and liberation from oppressive health structures, policies, politics, other peoples’
knowledge and power. She also observed, as did previous speakers, that the struggle for health is not
possible without a struggle for social change, connecting it to political and other processes.
3.4 Drivers of PAR and experiences in struggles over health

In the final discussion, delegates discussed and captured on flip charts the role PAR has played in struggles over health and the current forces for and drivers of PAR (shown in the adjacent photographs).

The experiences highlighted the potential, not always realised, for PAR to strengthen the power of affected communities, workers, health workers and others. This has often generated a collective countervailing power in the face of different forms of injustice in health. What was common was the fact that PAR has opened autonomous spaces. While the processes have varied, self-determined participation has had been a liberating effect. This has pushed debates on health beyond that of services and commodities to issues of social determinants of health, to progressive realisation of health rights, to acknowledgment of cultural and traditional structures in health and to recognising the political nature of health and health systems.

Social forces were thus seen to be major drivers of PAR, particularly activists and champions that facilitate social processes and reflection to explicitly connect knowledge, power and action, that may come from communities, universities, health workers, and other settings, often in confrontation with the traditional norms in these institutions. The PHC agenda was seen to provide greater space for this in the health system. Critique of the dominant paradigm and what has not worked is also a driver, calling for engagement with people’s perceptions and views to address these deficits. Research and new knowledge need to be seen as linked to action and change and action is a source of learning.

4. The features of PAR

4.1 Features and historical origins of PAR in health

Rene presented evidence from the Reader Section 1 on the features and origins of PAR and its relevance to health systems. She noted that while there are numerous types of participatory action and research methodologies but PAR is unique;

- It transforms participants from the object to the subject, from those being studied to active researchers.
- It organises local experience and has systematic processes for collective validation of these experiences, and collective analysis of causes, relationships and patterns.
- It reflects on and generates action that produces change and generates new knowledge/learning from that change/action,
- It moves in repeated cycles of this process of building action and knowledge.
She noted that PAR is about trying to build universal health systems, not simply universal health coverage. That is why it is not limited to poor communities, but takes place in a diversity of settings. This is a process of struggles to change every person's perceptions about health in a way that addresses population health needs at a wider scale and creates joint interest in sustaining those systems.

She traced the various streams of participatory research and that of PAR. This is summarised in the adjacent figure and more fully described in the Reader Section 1. There appears to have emerged two "strands" of participatory research: One is a pragmatic or utilitarian, along the lines of action research, motivated by the need for change and thus involvement of the "community" in the research to ensure change in areas where community perceptions and roles were seen as critical. PAR as a field was more ideologically and theoretically motivated, to recognise and address the power relations, consciousness and collective organisation that influence the production of new knowledge and its use in change. She noted the contexts of inequality in health that have motivated and continued to motivate this emancipatory form of PAR. The PAR work done in EQUINET exposes that despite the adoption of PHC, health systems intend to respond to community priorities, but don't in practice; don't link well across sectors, narrowly perceive community roles and have high legitimacy but weak capabilities for social roles. They generally have top down planning, with limited resources at their base, and weakly address social barriers and facilitators to health service uptake, leading to inefficiencies and burdens. While PAR can bring new evidence on social determinants and raise demand for equity in health, it generates knowledge within a wider concept of health that positions peoples experience, health literacy and actions as key for improved functioning of health systems.

In discussion delegates noted that it is the rooting of PAR in the experience and analysis by affected communities that raises the reality of what is taking place in health systems. This can narrow the gap between policy and reality that and lead to creation of better policies. However it faces obstacles, in unresponsive systems, narrow spaces for participation and people’s consciousness. The PAR process can itself increase peoples’ awareness of services and rights and raise a level of consciousness and self-awareness in those involved. If explicitly understood to be a key part of the process delegates said that it can lead people to not only understand their power, but also to use it transform their conditions and systems, and to demand accountability from duty bearers for their role in this transformation.

4.2 Applying the features of PAR in practice
Rene asked delegates to explore further their experience in applying the key features of PAR, as researchers, in social power and change, in building new knowledge, in changing health systems and in embedding PAR within institutional processes. Each of these issues was explored by a group of delegates, with five groups in total. The questions discussed by the groups are shown in Box 2 below.
Box 2: Questions discussed by groups on PAR

Gp 1: What benefits and challenges do PAR methods bring for researchers? What are the experiences of the group in this, and in overcoming challenges?

Gp 2: What methods and processes in PAR are most effective in building social power and change? With what challenges? What are the experiences of the group in this, and in overcoming challenges?

Gp 3: What areas of new knowledge in health systems have PAR methods been most effective for? What are the experiences of the group in this? With what challenges faced and how have they been addressed?

Gp 4: What methods and processes in PAR are effective for / have been used in changing health systems? With what challenges? What are the experiences of the group in this, and in overcoming challenges?

Gp 5: What methods and processes in PAR could be or have been institutionalized in health systems? What are the experiences of the group in this, and in overcoming challenges?

The facilitators and rapporteurs for the groups are shown in the programme in Appendix 2. Each group recorded the points raised in the discussions on cards (each group had its own colour cards, with researchers in pink; social power in blue, knowledge building in green; health systems in yellow and institutionalising processes in blue).

The groups put their cards in the appropriate place under the headings for the discussion on experiences, benefits and challenges in applying the features of PAR:

i. In relation to the **actors, social processes and institutions** involved

ii. In relation to challenges, opportunities in the **methods and the knowledge generated**

iii. In relation to **local and wider transformation of institutional practice**

Delegates gathered around the cards (as shown in the photo) to discuss each of the three areas and the cross cutting issues raised around social processes, knowledge and transforming practice.

**In the actors, social processes and institutions involved** (see photo overleaf)

Key experiences are of recognition of communities as researchers, and researchers acknowledging the community. PAR can inform how people can demand services and the community plays a vital role in distributive issues.

Delegates raised that PAR thus brings many benefits for social processes and institutions:

- Raising consciousness on historic deprivation and oppression
- Freedom, as the process does not dehumanise people
- Reciprocity and understanding of power relations
- Empowerment of the community, with the interests of communities driving processes and community ownership of knowledge
- A deeper perspective, and direction given by the community to research
- Raising the visibility of social determinants of health

At the same time there are challenges in

- **WHO do you engage with and how**;
- Addressing the needs of marginalised people where context doesn't allow participation, such as involving MSM, and the LGBT community in contexts where this is criminalised;
- Addressing socio-cultural beliefs, such as on family planning;
- Who sets the research agenda, and how communities do organise the direction of the research given the different views and power imbalances between research facilitators and communities;
- Reconciling the different interests, expectations of funders, researchers, communities, and
- Loss of interest or frustration, such as if change is slow

Various proposals were made to address these challenges:

- Know and understand the power relations in the situation and make them part of the process.
- Build the social connections of those involved and alliances with others.
- Dialogue with people involved to reflect on how to confront power imbalances and to understand the best means of engaging.
- Bring in actors who may oppose processes before they react, and be proactive on engaging them.
- Review processes to keep asking whether and how the affected community is organising the direction of the work.
- Use and share information on role models to show feasible responses to challenges.

Delegates raised possibilities of working through and with existing structures such as Health Centre Committees to embed PAR, to use forums and spaces that create a more supportive environment for collective processes and action. However it was also noted that these mechanisms may also dilute social power and limit transformation and that there are also struggles around their representation of wider community interests. Locating PAR within these mechanisms thus depends on the context and issue.

With the diversity of health issues delegates proposed it was apparent that there is need to take a wide lens on the meaning of community. While PAR is applied within homogenous groups of people with shared experience and basis for action, it is not only relevant to low income or disadvantaged communities but can also be used with workers, health workers and managers where they have struggles around health and health care. What is key is that the process is centred on those people that directly experience and are affected by the issue in focus, to enable their experience to be included and
to make the link between their analysis and action, so that the PAR is valid. The specific measures for overcoming challenges will depend on context, but they should enable, give time for and not displace the key processes in PAR that build the collective self-consciousness that create conditions for people to change their situation.

**In the methods, and the knowledge generated**

There are a lot of creative and innovative PAR methods and tools and they are being constantly refined and reinvented. But it’s important to realize that it’s not about the tools, but the principles of the method and PAR process as described earlier. Tools were thus clearly understood to be the servant of the PAR process, making it necessary to always ask ‘what it is being used for’?

Key features of delegates’ experiences of applying PAR methods were noted to be

- Starting with local concrete issues as entry point to evolving networks and issues;
- Respect for communities and their lived experience;
- The use of multiple methods and tools, with flexibility to be responsive to the PAR process and to the social, political, institutional transformation it intends to build;
- Processes and methods that facilitate social dialogue, processes for collective validation and for exploring differences within the group;
- Stories of change as effective and inspiring elements of process;
- Demystifying generation and use of visual images such as photography, media, video, that also have use in other social processes such as public hearings; and
- Use of technology such as cellphones more to generate social pressure within actions

There were numerous challenges noted in applying the methods and drawing the knowledge from action:

- In the nature of the ‘evidence’ as less familiar to those using more traditional methods, and the interaction with other methods such as ethnography;
- In lack of understanding of the PAR process;
- In gathering people when there are legal limits on the number of people that can gather, as in some African countries;
- In giving a voice and creating spaces for outcast, illegal and other marginalised communities to allow silent and hidden issues to be identified (the example was given of how older bedridden people could engage in PAR processes;
- In inability to sustain the spiral sufficiently and in making the link between more local PAR processes and the wider political, institutional and social movement processes that address deeper structural issues raised in PAR;
- In the time consuming nature of the PAR process, not often accommodated by funding cycles;
- In documenting the method, actions and outcomes to enable sharing, dissemination and building the knowledge from PAR

Various approaches were raised to address some of these challenges:

- Strengthening facilitator skills, exposure and support for community listening, for encouraging; reflection, for developing relationships with communities;
- Embedding PAR within processes, social movements and civil and other institutions able to sustain them over the longer term, although with caution over how this compromises the PAR process;
- Sharing strategies and lessons and encouraging peer review amongst those involved in PAR; and
- Documenting PAR in ways that maximise community control over the information and that are useful to those directly involved, as well as to the wider knowledge community.
In relation to the local and wider transformation of institutional practice

While the blue and pink cards reflecting researchers and social processes predominated in early themes, it was apparent that those from the knowledge group (green) predominated in transforming and institutionalising practice, with some ‘blue’ input from those discussing institutional processes and social processes.

It points to an observation made in the Reader that the production of knowledge and control over knowledge is not an academic process. It is a form of power that has a key role in how institutions are shaped and function. This makes building a body of knowledge for and from change a critical political determinant of institutional change, together with the social forces and institutional actors that drive change.

In reflection on experience, PAR processes were noted to transform institutions when they

- Embed PAR in wider national processes such as health literacy;
- Reclaim elected representatives that are accountable to communities in decision making, particularly on health and health systems;
- Roll out processes horizontally, spreading from local to local within a wider institutional framework such as local authorities;
- Widen social awareness and mobilisation around issues raised;
- Engage influential leaders and policy makers to create space for and support the process and outcomes; and
- Document and report the work to widen dissemination and use of the knowledge.

Institutionalising PAR was seen as a political process, involving social actors, and a knowledge process, engaging around the learning and understanding of health and the institutions that are involved in this. This raises questions about the struggle over both that those involved in PAR need to engage with: Is it possible in the neoliberal context for current universities, health authorities and other institutions to do or to build PAR? For which institutions and why? When is the institutionalisation of PAR a form to co-option and when and where does it reflect a moment in history when subordinate groups accumulate knowledge that can have an impact on wider change in society and in systems?
There were a range of challenges identified in transforming institutional practice, moreso that in other areas, suggesting that this is an area where significantly more focus is needed in PAR processes. These challenges were identified in:

- Poor understanding of PAR and poor understanding in health systems of how to use forms of knowledge generated from PAR;
- Top down culture in decision making in many health systems, with poor accommodation of different knowledge systems and political and institutional constraints on health workers;
- The time consuming and intensive processes of local to national scale up through local to local roll out;
- Weaknesses, top down cultures and limitations in democracy in social movements and civil society that should bridge the local to national level processes;
- The potential for loss of integrity of and social control in the process and of co-option when PAR processes are scaled up to higher levels;
- Limited evaluation of PAR processes and outcomes in terms that make sense for the nature of the processes;
- The difficulties people have in documenting the process and knowledge while also implementing the processes; and
- The limitations in funding the sustained processes needed for scale up.

Suggestions were made on how to overcome these challenges, drawing on experience. These were:

- Encouraging the understanding that different bodies of knowledge existing (including in formal education and training), and that planning and other processes need to use a wider spectrum of knowledge;
- Ensuring that processes for obtaining community needs and inputs are formally required in planning in health systems;
- Exposing medical students, health professionals, university students to PAR processes and to families and students working together;
- Using information technologies in PAR both to widen the processes and to support sharing and peer review of knowledge and process;
- Fighting for space and recognition of knowledge from PAR. This may involve publishing in traditional journals, but also raises questions of how far this is possible within the current journals given their approach and ownership. There was thus also proposal for those involved in PAR to generating own media and journals; and
- Strengthening and linking PAR with social organisations and movements, and with key skills, including legal skills, to address power issues.

Rene summarised the discussions and pointed to Section 2 of the Reader where many of these issues are further discussed. She noted in particular that the developments in information and communication, including in visual technologies, cell phones, internet platforms, were not only creating new opportunities for social movements, but also for PAR processes in linking experiential and spatial evidence at wider scale and more importantly in allowing for real time social dialogue for collective validation and analysis at wider scale. Notwithstanding this, the same questions about the distribution of power and how the methods are used and embedded within PAR process apply in using new technologies, and would need to be addressed. She noted that TARSC/ EQUINET will be taking forward work to explore this further in the coming years.

5. Ethical issues in implementing PAR

Discussions in the meeting raised at various times the issue of ethical norms and their application in PAR. Zubin Shroff, Alliance for Health Policy and Systems Research presented a discussion on the ethical norms in research and in PAR, drawing on Section 3 of the reader. He noted that PAR in common with other research approaches must be subject to ethical review. Existing ethics codes in traditional research are designed to view research participants as passive subjects. The subject-object shift in PAR has several implications for ethical review. PAR processes aim to transfer power to the people directly affected, so protocols must demonstrate how the research can serve to emancipate people and enable them to act on the social, economic and political determinants of health. Ethical
processes need to ensure fair involvement in the process, such that participants in the research are those who benefit from it and that traditionally under-represented groups are fairly represented. There needs to be evidence that the research process is not driven by narrow or individual political agendas and interests, including that documentation involves and reflects the input of communities. He noted that the emancipatory role of PAR while usually positive, can intensify conflict with entrenched groups and pointed to papers such as that by Estacio and Marks (2010) that describe this, particularly as groups become more aware of their oppression. There are also logistic issues in reconciling the need for independent ethical review with the PAR process where community engagement is needed before the research question and methods are formulated and where the process itself is community determined. This raises the question of who should give and receive consent, how the process should be designed for PAR, and how it relates to formal processes for ethics review? He raised these questions for discussion by delegates.

Mauricio, ALAMES also asked whether it is correct to ask the traditional ethics questions? If one looks at ethics from a traditional perspective there is a risk that critical information may be lost. Ethical decisions must consider the processes and values that aren’t part of traditional methodologies of love, justice, rebellion, solidarity, and relationships in the community. Issues of ethics must respect cultural norms, the ways of life, and ensure a continued connection with the community - even beyond the research phase. He stressed that it is important to ensure, as in PAR generally, that there is complete control by the community. They as investigators must be involved in the mechanisms for change being studied, in the hierarchies of class, gender, culture and knowledge to stop information being lost and in the processes that facilitate sharing of knowledge and information using mediums available and accessible to the community, facilitators and organic researchers.

Delegates discussed these issues further, noting the tension over issues such as how communities in PAR are involved in how evidence and analysis is documented and how the community is involved, and who gives and receives consent and how the process should be designed, recognized and politicized. While reflecting on the compilation of ethical principles presented in Box 27 of the reader, delegates questioned whether it would be better to provide a small set of broad ethical principles, such as ‘do no harm’ that are applied in PAR, and having other elements as guidance for local application. These principles need to reflect that fact that PAR is commonly a contrahegemonic process, challenging dominant forces when these lead to social injustice. There wasn’t adequate time for discussion on the issue and it was noted that it would be useful to share the wider debates and discussions on this issue to take it forward. A number of delegates shown in Box 3 indicated their interest in being part of a group discussing the issue of ethics in PAR as a follow up.

<table>
<thead>
<tr>
<th>Box 3: Delegates interested in taking forward and exploring ethical issues further</th>
</tr>
</thead>
</table>
6. Learning networks, future work and closing

The cards on the questions that people had were reviewed by all. It was agreed that many had been addressed in the discussions, and Rene noted that some were also discussed in the Reader. Some were not addressed, shown in Box 4 and would be carried forward in future discussions, including through the shared pra4equity mailing list.

Box 4: Questions for follow up discussion

- How do we handle outliers and exceptions in a process that is based on collective validation? Can we provide more information on the processes for collective validation?
- We have talked of change in social norms in PAR- are we sure this is happening? How do we measure this impact?
- What is the optimum level of participation by researchers in planning and designing PAR processes? How does this and the implementation differ for significantly marginalised groups, or for groups that are less vocal such as very young children?
- How do we build in the process a strategic understanding of the power dynamics and drivers of change within PAR?
- When does publication become a diversion from change?
- How do we reconcile the necessity of PAR and its transformative agenda with the current ‘incentive’ and biomedical processes for funding and organising health systems and with the current project funding and culture in academia?
- How do we balance the duties of the state to resource, provide and deliver with the rights to and processes for social participation and action so that a more neoliberal notion of people taking over state roles does not happen?

Rene observed that with the time limitations of a one day meeting, the meeting would naturally raise many issues that could not be answered in the day and leave many questions to be followed up on. This included exploring some issues raised at greater depth and methods for implementing PAR processes, especially given the wide range of contexts, and levels of experience in PAR gathered in the meeting. In a short panel discussion delegates presented the work underway in various networks that provided opportunities for further addressing issues raised and for taking forward work on PAR.

**Mauricio Torres-Tovar, ALAMES** expressed pleasure in advancing the relationship between ALAMES and EQUINET, between south and south, and the opportunity to collectively tackle challenges and contribute towards numerous processes of social transformation. ALAMES is attempting to create dialogue between the academics, government, public services and the community, and is eager to involve other regions such as Africa. He noted that ALAMES contributes a way of thinking that is contra-hegemonic and welcomes the dialogue and exchange to deepen the thinking and processes.

**Clara Mbwili Muleya, for EQUINET’s pra4equity network** also welcomed strengthening links between Latin America and Africa as the exchange would raise new perspectives, experience and bring new thinking and resources to both regions. She noted the existence of the pra4equity mailing list as a good vehicle to widen dialogue and exchange information. The pra4equity learning network has in east and southern Africa provided an accessible- and contrahegemonic- space and a voice for PAR, especially when supported by periodic regional meetings. She welcomed the expansion of the mailing list to include those from other regions and hoped for greater exchange and direct exchange with others from Latin America and Asia to create opportunities for sharing, learning across borders, and also sharing the African experience.
Greysmo Mutashobya, Bernado Community of practitioners on social accountability in health (Copasah) spoke as a local level researcher in Tanzania and as a member of the global COPASAH network that is locally driven by activists working on community action for health rights and accountability. COPASAH uses various participatory methods and has numerous resources in newsletters, trainings, exchange visits that give members room to exchange knowledge, learn, share experiences and dialogue. Greysmo called for improved communication to simplify and encourage the sharing of experience and learning on PAR, and to support and sustain the work of actors at the local level though mentorship. He noted the importance of links across practitioners to bring this experience and support to those implementing PAR, the challenges of organising this from the global level and the value of regional networks that could provide such support in PAR, as he had found from TARSC/EQUINET.

Abhay Shukla, Peoples Health Movement (PHM) raised the importance of the PHM as a global movement that is advancing social rights and social justice in health. He noted the various forms of participatory research underway, and pointed to the need to combine links between those working on different forms of participatory research, including PAR. He suggested that the different networks working with forms of participatory research create a joined platform where they can build shared areas of work and exchange. He suggested that networks can identify hubs for this, with people in them who are willing to act as focal points and to play a role in this for their networks. Abhay also showed a short film on Community based monitoring in Maharashtra, India after the closing.

Godelieve Van Heteren, Health Systems Global talked about the origins of Health Systems Global from a group of people doing health systems research to the current association of a wide range of institutions and people globally, as demonstrated at the 2014 GSHSR. She noted the existence of a thematic working group of Health Systems Global that convenes a range of activities and discussions on the use of social science approaches in health policy and systems research (HPSR) and a cluster within this on participatory action research. She said that there is need for a platform that allows for further collaboration and organized dialogue, where people can meet, share, learn, connect and gain more interest and increase their engagement in the PAR agenda.

Delegates from each region raised comments on the workshop and the next steps. Elena del Carmen Vargas Palacios observed that the workshop stimulated reflection that needs to be taken forward on how PAR can work in addressing health gaps and in social transformation in Nicaragua, and on the spaces and drivers for PAR. Christine Fenenga noted that it was interesting to see that PAR, as an important research approach, is applicable in different settings, including in the European setting, with initiatives in Europe that are using PAR and raising awareness on its use in policy processes. She observed that many use PAR-alike approaches and principles, but with different names, so that there is need for some shared language and definition. She also noted the numerous challenges in research, documentation and communication. Erlyn Rachelle Macarayan felt that the workshop was an eye opener and that PAR is essential to answer questions that looking at data alone cannot answer. It is being used but is still not being given the recognition it deserves to make it acceptable. Wilson Asibu said that he learned that for PAR to succeed there has to be collective engagement centred on values, including traditional values. The day had created a thought provoking basis for the next two days of exchange in the learning network on PAR in East and Southern Africa.

Rene and Mauricio thanked delegates for the energy, ideas and reflections in the meeting. They noted again that PAR is a process in permanent construction. It needs continuing dialogue and exchange that builds on learning networks and processes that have grown over some time, in ways that allow for honest, critical exchanges and reflection to deepen and strengthen the understanding and the work.

The report of the meeting would be shared with delegates and others who had not been in Cape Town and who were working with PAR together with information from other sessions on PAR at GSHSR, using the pra4equity mailing list, for delegates to share it in their networks and to let colleagues know where they can download the reader. Rene indicated that the pra4equity mailing list has been used for several years as a vehicle for exchange across people working with PAR from different institutions and networks. Delegates from the meeting will be included on the list so that it can be used as a communication channel for taking forward further exchanges specifically on PAR until new tools and spaces are created. Rene thanked the colleagues from ALAMES for their rich contribution to the meeting, and recognized the challenge they faced of having to engage in English. EQUINET and ALAMES colleagues wished all delegates a safe journey home.
## Appendix One: List of Participants

<table>
<thead>
<tr>
<th>#</th>
<th>Name</th>
<th>Institution, country</th>
<th>Address</th>
</tr>
</thead>
<tbody>
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<td>Name</td>
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<tr>
<td>28</td>
<td>Clara Mbwili – Muleya</td>
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<td>Cynthia Ncube</td>
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<td>Dickson Okello</td>
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<td>37</td>
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<td>Merlin Willcox</td>
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<td>Box 50827, Lusaka</td>
</tr>
</tbody>
</table>
## Appendix Two: Meeting Programme

### 4 October 2014

<table>
<thead>
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<th>TIME</th>
<th>SESSION</th>
<th>PROCESS INFORMATION</th>
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<tr>
<td>8.00</td>
<td>Registration</td>
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<td>8.30-9.30</td>
<td>SESSION 1: EXPERIENCES AND ORIGINS OF PAR – Moderator Rene Loewenson, TARSC/EQUINET</td>
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<td>8.45</td>
<td>Welcome</td>
<td>Opening remarks from convenors</td>
<td>Rene Loewenson, TARSC/EQUINET, Mauricio Torres Tovar, ALAMES, Rene Delegates</td>
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<td>8.45</td>
<td>Objectives of Workshop Introductions and interests</td>
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<tr>
<td>9.15</td>
<td>Experiences of PAR</td>
<td>Regional experiences of PAR PAR experience in Latin America PAR experience in Malawi Africa PRA4equity in East and southern Africa</td>
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<td>Mauricio Torres Tovar, Jaime Ibacache, ALAMES, Kingsley Chikaphupha REACH Trust, Barbara Kaim TARSC</td>
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<td>10.00</td>
<td>The background to, drivers and emergence of PAR</td>
<td>Country conditions and experiences 1. Brazil 2. Pakistan Discussion  • PAR role in struggles over health  • Current forces for/ drivers of PAR</td>
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<td>10.00</td>
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<td>Vera Coelho, CEBRAP, Kausar Khan, Agha Khan University, Mauricio, Barbara</td>
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<td>10.50</td>
<td>Tea/coffee</td>
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<td>11.20-13.00</td>
<td>SESSION 2: FEATURES OF PAR, Moderator: Therese Boulle,</td>
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<td>1120-1215</td>
<td>Key features of PAR:</td>
<td>Features and origins of PAR and its relevance to health systems, PAR reader Section 1 Discussion on Q1: Does PAR make a difference to new knowledge? Q2: What is the relevance of features of PAR for health and health systems? Plenary feedback and discussion</td>
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<tr>
<td>12.10-13.00</td>
<td>Experiences of applying PAR features (processes, methods) in people-centred health systems</td>
<td>Facilitated discussions on process, methods and experiences of PAR: Gp 1: What benefits and challenges do PAR methods bring for researchers? What are the experiences of the group in this, and in overcoming challenges? Gp 2: What methods and processes in PAR are most effective in building social power and change? With what challenges? What are the experiences of the group in this, and in overcoming challenges? Gp 3: What areas of new knowledge in health systems have PAR methods been most effective for? What are the experiences of the group in this? With what challenges faced and how have they been addressed? Gp 4: What methods and processes in PAR are effective for/ have been used in changing health systems? With what challenges? What are the experiences of the group in this, and in overcoming challenges?</td>
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<td>TIME</td>
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<td>processes</td>
<td><strong>Gp 5:</strong> What methods and processes in PAR could be or have been institutionalized in health systems? What are the experiences of the group in this, and in overcoming challenges?</td>
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<td>Discussion on the implications for the process and practice of PAR</td>
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<td>1.00</td>
<td>LUNCH</td>
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<td>1.00</td>
<td><strong>SESSION 3:</strong> IMPLEMENTING PAR PROCESS AND METHODS Moderator Rene Loewenson, TARSC /EQUINET and Mauricio Torres Tovar, ALAMES</td>
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<td>14.00-15.00</td>
<td><strong>SESSION 3:</strong> IMPLEMENTING PAR PROCESS AND METHODS Moderator Rene Loewenson, TARSC /EQUINET and Mauricio Torres Tovar, ALAMES</td>
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<td>14.00</td>
<td>Exchange of learning from the parallel groups on experiences of applying PAR</td>
<td>Plenary review of group discussions i. In relation to the actors, social processes and institutions involved ii. In relation to challenges, opportunities in the methods and the knowledge generated iii. In relation to local and wider transformation of institutional practice Issues and areas for development in future PAR practice- PAR reader Section 2</td>
<td>Rene</td>
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<td>15.00</td>
<td>Ethical Issues in taking forward work on PAR</td>
<td>Ethical norms in research and in PAR and Discussion</td>
<td>Zubin Shroff Mauricio Torres Tovar</td>
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<td>15.45</td>
<td><strong>SESSION 4:</strong> LEARNING NETWORKS AND FUTURE WORK ON PAR Moderator Rene Loewenson</td>
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<td>15.45-16.30</td>
<td><strong>SESSION 4:</strong> LEARNING NETWORKS AND FUTURE WORK ON PAR Moderator Rene Loewenson</td>
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<td>15.45</td>
<td>Learning networks and communities of practice in building capacities for, exchange on, documenting and reporting PAR</td>
<td>Moderated panel discussion EQUINET Pra4equity ALAMES COPASAH Health System Global Peoples Health Movement</td>
<td>Clara Mbwili Muleya Mauricio Torres Tovar Greysmo Mutashobya Godelieve Van Heteren Abhay Shukla</td>
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<td>16.30</td>
<td>Consolidation and closing of the day</td>
<td>Delegate remarks from each region Issues for follow up, thanks and closing</td>
<td>Rene and Mauricio</td>
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