



# **SESSION REPORT**: Shaping health participatory satellite session Tuesday 9 October 2018

In the Global Symposium for Health Systems Research (HSR2018), Liverpool, UK

This document presents a summary of the discussions at the Shaping Health Consortium satellite session at the 2018 Global Symposium on Health Systems Research in Liverpool UK. It briefly captures the ideas exchanged, and images of the session as a reminder (better than words) of the energy and connections in the room!

The list of those hosting, presenting, facilitating and participating in the session and acknowledgements follows the session summary. Thanks to Shaping health colleagues for the session notes and photographs used in this report.

#### Our session involved:

- 1. An introduction to the session, and key concepts involved in our Shaping health work on social power in health
- 2. Two groups, introducing on country case studies with discussions on issues raised from the case studies and participant experiences on grounding health action and services in community systems
- Grounding social power in health in local economies Slovenia and Ecuador
- Building and bridging synergies between formal state mechanisms and informal community processes- Chile
- 3. A plenary review and discussion of key themes emerging and feedback from findings from Shaping health work
- 4. A fishbowl discussion on adapting approaches and learning across settings and countries, and sharing learning to encourage local practice, with discussant inputs from Athens County Ohio and PHI Health US on their experience, from Robert Wood Johnson Foundation on experience as a funder of global exchanges and from participants.
- 5. A final summary of follow up points, resources and links

### 1. Introduction and concepts

Rene Loewenson, Training and Research Support Centre (TARSC) welcomed all and introduced the session objectives, process and contributors. She appreciated the holding of this conference in a city celebrating 70 years of a tax funded National Health Service (NHS) free at point of care, and at a time that shows how critical it is that people defend its principles and continuity.

She noted that Shaping Health had involved local health systems in 12 countries globally and also five local sites in the USA. Not all Shaping health colleagues were present in

the session. We have, however, met online and in person as a community of practice over the past 2 years to discuss experiences and learning on social participation and power in local health systems, and to contribute, with support from Robert Wood Johnson Foundation, to uptake of learning in local health system sites in the USA. (The graphic shows the distribution of the sites).

Rene shared briefly some of the key concepts and learning from these exchanges in Shaping health that framed the session. She noted that social participation and power in health is **an end in itself**, integral to health, intrinsic to people's identity and a right and a democratic goal of society. It is also a

means to improve action on health, to improve health services and outcomes and to hold public and private actors accountable. In our experience in Shaping health it has been found to drive more holistic, comprehensive primary health care systems. As a key informant said in Chile: ...we understand that health is not just illness, which is limited, but we understand health as a vision of the world, of life, a concern that has to do with human rights, decent housing, free spaces, healthy environment, freedom from violence...

**Power is central.** Building shared values, decision-making and action involves a 'bottom-up' claim of and growth in social power within affected communities to transform the conditions affecting their health, moving from dominating, controlling power over, to 'power to' act







Nutrition centre outreach, WSB Vanuatu 2016

and influence conditions, the power within, the capacity, self-confidence, and self-consciousness to support self-determined thinking and action and the power with, through acting collectively.

Analyses of social power in health have interrogated its level, interests, the processes, knowledge and spaces that initiate, sustain (and suppress) it. However she pointed to a key question raised in Shaping health: Where is the centre of gravity? As a community member in Ngāti Porou Hauora, New Zealand raised: *My care isn't sitting there in a file on the doctor's computer, it's me and my actions*. People who see themselves as in control of their own destiny see the onus being on the external party, such as the state, to participate as an equal partner in their processes or journeys.

The fact that processes that build social power in health thrive when services go into community lives and settings has thus raised two lenses for our session:

- Grounding social power in health in local economies
- Building and bridging synergies between embedded community processes (informal) and formal state mechanisms for decision making in health

She introduced the two groups that would be discussing these case studies and issues and participants chose the group they wanted to join.

### 2. Group discussions

### Group 1: Grounding social power in health in local economies

The groups was facilitated by Sarah Simpson, EquiAct.

Peter Beznec, Centre for Health and Development Murska Sobota Slovenia presented the experience of the Regional Action Group on health and development in Pomurje region.

As a region with high unemployment, low incomes and low life expectancy, the challenge was to embed health improvements in economic improvements and vice versa. This was especially important to ensure that within the universal policies for social security, education, health, taxation, there were also approaches to reduce gaps between the weakest and the most privileged.

This led to the establishment of the Centre for Health and Development (CHD) by the Public Health Institute, to build cross-sectoral cooperation for this. At the same time the CHD recognized that the community was critical for this, and opened dialogue with the range of community organisations and associations working in economic and social activities that affect health. They brought together in a flexible structure people from community associations and regional "champions" in development planning. This informal 'bottom-up' mechanism for dialogue and planning was called the Regional Action Group'.

People identified working groups for areas that would create the conditions for joint health and economic benefit, and that would address inequalities in health. The chosen areas were healthy community conditions, health food and agriculture, healthy tourism and nature and environmental health.







Many practical initiatives were implemented in making this synergy between health and development. Peter noted that in relation to social power in health, it rooted the work in people's daily lives and occupations. Having an informal, open horizontal structure for building dialogue across communities and sectors was important for



communication and for sustaining the work. Having a coordinator (in this case the CHD) was important to collect, evaluate and present the results of working groups in the RAG and to work with the groups to prepare the formal inputs for the Regional action plan.

He also noted the challenges, in sustaining the commitment during periods of austerity, in integrating good practices into the formal system and in evaluating the health and economic outcomes in a complex system to produce evidence to support the investment in health and development as a concept for the region and country as a whole.

Francisco Obando. Municipality of the Metropolitan District of Quito (MDMQ), Ecuador, presented their experience of closing the gap on health inequality in 'healthy neighbourhoods'.

The local government (MDMQ) aimed to strengthen social power through fostering participation in health to decrease health inequalities. They facilitated the formation of intersectoral community



health teams that led the efforts to address issues affecting health and well-being in their neighbourhoods. This involved making a community diagnosis, prioritizing the problems to be acted on, with a focus on those that reduce inequalities in health. The teams

developed and implemented the plan and evaluated and made changes based on the learning from the actions taken.

Francisco outlined the steps taken in implementing the work, with various meetings, training activities, dialogue meetings in neighbourhoods and information sharing and reporting to bring the work alive. The DMDQ set up MoUs for the Health Team making clear the vision, mission, objectives, rules of procedure. They also provided a template for people to fill for the action plans, simple methods and tools for the community diagnosis and prioritization, and ways of making sure that any data collected or presented is easily understood within communities, whether from the community or the services.





This allowed the process to focus on answering the questions from the perspectives of the different sectors and the different neighbourhood associations and community organizations and institutions involved in the community health team. The work was problem and solution focused, looking for actions that would improve conditions in neighbourhoods that would make the biggest improvement to health and to reducing inequalities in health.

The actions arising from the community diagnoses involved work in the schools, in the market places and other neighbourhood settings. The plans were results oriented, setting goals for change and embedding evaluation and review in the process from the beginning.

Francisco described the issues faced in ensuring community voice. He noted that community perceptions may not take the statistics collected by services into account. At the same time, the services may not have data on issues that are of concern to the community. It was important to find methods that work for people with little or no formal instruction, such as for prioritizing areas of action, to involve local actors and community organizations that are key for change, and to maintain the momentum and follow through on commitments.

The exchanges between neighbourhood actors and sectors needed alot of preparation. The team needed to be mindful of the market forces at play, both to understand the causes of problems, and to create new approaches to respond to problems.

In the discussions around these presentations, session participants observed that these community level processes call for solidarity and valuing of equity, and that this is disappearing in our communities.

The experience in South Africa was shared, where participation has been very formal, structured and bureaucratic, often crisis driven, and that this shifts the focus to compliance. People thus come into it with their own interests, rather than shared interests.





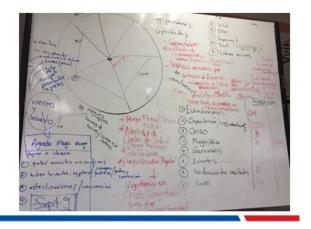




Community Health Teams affecting schools.



Evaluation – change oriented



The identification of issues and processes used is thus as much about rebuilding confidence and commitment to values of solidarity and equity as it is about building social power. This can happen in the health system, but it may also be important to step outside the health system into other mechanisms, sectors and processes to do this. The discussion thus located processes for building social power within those that build these solidarity and health equity values, in approaches that made sense within local economies and conditions.

As the discussion was progressing, participants noted key issues for reflection on cards, that were collected and put on the wall for a later plenary discussion.

## Group 2: Building and bridging synergies between formal state mechanisms and informal community processes

The group was facilitated by Ruth Dudding, Athens County Health Department

Tania Alfaro, School of Public Health, University of Chile discussed the work in local health systems in Chile on building synergies between formal state mechanisms and informal community processes for social voice in health.

The Chilean health system applies a biopsychosocial model in an integrated primary care system. This is a more holistic approach for health with team and intersectoral work, encouraging social participation.

Tania noted that there is a law of citizen participation in Chile but with gaps in implementation, due to shortfalls in resources and political support. There are formal mechanisms in place for participation but these may be implemented in a way that is more for consultation and information, than for deliberative, decision making. So people can become disaffected with the system.

She recounted some of the experiences described in the Chile case study in Shaping health on how various local health system sites are addressing these challenges. One site was



experiencing resistance to engage in participatory spaces offered by the health sector. In another site many community members were unaware of the local health council, the formal mechanism for participation, did not know about participatory public accounts and most had not heard of citizen dialogues. In new elections for the local health Council, of the 13 places for candidates, only two were filled.

Community members resisted the bureaucratic approach of formal mechanisms: We have said in various meetings and congresses that we do not want to be a performance goal, we want to be actors in health (community leader, 2017). Others said: Sometimes, when we review plans, we still observe workshopism, or focusing too much on activities rather than focusing on the objectives, transformation processes, better health, impact on quality of life, social integration and reduction of equity gaps (central level respondent, 2017)

### Social participation plans elaborated







implemented (2017) Tania described how the different sites were engaging in informal processes that then interfaced with the formal processes.

She described that a demand to keep the engagement authentic led to two proposals in the sites:

- First, that mechanisms should make a binding link between participation in expression of needs, and in the actions to solve the issues raised.
- Second, that performance indicators should focus on structural changes, such as local level networks and capacities and not on how many activities were performed.

The group did not hear the second case study from India that focused on the strengthening of activist citizen leaders and community based organisations to engage formal panchayat mechanisms, as Ranjita Mohanty had not been able to travel to Liverpool.

In the discussion on the Chile experience participants noted that participation in health is often driven by the needs of the health system, and fails to accommodate the issues of communities. Organisations in the health system may be reluctant to follow through with community engagement, as they fear fault finding.



The divisions within communities were also noted, and the fact that formal approaches may adopt more paternalistic styles. This was felt to be prominent in addressing issues such as mental health, an issue that was perceived to need an activist focus given the issues it raises in relation to social power and



disempowerment. As a further experience, a lesson from DR Congo was for those affected to organise to advocate for themselves, noting that this often happens in informal processes in the community, outside the formal mechanisms.

As the discussion was progressing participants noted key points on cards that were collected and put on the wall for a later plenary discussion.

The cards from the two groups were put on the wall by Rene and Lucia D'Ambruoso, University of Aberdeen, under key themes. At the end of the group discussions, participants convened as a plenary to review these points raised.

### 3. Review of key themes

Rene Loewenson. TARSC facilitated the discussion.

The information below summarises the points raised in the cards and discussion, and adds some of the reflections in each area from Shaping health work.

# 1. Grounding health in community values, rights, experience and evidence

We do not want to be a performance goal, we are actors in health!

Many people put this statement on the cards, as it captures participation as a goal (building social power) vs as a utilitarian means.

Health systems thus need to recognise the different roles people play in their work and social networks as important for health.

Communities are diverse and engagement may bias towards better off people and communities, such as in open calls or due to language barriers. While there are

processes for grounding health in communities, such as community diagnosis, participatory priority setting, and participatory identification of problems and actions, we need to be sensitive to political contexts and social differentials. Grounding health in community values is thus linked to identifying and being responsive to social inequalities in health. and social differences in the impact of actions.





Participants observed that the case studies and these issues point to the role social power plays in advancing equity values; and equally of the role values of solidarity and equity play in advancing social power.

Rene noted that work in Shaping health found similar issues. Social participation and power was identified to be stronger when more embedded, claimed, sustained and defended than when primarily organised as a functional need of health services. It was found to build on and to nourishes community belonging, shared identity, history and values.

### 2. Community activism, leadership supported by facilitators, catalysts

Different groups are looking each other in the eye

Session participants noted that the processes for community involvement build relationships, bringing different groups to the table and convening discussion and planning across diverse groups.

This raises many issues for activists and facilitators of processes for social participation in health:

- What level of autonomous networking and organisation and what interest is there amongst community actors for these relationships?
- Noting the inequities and power differentials within communities, how far is the power and willingness to dialogue and act in different groups a result of how informed, articulate, organised and confident they are?
- How are the different interests and power inequities between community members and other health actors addressed in the processes and places where these links take place?
- How empowering and transparent are these processes for communities? What are the consequences of these interactions for those involved?

Rene observed that learning from Shaping health on these interactions call for a range of community health activists to be nurtured (health literacy facilitators, local community leaders; community volunteers and teams; expert patients, peer networks). Elected community health workers complement, link with but don't displace these other forms of social and citizen leadership.

3. Grounding in community settings, acting on wider health determinants and holistic wellbeing

Should we embed the health system inside the community health system? Participants raised that the community contexts linked to social power call for health to be 'more than health care', including health promotion and prevention activities in communities, working with other sectors, applying a comprehensive biopsychosocial approach to care and with community health teams that are able to work holistically beyond health care.

However, we also noted that the current health services have many shortfalls in this respect. It's thus not simply a matter of embedding the current health system inside communities or vice versa. Health promotion approaches often don't build real power in communities to transform social determinants of health, services have limited resources and health care is often

delivered as an industry or a business rather than as a service building solidarity ties in communities.

Public sector services and holistic, reenergised and innovative neighbourhood approaches are needed that address quality of life and wellbeing and protect health as a public good.





In Shaping health work, processes were seen to thrive when services go into community lives and settings centred on community processes- schools, workplaces, market places, sports, and within *community* processes. These settings are more widely inclusive and transparent. As noted by participants in the session this raises a demand for health systems that are holistic, population health and PHC oriented. Rene noted that experiences in Shaping health also raised how social participation also elicits these approaches.

### 4. Building formal and informal processes, linking informal and formal

Formally established civic councils and committees were recognised by participants to be an important platform for horizontal interactions (across sectors) and vertical interactions (across levels and alliances). But we also questioned the autonomy of these formal mechanisms, the role of political interference and the power differentials in them between community and state. Some raised that formal state mechanisms are 'out of sync' with the needs and views of the population.

Participants observed that the range of informal, 'bottom up' and community led processes may thus offer space for social action, as suggested by the case studies. But the extent to which synergies are built between formal mechanisms and community processes and the institutionalisation of these processes was seen to depend on the political situation. It assumes a willing state committed to health equity.



In the experiences in Shaping health, formal and informal spaces and processes, both play key roles in a two way dynamic, the bottomup' interacting with 'top-down'. Informal processes were often more accessible, safe spaces to organise input for formal mechanisms, ranging from social audits to protest. Community representation in formal spaces was stronger when representatives interacted with communities in other social processes. The interaction itself was complex, sometimes spontaneous, sometimes consistent and facilitated by trusted, competent consistent institutions able to

mediate and let processes evolve.



5. Co-determination, linking decisions to resources, action and strategic reflection Session participants noted on the cards that co-determination depends on governance (and formal measures for authority and power) in the health system and in the community. Co-determination was seen to demand a space and processes for negotiation of interests. It also needs sustained partnerships to build mutual trust, and for decisions to be linked to meaningful financial resources.

These issues were also raised in other Shaping health work, together with the importance of transparency on the rules, criteria and principles in decision making and the setting of shared goals, with monitoring and review of stepwise progress markers to build shared confidence.

Participants observed that progress is not simply a matter of health status outcomes, but of what impact processes have had in changing the power dynamics between communities, local government and other players and in building collective, informed social power.

Social participation without a claim of social power was felt to be empty, tokenistic and not sustainable. Let's talk about social power in health and not just social participation in health.

### 4. The Fishbowl: Adapting approaches and learning across settings

We reorganised ourselves into a 'fishbowl, with chairs in the centre, to discuss what these findings imply for sharing learning across countries and what this means for future health systems research.

Francisco Obando and Lucia D'Ambruoso, facilitated the fishbowl discussion and introduced the two discussants from the USA, Ruth Dudding from Athens County Ohio and Roberta Delgado from PIH Health in California, both working to strengthen social voice, participation and power in their local health systems.

Roberta described the journey of PIH Health, a two hospital nonprofit healthcare system. Her department plays a unique role as a bridge between the leadership of the organization and the community. Nonprofit hospitals in the US have a mandate to not only meet the healthcare needs of patients, but also those of the communities it serves. She explained that over time the organization has grown from a 'power *over*' approach in which PIH Health designed and delivered the programs based on their knowledge, to one where PIH Health uses its role to encourage and advocate for community participation and engagement in its work. Power *with* the community is being applied to make community health improvements, working in four Health Action Lab coalitions on self-selected issues of chronic disease prevention and management, mental health/substance use/homelessness/criminal justice, opportunities for youth and food security. Roberta described how approaches used in other countries shared in Shaping health were then shared with the local coalitions and discussed with communities. This has

strengthened community engagement and the role of community members as champions and lay leaders. The involvement of the community in the coalitions and trust between sector leaders and community members in two of the coalitions is now hoped to inform practice in the other two. Roberta noted that despite resource cuts, they have managed to increase allocation of resources for this work. She raised that a major lesson learned from other sites was to trust and be flexible in the process. When we do it this way the work actually moves faster.

Ruth Dudding reported that in Athens County Health department they did not in the past have a platform for community exchange. We used to have the approach that we would say 'what do we want to know' and then go and see if people would tell us. Now we have a very different approach. They became involved in Shaping health because their rural county was starting to involve CHWs in chronic disease prevention. At the same time, they learned from other sites on laws, participatory budgeting, and CHW roles as community advocates.





They have now hired CHWs but have also explored wider practices. The experience in Quito, Ecuador triggered ideas about strategies to build a greater sense of citizenship and community teams. As in Quito, they now aspire to introduce a healthy places designation. The Community Improvement Challenge teams that they set up achieved successes in areas that the department didn't expect, in land banking, unincorporated zoning, reopening a library, music school and advocating for a grocery store, all relevant as determinants of health. She reflected that being part of a consortium and having access to the shared information on the website enabled her to raise questions and bring information needed for these transformations. Community engagement is now the way we think as a health department. It has been a priority as we developed plans for accreditation. We don't have models for good community engagement in the states, but we are grateful for the models from other countries. We have been inspired.

Participants joined the fishbowl to add further insights on sharing practice.

In an experience from Zambia, one participant conformed the need to trust the process. She reported how communities themselves ended up in the driving seat in work on Safe Motherhood Action groups. Over six years they built a sustainable volunteering system for MCH and are now moving on to look at malaria prevention and control.

A further reflection was raised on the need to find better ways of communicating information across contexts. For example Brazil has one of the strongest systems for community engagement. While colleagues from Brazil initially did not feel they could learn anything from Mozambique, they did find interesting experiences there to strengthen their own practice. At the same time in the UK there is resistance to learning from Brazil's model of participation. We have to think of ways of overcoming this block to learning across different contexts. At the same time while people with greater power may not want to learn, researchers too often duplicate and don't learn from the knowledge in local communities.

The experience of El Salvador was shared, where contexts of conflict and violence affect the possibility of reforms for community participation, calling beyond the sharing of information for strategic alliances with others. Shaping health has offered this kind of opportunity, and others raised alliances such as the Peoples Health Movement and EQUINET that share learning and also strategic advance from others engaged in similar practice.







Rene raised that for HSG, the lesson from such knowledge coalitions and communities of practice is that conferences as isolated events and sessions that reduce experience to soundbites risk missing key forms of knowledge and exchanges of learning that are relevant to health system practice.

Susan Mende, RWJF joined the fishbowl and shared her reflections from their work in funding and engaging in the USA and in these global exchanges. She called on people to *take risks*. The current challenges depend on research that asks the difficult questions and that finds ways of making more direct links between research and changes in practice.



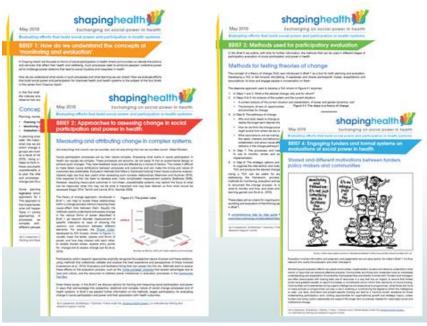
#### 4. Final remarks

Rene concluded the session. She thanked all for their inputs in this rich and wide ranging discussion. She thanks the facilitators and presenters for their contributions and the participants for the thoughtful contribution of their own experience and insights. Rather than summarising all the points she indicated she would send a report of the session to all. She pointed to the various materials available from Shaping health in hardcopy for distribution and welcomed all to take copies.



There were many other issues and areas of learning on social power in health systems raised in the experiences in Shaping health. We did not have time to review all of them. However, she raised a question that we raised in Shaping health that we need to think further about, and that is how do we assess what difference we are making?

Processes building social power are often not evaluated, indeed that there is a caution on formal externally driven evaluations as they can be themselves be disempowering for and treat communities as objects, and that there is often an absence of data in routine information systems to assess the sort of changes we identify as relevant in strengthening social power in health. But we do need to know what difference we are making, as facilitators, as those involved and to share learning. Participatory monitoring and review can build confidence, learning and insights from practice. She pointed to work undertaken in Shaping health to gather information on evaluation of social power and participation in health



and on how such participatory evaluation is done and drew attention to a series of four briefs on the findings that may be useful for delegates, also available online. Given that this often depends on ...who initiates and undertakes the process, who learns or benefits from the findings, one of the briefs also discusses issues in and how participatory process evaluation can from early stages also address funder and management concerns.

The discussions in the session had raised insights and questions on moving from tokenist to meaningful forms of participation for social power with and within, for this to be claimed and applied to improving the solidarity, conditions and holistic health system approaches for health equity.

For HSG, the discussions pointed to the issue of ensuring that health system research and the knowledge shared recognises the different lived experience and knowledge of those involved in health. This raises a need for processes that 'ask the difficult questions' and that translate, share, negotiate and respect these different forms of knowledge as a public good. HSG should provide a means and space to challenge the current context of knowledge production often reflecting an unequal distribution of power in health and health systems. This means paying greater attention to ongoing reflexive and participatory means of research and evaluation. It also implies creating space between and within conferences for the type of ongoing, sometimes iterative exchanges across communities of practice that contribute to such reflexive knowledge and learning from practice. It would be expected that HSG nourish the sharing of such knowledge, and confront commercial and cost barriers to the production and sharing of such knowledge (such as by journals that reject these forms of knowledge and that are not open access). The session raised that in many ways health and the health sector provide a fertile platform for the values, thinking and practice that strengthen social power in and for health, but that it doesn't always do so. This implies work within the wider public life, rights and conditions that contribute to health, and

recognising and explicitly building knowledge on how

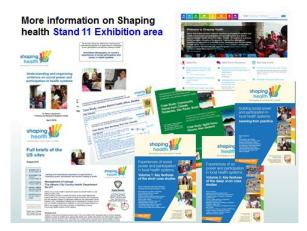
such work advances health.

In conclusion Rene welcomed participants to visit the Shaping health website for further information, to read the changing stories of change on the site and access some of the documents produced. She invited participants to send and share their own stories of change.

She also drew attention to the EQUINET website (www.equinetafrica.org/), the pra4equity network and PAR portal where information on participatory work and international resources on participatory action research can be found.

Finally she invited participants to continue the discussions on the issues raised in the session and on other information from Shaping health at the Exhibit Stand in the conference hall.





### 5. Session Participant list

- 1. Session co-ordinator: Rene Loewenson, Training and Research Support Centre
- 2. Session co-contributors and facilitators:
  - Peter Beznec, Centre for health and development Murska Sobota, Slovenia;
  - Ruth Dudding, Athens City County Health Department, USA;
  - Tania Alfaro, Escuela de Salud Pública Salvador Allende, Chile;
  - Francisco Obando, urban planner, Municipality of Quito, Ecuador;
  - Roberta Delgado, Community Benefit Manager, PIH Health, USA;
  - Lucia D'Ambruoso University of Aberdeen, Scotland
  - Sarah Simpson, Director, EquiAct, France.
- 3. Session contributor and acknowledgement with thanks for support of Shaping health: Susan Mende, Robert Wood Johnson Foundation, USA

## 4. Session participants (with apologies for any misspelling in reading the handwriting in the delegate list!)

- Vera Coelho, CEBRAP, Brazil (also a case study site in Shaping health)
- Barbara Kaim, TARSC/EQUINET
- Mauricio Torres Tovar, Universidad National de Colombia, ALAMES, Colombia
- Ketaki Das, West Bengal Voluntary Health Association, Kolkata, India
- Kate Gooding, Malawi Liverpool Wellcome trust clinical research programme, Malawi
- Masuma Mamdani, IHI/ EQUINET
- Godelieve van Heteren, Rotterdam Global Health Initiative (Erasmus University)
- Ligia Paina, Johns Hopkins University School of Public Health
- Bridget Pratt, University of Melbourne Austrralia
- Moeketsi Modisenyane, Dept of Health, Govt of South Africa
- Troy Jacobs, USAID Global Health Bureau, USA
- Sara Sulzbach, USAID Global Health Bureau, USA
- Jean Maca, UGLOUVAIN, Belgium
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- Dividonne Burire, Masstricht university, Netherlands
- Sana Contractor, CHJ, India
- Mwanamvu Boga, KEMRI, Kenya
- Soraya Elloker, Coty of Cape Town, South Africa
- Emilia Slezak, LSTM, UK
- Kingsley Chikaphu[ha, Reach Trust, Malawi
- Anne Hyne, Jhpiego, USA
- · Ketki Shah, IPH Bangalore, India
- Mazvita Zvanamwe, WHO, Switzerland
- Barbara Hughes, USAID, USA
- Alex Shankland, IDS, UK
- Pol de Vos, IGHD-QMU Edinburgh, Scotland
- Amuda Baba, IPASC, DRC
- Silvia Anie, Results, UK
- Teresa Hall, Nossal Institute for Global Health, Austrralia
- Krish Vallabhjee, Dept Health Western Cape, South Africa
- · Benjamin Rouffy, WHO, Switzerland
- Genevieve Dubois Flynn, Canadian Society for Internartional Health, Canada
- Mairead Finn, Trinity college Dublin, Ireland

### Appendix 1: The Exhibit stand at the symposium

We had a shared Shaping health, EQUINET stand for disseminating work and having exchanges with conference delegates on work and learning on social participation and power in local health systems and, for EQUINET, on different aspects of health equity. Colleagues from Shaping health and EQUINET took shifts at the stand and it was a buzz of discussions and interactions for the three days of the conference, with many people bringing experiences of their work and connections made.

We had a 'post-it' board for people to make comments on their own learning on what matters in claiming and building social power and participation in health.

Here are some of the comments people made...

Some were that this is an intrinsic aspect of advancing health and wellbeing, a right and a matter of identity Its not about why participation, but why not! Nothing about us without us! Health is a human right- claim it! Whose problem is health? Not patronage- empowerment

Others raised that it is an essential for the success of health systems and practice
Social participation is key for acceptability of health systems
Community engagement is key to success in any programme

Still others commented on what is necessary for such knowledge and practice
Put people at the centre of focus
Get out of the office!
Base it on lived experience
Find and keep champions
Nourish community activism
Educate and inform all
Build citizen science for healthy public policy (as implemented by local social networks in Brazil)
Generate social dialogue for participatory health policy (as in Tunisia)

Keep an open and honest dialogue Empower the community in decision making Don't relying only on voluntary work, pay for efforts Ensure resources- for sim cards, internet access

Finally there were some insights for those involved in such work

There is no such thing as best practices- it depends on what circumstances, culture and community Lean into discomfort to build trust Create opportunities for learning by doing Be patient and press on- glaciers change the landscape



