## Social Participation and the Right to Health: Report on a workshop at the 3rd People's Health Assembly, Cape Town, July 2012[1]

As part of the People's Health Assembly, the Learning Network for Health and Human Rights (or LN; http://www.salearningnetwork.weebly.com) in South Africa, the Center for the Study of Equity and Governance in Health Systems in Guatemala (or CEGSS; www.cegss.org.gt) and the National Campaign on Health and Social Security as Fundamental Right in Colombia ((http://www.octavapapeleta.org/) organised a workshop on Social Participation and the Right to Health. The workshop brought together speakers from countries in Latin America, Africa and Asia to share experiences of different spaces, structures and approaches to social participation aimed at realising the right to health.

**Rationale:** For many decades, countries have been implementing different organizational structures in which communities interact with health services. In some cases, this interaction emphasizes providing labor and/or support for health care delivery. In others is a space for demanding transparency and accountability and in others, it is a legally regulated space in which community representatives have a say in the planning and resource allocation of health care services. All the structures described above might play a potentially critical role in realising the vision contained in the Primary Health Care approach – particularly in ensuring meaningful community participation and the realisation of health as a right. However, this role might be facilitated or obstructed by different factors such as power relations, regulatory frameworks, accountability mechanisms, legitimacy and others.

This workshop sought to map experiences of social participation around the globe, exploring how such participation takes place, in what spaces and structures and, within this mobilisation, to see what types of interaction occur and how social participation translates into civil society mobilisation for Health for All. The notion of spaces for participation can be contested spaces – some spaces are invited spaces, when health services invite communities to set out their ideas; whereas others are claimed spaces, which are created or claimed by citizen's demands. Depending on the political context, spaces for social participation become subject to more or less regulation if they are to be institutionalised.

However, all these spaces have their own limitations, and a major challenge is how each of these spaces can be used and can help to fight for community health. Behind each space, no matter how limited, there is a history and story of a movement—they weren't a gift from above, but had to be struggled for to be created. Nonetheless, no matter what the limits to these spaces, the challenge facing PHM is how can they be used for a more strategic approach for the fight to health and community rights.

**Experiences**: Presentations were made from South Africa, Mexico, Argentina, Paraguay, Bolivia, Guatemala, Colombia, Uganda and Cambodia.

The **South African** presentation highlighted a difficult situation in the Western Cape province of South Africa. Despite a statutory structure for community participation established in law, in the form of health committees, research had shown many challenges to effective and meaningful participation. Besides questions related to sustainability, functionality and representivity of health committees, the key obstacle was a very limited participatory role envisaged for committees. This role saw health committee members as extension of the services, rather than exercising oversight over the services or acting as a watchdog. This was mainly because of the failure to progress in ratifying a draft policy in existence since 2008, as a result of which health committees were disempowered by lack of role clarity. Thus, whereas the vision of the draft policy is for health

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committees to be functional in 100% of facilities and to exercise governance, oversight and planning functions, the reality was that health committees tended to exercise limited participation, assist in day-to-day services, acting as auxillaries to the services. The proposal to strengthen committees as vehicles for community voice required the creation of a supportive environment, and capacitation of committees with proper resources and training, in the context of policy that recognises the need and place for meaningful participation.

A presentation from **Mexico** shared experiences of working in a small civil society organization on community health and education issues with Mayan communities in Chiapas. Amongst the indigenous populations, the first question to address is what type of health we want. Whereas institutions tend to be directive about the nature of participation and what people do in these spaces, the local communities saw health in a much more holistic way, as more than just about access to doctors. Rather, participation in this context was about finding ways to take control of one's own lives and to change the conditions that determine health. In that way, participation was viewed as not just about health workers and personnel, but being about the social determinants of health that belongs to the entire community. A discourse of being told what to do and how to think disables people from being able to see what small steps people can take on their own, that they control, to address their health needs—that is the way forward. This experience may not be replicable in other parts of the world, in that it is a close to utopian vision, but we should try

The situation in **Argentina** was described in terms of the daily work of PHC workers, who are the front line of health and whose work, which is outside of the hospitals, is more difficult and challenging. The way in which health workers are paid does not reward engagement with communities, and health workers are micromanaged in a way that doesn't allow them to practice and think in a reflective manner. For social participation to work, health workers need to be in two places - on the one hand, to operate on the local level, and work with the community, but from that space, to reach out to other spaces, collective spaces, otherwise work will not be visible. In other words, social participation is dependent on the collective efforts of people, both health workers and communities.

The presentation from **Paraguay** highlighted how views about participation and non-participation in health were framed in terms of stigma against indigenous peoples. When asked why there is poor participation, the explanation provided was that the locals were lazy because they use their indigenous language. Through exploring the work of mental health teams, the presentations showed how participation is limited by a focus on medical information and medicalisation of mental health, which aggravates stigma. In the end, it was political awareness that was required to be critical of the content of training provided, and class differences amongst health workers and between health workers and the community are serious obstacles to social participation.

**Bolivia** is a country with a large indigenous population **(**60%) who have been treated with disrespect since conquest by colonial Spain. This continues, despite the fact that Bolivia has an indigenous president today. Social participation in this context means taking seriously how to incorporate traditional healers into the system, since "western" medicine represents and invasion of the terrain when there are other methods that can be given to local communities. Medicine reinforces a broader western hegemony in which the west is seen as the best model, a form of neo-colonialism causing people to reject their own roots. This focus on 'western medicine' leads to a health system focused on individuals and ignores the social determinants of health. It also ignores the need for health to be a dignified existence which requires people to build together, rather than an authoritarian approach where the doctor is the expert. The challenges of social participation in this context are therefore to challenge the hegemony of 'western' health models and to find a balance with the environment and one's individual situation, within a community. Health is something that is built together, because the suffering of others affects everyone, not just the individual.

In **Guatemala**, there are strong community-based associations for community care, who have different bases and mandates (e.g. some work in health, some are political associations, some are community in nature, some global in nature, some focus on women) but all are fighting inequities and their causes (social, gender, etc). Social participation in Guatemala seeks to change society through health and through promoting health as a right, using the PHC approach. Given that between 25-30% of people have no access to health care, there is heavy reliance on health promoters. However, health promoters play a key role in social participation, since government has very poor idea about what access to health services people actually enjoy. Health promoters carry out training for midwives, who carry the burden of deliveries in Mayan communities, where birthing is a deeply cultural event important for the self-esteem of young women. The health promoters also work with groups of peasants, helping to develop testing of medicinal plants in local pharmacies run by community

members, and mobilising communities around food production to address under-nutrition. Through this citizen's space for people's health, this led to the establishment of a health institution, which is developing into a citizens' forum holding special events and fostering processes for social participation.

The **Ugandan** experience differed somewhat from the others in that the Ugandan health systems is highly decentralized but lacks any system to ensure that people participate actively in decisions that affect their own health. The concern is that the pretence of participation might simply become a pacifier unless it is able to exercise a critical gaze on the health system and be framed within a human rights perspective. At the lowest levels, village health teams/committees (which are the smallest units) are in charge of health promotion and primary care service. The key challenge is how these VHTs can ensure that people at that level participate in identifying community needs and translating this claim to higher levels of the system. If campaigns begin at the village level, there will be less resistance to those changes in a national program. However, there is uncertainty as to how oversight can be exercised from the village perspective over services at higher levels. How does one ensure that participation in that system is actually accessible to everyone (particularly since there are different actors at every level), that there is transparency in terms of budget, continuity of programs and accountability of national decisions to people at the village level. The problem highlighted in Uganda is the effect of legal provisions mandating that people at all levels should participate before decisions can be made. As a result, participation is token in that people are brought into meetings simply to comply with the law, without enough information to truly participate in the process before the law is enacted. A further challenge is that there is uneven participation from elected leaders, and by CBO's, which varies greatly between districts. The development of participation structures is evolving in Uganda with great opportunity to ensure stronger voice for communities. However, many of these challenges are linked to health system weaknesses.

The presentation from **Colombia** highlighted the problem of a health system that is based on the market in which services are sold, there is limited attention to basic health care and the focus is on treatment of illness rather than health promotion. In many international forums, Colombia is held out as an example of a health system offering universal protection, but, in reality, that is not actually the case. While it is true that people are insured, having insurance does not guarantee health care let alone quality health care. The poorest people in Colombia are covered by what is known as "Guardianship" (in which the state pays the insurance levies for those unable to afford). But if you fall under Guardianship, you are like to be denied access to medicines or admission to hospitals, or have your surgery delayed because you get lower preference as a result of geographic distance, economic status, unaffordable co-payments or administrative barriers. This gives rise to inequities, known as the "walk of death;" with people going from one hospital to another seeking treatment, only to be denied. As a result, Colombia has both an inequitable health system and one that boasts the most expensive medicines in the world, an example of how medicine becomes a business.

Because of the many violations of the Right to Health, a national movement has grown out of people's anger over the last decade. Different strategies to defend people's rights have been tried, but are difficult to implement. For example, the Colombian Constitution has a weakness in that health is not defined as right, but as a public service, which allows private intermediaries to play a role. Although there are institutions for participation in health in Colombia, they tend to draw in older people who are less willing or able to identify the violations in the health system, and the structures are therefore co-opted by the system. As a result, a national campaign has developed over the past 2 years called the "Voice and vote for your rights", to establish conditions to change the system itself.

The objective of the 1st phase of the movement's strategy is to raise awareness, because many people don't realize they are subject to human rights violations and accept the situation as it is. The 2nd phase will create a wider national movement including different regions of the country, which will focus on the out ethical and political dimensions of violations, focusing on the obligations of those who are doing the violating. The third phase will set out an alternative model to the existing inequitable and unsustainable system. This will be followed by a national consultative process, driven by civil society to see if people think the law that has created Colombia's dysfunctional health system should be repealed and replaced with an alternative system.

Interestingly, the campaign sees health workers as victims as well, since the Insurance companies place impossible and unethical conditions on the provider, as a result of which the doctor-patient relationship is compromised and the autonomy of providers eliminated. Doctors have unmanageable dual loyalties in that they recognize their ethical obligations to their patients but they also are expected to be accountable to the insurance companies.

The discussion highlighted clearly the difference between health as a right and health as a public service. When health is a public service it becomes something you need to pay for. But one should not have to pay for something that is a fundamental right. Because the national constitution didn't put health as a right, but as a service, this opened the door for neoliberal reform. People generally don't understand the difference but the difference is very important in practice. Countries planning to adopt National Health Insurance models should beware of these problems.

A second issue to emerge in the discussion was that people consider denial of health care as an individual problem and do not understand it is a collective issue that requires organization and mobilization. This is partly because of the political and economic power of the insurance companies, in collaboration with the health department, the ministry and the World Bank, that legitimize this view of health as an individual service. As a result, it is an open market for insurers, and multinational companies come to country to make money.

Lastly, as was raised in the case of Uganda, the structures for participation are sham. The organisations that have been invited to participate in discussions on revising the obligatory health plan do not have the technical capacity to engage, as a result of which, these spaces are just an image of participation. The health system remains very undemocratic with top-down planning in which people cannot participate meaningfully. Whatever participation exists is simply instrumental to justifying the policies decided, since although the state creates the mechanism for participation, it controls how people participate. Social mobilisation in spaces outside of formal spaces therefore is an important alternative means to exercise power for participation.

In **Cambodia**, the Right to Health elaborated in the form of a Client's Right (called patients not clients) Charter, which includes the right to expression of opinions, which many people take to be a form of participation. Complaints are dealt with through this system. However, there are some constraints - health care providers have limited capacity to respond to patient's complaints, and the health system is structured in tiered levels which may preclude certain kinds of care delivered at primary level. There are some mechanisms for communities to participate in the development of annual plans of action by the services. And there are also client satisfaction surveys with suggestion boxes, but this does not capture the views of users who are illiterate. Because the Cambodian system requires copayment, there are still problems in full coverage for the poor.

**Discussion:** The presentations from different countries showed how some of those spaces can be classified as invited spaces, where authorities allow communities to enter but control the terms of participation. Then there are other spaces that are 'grabbed' spaces which arise from popular dissatisfaction prompting the creation of social movements that take over the spaces to make their voices heard and to effect change. It is important for PHM to understand the mapping out as some spaces are highly regulated and other not regulated at all. Having highly regulated spaces can be good for moving forward but can also carry their own limitations.

In Brasil, for example, community members have 50% of the seats in the decision making process and their signatures have to be present in agreement, without which, public budgets to implement policies and programmes cannot be approved. This is a very high level of decision-making in policy. In Guatemala, there is also a lot of structured community participation, but the municipal government can still override the decisions made by community representatives, as they have the final say. However, the social pressure and demands for accountability by community organizations are key strategies being implemented so communities can benefit from those spaces for participation.

What is important to note in different country experiences, is that the positives and negatives are completely related to the context of our own countries. So, we should not just take ideas from other context to model in our countries without understanding why they worked in their particular context.

So, for example, we need to understand what kind of strategies were successfully implemented in that country in that context. Sometimes social movements can grab spaces and have quick success or it can take many years and be difficult to sustain. What is clear is that Social

Movements need to be built up from the ground to infiltrate higher into the system. Then, it is a question of what is actually done in those spaces? We interact to demand services and understand each other. But it's also a space to negotiate.

It is very important to note that even marginalized communities want to have political voice—access to the decision making, not to be politically marginalized and written-off because the issues are perceived as being too difficult for community people to understand. This raises the question of what types of resources are at your disposal, human, financial and otherwise. Mobilising technical expertise to support communities and reduce power asymmetries is important.

The relationship with power is therefore important to understand. Experience with participation can be different depending on the context, and power is always a necessary consideration. Without power you cannot make or influence decisions. The experience of Colombia shows how it is mainly the insurance companies who hold power, but the social movements are seeking to create alternative power. It was also suggested that politician's power should be part of the considerations. Civil Society has power to influence parliamentarians since parliamentarian's authority comes from the people. If the civil society can engage parliamentarians, this may be an additional strategy to redress power in enhancing social participation.

We also need to understand that spaces for participation are dynamic. Being invited into a space may occur under certain conditions, conditions that seek to limit popular or community power. Participation is therefore a contested process because it is about challenging or reconfiguring power. What is important is how one uses those spaces. Thus, even in invited spaces, there may be opportunities to make it a dynamic space that is more responsive to the need of marginalized populations. This means that through applying certain strategies, invited spaces can become grabbed spaces.

Institutionalized spaces for social participation are important. In many cases, such spaces emerged from demands and social mobilization. For instance, the social participation in health at the municipal level in Brasil was initially generated by popular mobilization. Later, that participation become mandated by law. One could argue that in the long term, spaces must become institutionalized so there is somewhere to go. The idea is how we use and see these spaces working collectively towards a common goal. What are the possibilities of acting on those spaces towards a specific goal? This is a dynamic situation, which requires continually reflecting on the experience and power, because the nature and context of spaces change over time.

**Conclusion:** The workshops shared a range of experiences which highlighted different strategies to build participation for the Right to Health – both social movements in informal spaces, and other kinds of collectives in both formal and informal spaces – all of which are about enabling people to be heard and to exert influence. To consolidate this learning, the workshop participants agreed to

a) commit to strengthening social participation in health, recognizing the role of power as key to participation;
b) commit to stronger global networking through PHM.
c) collaborate through PHM on a process of mapping community participation in different countries with a view to further sharing experiences and consolidating lessons for effective and meaningful participation in health to realize the right to health.