Project Title: Health System Governance: Community Participation as a key strategy for realising the Right to Health

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1.0 Summary:

This project aims to identify, in two sites, one in South Africa and one in Uganda, opportunities for best practice in utilising community participation as a vehicle for realising health rights. The focus on developing models for community participation in health is intended to speak to strategies that advance health equity and strengthen governance systems for health. By testing approaches and sharing experience gained using rights-based approaches to health, we anticipate generating knowledge of relevance to other developing country contexts.

The focus of the first year has been on identifying training needs for health committees and advocacy and networking to strengthen health committees' voice, both locally and internationally. Strong links have been built regionally and international from engagement in the People's Health Movement's People's Health Assembly in July 2012. The emphasis has been on building the agency of community structures to articulate more strongly claims for health rights, with a view to proposing models for best practice. The networking and sharing of experiences has worked well in the first year, which has also concentrated on identifying and recruiting students to conduct different sub-studies. In Uganda, it was realized that there exists ignorance and lack of knowledge on the need and importance of community participation. As a result, the first contacts with the communities including district leadership have been done and a workplan for a small intervention to improve community participation in the focus districts for the subsequent years has been developed together with the communities. As the project advances, it has been realized that the communities are becoming more knowledgeable and equipped with the rights that they are entitled to specifically the right to participate meaningfully and therefore claim for such a right. Although in South Africa we have been relatively successful in having 4 students and a post-doc on the project, we are still intending to recruit a postgraduate student or post doc to focus specifically on gender in the project. In Uganda three students have been successfully recruited and one PhD candidate registered on the project.

The wider health system governance interventions, including training for health care providers, testing of models for using complaints as learning opportunities, and policy interventions aimed at raising awareness amongst key leaders will form a more prominent component of work in years 2 and 3. While the focus is on strengthening civil society agency, it will also advance conceptual understanding of how to frame health rights in ways that are complementary to strengthened health governance.

Progress on the different objectives of the project is outlined in the report. Training and capacity building for health committees has involved the development of a curriculum drawing heavily on results of the audit of Health Committees in the Cape Metro completed early in 2012. The curriculum includes four broad areas (a) understanding the health system; (b) skills to act as agents of change; (c) understanding of health rights; and (d) meeting and procedural skills to support organizational work. In Uganda, using the PRA methodology, the first community meetings involved a capacity building component on the concept of community participation and what the human rights based approach would require to have meaningful community participation. Building Civil Society networks has been a strong and successful feature of the project demonstrated in mutual support between LN members in South Africa. In Uganda, this first year has been an opportunity to bring together civil society organizations working in other districts to discuss the importance of mainstreaming community participation as part of their community work in their districts of focus. Engagement with health officials has yielded mixed results. On the one hand, the LN submission on amendments to the Hospital Facilities Board Act has been well received and elements included in the Provincial Health Plan for 2020. On the other hand, there has been no movement for formal adoption of policy or regulations to empower health committees, and the establishment of District Health Councils appears to hindered rather than helped community participation. Nonetheless, there are promising links with high level officials supportive of increasing patient voice in the health services in a meaningful way. In Uganda, there have been many synergies created with the district health workers as it was clear that, although community outreach programs are listed as one of the key areas, they have not been having the resources the undertake this. Based on this, VHTs during the community meetings indicated some priority actions we will need to undertake as small intervention to indicate how best community participation can be promoted in their work, since, at the moment, there is a huge gap. It was also indicated that some work needs to happen to rejuvenate the role of health committees at the various

health facility levels as, at the moment, these are not very actively involved. It has also been evident that Community leaders at the various Local Council levels in the existing decentralized system have a key role to play. However, their role has not yet been satisfactorily played as a result of among others lack of knowledge on the need and importance of having community participation and general lack of knowledge on the relationship between human rights and health service delivery.

Training for health workers is still in process in both sites and in Uganda district hospitals expressed a need to take them through some human rights trainings as these are currently not happening A number of collaborative links to other health systems projects are useful avenues and in South Africa a Masters student is to undertake a study of facility managers which will be likely to identify a number of 'best practice' opportunities for interviews which we hope to capture on DVD towards the development of a training tool. Testing of local model complaints systems will be implemented in 2013. There is extensive sharing of printed materials with adaptation of materials (in Angola, Uganda) and primary development to meet local needs. Indeed, in Uganda, health rights pamphlets developed by the LN have been adapted to national context and working on pretesting the Health and Human Rights Manual for health professionals will be happening in the coming months. A regional meeting will take place at the end of February with participation from at least 6 countries planned. Mutual exchange of interns/activists is on track with two South Africa CSO participants to visit Uganda in March 2013 and the return visit planned for later in 2013.

Although it is too early to produce findings from the project, some important insights have emerged in the course of the work. Firstly, in South Africa for instance, the concept of vulnerability needs to be more carefully constructed and analysed to be useful in a rights framework; secondly the experience of policy formation in relation to institutionalizing community participation has proven to be far more 'messy' and non-linear than initially conceived, so will require more reflexive and adaptive strategies to achieve objectives; lastly, the tension in the two contrasting roles of health committees (governance/oversight versus supporting services) has emerged more forcefully in our research.

In Uganda, it was clear that, although the concept of community participation is talked about both by the community and health professionals, unfortunately, the preliminary results indicate that communities feel that their roles have been sidelined and they are simply expected to consume and abide by what has been decided on at the top health policy level. Some clear examples mentioned included failure to involve them in budget processes, procurement of necessary equipment such as bicycles, and very limited community mobilization on even Primary health care programs such as immunizations. It is also clear that both the community and the health workers have an idea on what needs to happen to ensure meaningful community participation as provided for under the work plan developed. It has also been evident that Community leaders at the various Local Council levels in the existing decentralized system have a key role to play. However, their role is still lacking as a result of among others lack of knowledge on the need and importance of having community participation and general lack of knowledge on the relationship between human rights and health service delivery. Within Civil society organizations, it has been clear in the first year that indeed a lot of work is happening in a number of districts and having a national forum on community participation would offer as an opportunity for sharing best practices and sharing of resources across a number of organizations at the national level.

Lastly, progress is more or less consistent with plans. Project milestones and outcomes are reviewed in this report and although some are slightly delayed, overall the project is on track as planned.

2.0 The Research Problem:

Despite increasing global recognition of health as a right, the mainstreaming of the right to health in the UN system and increasing literature on the relationships between human rights and health, health inequalities continue to present a key development challenge for the bulk of the world's population. This proposal presented evidence for the way in which such inequalities continue to loom large in both South Africa and Uganda and for which a human rights approach offers the

possibility of addressing inequities. This is because underlying health inequities are varying degrees of powerlessness that render communities and individuals vulnerable to factors that lead to ill-health, with the social determinants of health being unequally distributed by race, class, gender and many other factors. At face value, a rights-based approach to health offers an important counter to the current inequalities that pervade health systems in many countries and which affect relationships amongst countries and between countries and donors. By preferencing the vulnerable and recognizing the agency of civil society as those most affected by violations of the right to health, a rights-based approach offers important strategies for advancing health equity and promoting good governance for health. It also speaks to the importance of recognizing how health care users are treated and the environment in which they are treated as part of health system responsiveness.

Central to this is the role of participation in health. Not only is participation a right in and of itself, it is also instrumental to realizing other rights, such as the right to health. Further, community participation in health has been argued to improve the effectiveness and sustainability of health interventions, programs and services in various ways – for example, by lowering costs for service delivery through voluntary community efforts and mobilization of resources from outside the health sector, increasing service responsiveness, enabling more equitable client-provider relationships with improved feedback; ensuring more equitable access to health services; and increasing a sense of responsibility for health and ownership amongst community members resulting from new skills and securing control over resources.Civil society participation in health is therefore a critical way of holding health services accountable and creating a sense of community ownership of health services. It has the potential to strengthen trust and good relationships between patients and health workers. It allows communities to participate in defining models of care and resource allocation in health and for communities to become involved in dealing with the social and economic determinants of health. In this kind of system members of the community are no longer passive recipients of health care, but actively participating in the creation of a health care system that serves their specific needs. Not surprisingly, the work of the Special Rapporteur on the Right to Health, in developing a range of indicators for measuring the right to health in a health system perspective, included measures which reflect the extent to which health systems actualize community decision-making in health. In essence, they propose more responsive governance mechanisms at local level that reflect participative democratic processes in health and that are more likely to be effective in reducing health inequities.

However, despite a recent systematic review of the effectiveness of health committees[1], there remain many unanswered questions as to the factors likely to enhance the success of community participation. What models of community participation are likely to generate meaningful input by those most affected and how can the needs of particularly vulnerable groups be built into effective participation? What are the health system implications for institutionalizing such participation? Further, the extent to which community participation is strengthened is partly dependent on how receptive health workers are to rights claims. Health workers can both facilitate and obstruct the achievement of health rights and have often been reported as being deeply ambivalent about recognizing rights claims and rights-related accountability in health – principally because of fear of victimization. How can health professionals be won over to being rights advocates, or, at the very least, receptive to community action for health rights? How can participatory mechanisms avoid the type of conflict that limits the extent to which health rights can be realized?

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[1]McCoy DC, Hall JA, Ridge M. A systematic review of the literature for evidence on health facility committees in low- and middle-income countries.Health Policy Planning 2012; 27: 449-66.

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These questions remain at the forefront of the project's intellectual and practical focus. However, three new insights have emerged in the first year of work which, though not changing the trajectory of the research, provide new angles on the existing approach in this project.

Firstly, the question of vulnerability has emerged as a more nuanced concept than previously envisioned. The multiple axes of vulnerability (race, class, gender, etc) often exist in tandem and are expressed in different ways at different time points, making it less useful to identify 'vulnerable groups' (which are static bounded constructs that bear weak relationship to real lived experiences). Rather, dealing with vulnerability, per se, appears to offer a more useful way to understand how individuals and groups may experience disadvantage, denial of access to care and violations of their right to health, based on social factors amenable to action. Thus, as reported below, three studies of different aspects of vulnerability (disability, sexual orientation and gender) will be explored less as discrete entities but explored with a focus on the vulnerabilities that emerge from the findings.

Secondly, the institutionalisation of community participation structures was originally conceived as a linear process of establishing a common vision through participatory dialogues. We are increasingly realising that the process of achieving coherence in policy on health committees is, as is the case with much other policy, a much more 'messy' process, that is non-linear and located at multiple levels of the health system. This is discussed in more detail below in relation to our engagement with health officials and policy-makers, where there has been progress in areas that were unexpected, while other actions that were hoped to lead to direct progress on policy have been less successful. This experience is consistent with the literature on policy development which signals the process of policy advances as one that is non-linear and multidimensional, requiring more reflexive and adaptive strategies to achieve objectives.

Thirdly, in conceptualising the authority and responsibilities of Health Committees as vehicles for participation, a tension has become more explicit relating to their potential roles. On the one hand, an oversight (governance) role is critically important but would place them at a distance from direct provision of support services. In fact, there may be a conflict of interest if members of a health committee saw important roles for themselves to assist Clinic staff in community outreach, whilst at the same time exercising oversight over the performance (or lack thereof) of clinic staff in the same regard. This tension may not need clarification upfront, but it will need to be taken into account as the training programme is rolled out.

However, none of these insights represent major deviations from the original planned research, but rather perspectives to be incorporated into the data collection processes.

3.0 Research Findings

The overall objective for the South African research (to explore the hypothesis that building civil society capacity to participate in health care and in services that provide the social determinants of health using a rights-based approach, in the context of interventions to enhance service responsiveness will help to address inequities in health and promote stronger and more sustainable governance systems for health that give voice to the poorest and most marginalized) remains the main objective to be answered at the end of the project. It is too early to provide evidence as to whether this hypothesis is true or not. We anticipate meeting this objective through the various sub-objectives set up in this study. Not very different from South Africa, in Uganda the project is an opportunity to explore the role of the rights based approach to community

participation in health and to use the models of good practice for Health Committees in South Africa to build the capacity of the village health teams and the Parish Development Committees to engage with the local government in planning and participating effectively in heath programming through a human rights approach to participation.

The first sub-objective is to develop and test **models of good practice for Health Committees**. In the next section we report on implementation and management related to this objective and activities under this objective. However, in terms of research results and contribution to knowledge, a number of studies of Health Committee practice are still in development in South Africa. Three studies of health committees are in development involving two postgraduate students and one postdoctoral fellow. One student is exploring the way in which health committees engage with issues of disability in their roles, a post-doctoral fellow is doing a similar study exploring engagement with the needs of gay and lesbian patients attending primary care services, and a third student is addressing the understanding and practice of health managers in terms of their receptiveness and responsiveness to health rights. Although all studies are still in early phases, the preliminary work in all the studies suggest the need to rethink rights as moving away from adversarial expressions in claims to access to services, and to think more broadly about diversity inherent in the needs of vulnerable groups. Indeed, the preliminary understandings arising from the preparatory literature for these studies points to the need to think about the centrality of vulnerability as a core concept rather than homogenizing 'vulnerable groups.'

A fourth study is currently using photo-voice to surface the understanding and agency of women in four communities in the Cape Metro area. This study will form the basis for a Masters degree for the study coordinator. Three of these groups are members of the LN, The Women's Circle (TWC), while the fourth is a community network involving a health committee in Mitchell's Plain, the site of the District Innovation and Learning for Health Systems project (DIALHS). The DIALHS project is a collaboration of the Schools of Public Health at the University of the Western Cape and the University of Cape Town and is building links with the Learning Network particularly around its work on Health Committees. Analysis of the photos taken by the Women is currently in process. A further small grant was secured to hold an exhibition in 2013 of the photos in the project, and will be used as a form of dissemination of community voice, and will be used to target policy-makers who will be invited to the exhibition and a linked colloquium. This will represent a novel form of policy advocacy and dissemination and we hope to learn useful lessons from this as a strategy.

What has also emerged from the DIALHS engagement has been a realization amongst participants that local communities have extraordinarily rich and diverse resources that are potentially hugely helpful to health services. This understanding was achieved through a participatory mapping process in DIALHS which has been assisted by the photo-voice activities led by the LN. In terms of local learning, the application of the photo-voice method has added new tools for implementing processes of reflective learning.

Progress in the South African site to meeting objectives has thus been steady although not as rapid as originally intended. We anticipate the four studies in process will pick up in year 2 and generate a rich set of data for further analysis.

In Uganda, two districts were indentified for the research and during this first year initial visits where done first to introduce the work to the local leadership, the community and health workers and second to create community networks and partnerships for undertaking the our operational

research intervention in the selected districts. The first visit to the Districts provided a number of interesting insights. For example, it was clear that the leaders in the two districts are aware about health problems in their areas – indeed, some of these leaders were able to link the health gaps in the districts to some human rights violations. However not much has been done to address these challenges. It was also clear that participation of VHTs in health programs is voluntarily and is dependent on individual interests and expectations for some opportunities such as capacity building. This is the case, even in situations where health facilities are some distance away from homesteads and therefore VHTs are critical for meeting health needs in the communities. The roles of VHTs are mostly visible at Health Center One level, which is the lowest level of health service provision, even when this is important for participation of VHTs in monitoring health problems. Yet, in the two districts VHT monitoring was minimal because of a number of reasons, including not being well supported by the services to undertake their tasks. It was, however, highlighted that it is important to create a platform for the health leaders to communicate the government policies and projects in health that are meant to help the communities as there seems to be a gap. Since most of the district leaders also recognized and acknowledged the critical role played by VHTs, it would be important that VHTs attain legal status to move away from the voluntary work given the critical role they are playing in the health system.

Other aspects highlighted in the first year's work include the need to encourage community participation to solve some of the health challenges, more community workshops on their health rights and responsibilities and creating an awareness base for the government services to better health services like the M.Trac system and the budgeting conference for the district budgetary allocation.

In addition to district visits, using the PRA methodology, community meetings were also done in the first year with the aim of introducing the work in the target districts, mapping out the project area and also generating information to inform implementation. The meetings saw the participation of the VHTs and PDCs; the lower local leaders, religious leaders and community members. The meetings assessed community participation in the health programmes from a human rights perspective; drew on community experience in relation to community participation in health programs from a human perspective; mapped out the areas of action within the communities /identify and prioritize barriers that are affecting community participation in health programmes from a human rights perspective; agreed the key barriers to act upon as discussed above and developed an action plans to act on barriers identified for the next 12months. It is expected that the agreed action will provide some insights on what needs to be done in the community to improve community participation within the health systems. It is interesting to note that many of the key actions indentified in the work plans actually relate to more community mobilization, capacity building and supporting VHTs and PDCs in undertaking their work.

The project's second sub-objectives is to disseminate experiences of good practice within the Southern and East African region through production and distribution of materials on the right to health, hosting one or more meetings of participants from the region to share experiences and building strong local, national and regional networking on the right to health.

In the next session we report on implementation and management related to this objective and activities under this objective. However, in terms of research results and contribution to knowledge, the project has identified some preliminary insights.

Firstly, as a result of hosting a set of workshops at the People's Health Assembly (see report at URL http://salearningnetwork.weebly.com/resources.html), it is clear that the model of structured

participation contained in South Africa's legislation is rather unusual as a vehicle for community participation in most developing countries. Rather, the forms of participation are fluid and contested. Even within South Africa, preliminary findings suggests that even with a legislative mandate for health committees, almost all provinces have not promulgated legislation to give effect to powers and functions for health committees. A useful framework for thinking through the contestation of power in this context was suggested by a colleague from Guatemala on a visit just prior to the PHA, which is the Power Cube[2] in which power is conceived of as having three dimensions – spaces (closed, invited and claimed), places (local, global and national) and visibility (invisible, hidden and visible). This heuristic has proved very useful in thinking through some of the responses evident in the Cape Metro Health Forum to the sudden withdrawal of support by the provincial health department in the course of 2012. From being a structure occupying an invited space, the Forum has decided to register as an independent non-profit organization, thus moving into an uninvited space, and seeking to wrest power back as a claimed space in its ongoing advocacy. Using this model with the Health Committees will form part of the discussion around empowerment central to the training to be tested.

Secondly, we have found a much wider audience for health rights materials than initially anticipated. Participants from as far afield as Angola and Mozambique have taken up the health rights toolkit (see URL http://salearningnetwork.weebly.com/resources.html) developed with the LN partners and used the materials in their health rights advocacy training, including a process of translation into Spanish. The language of health rights appears to resonate almost universally, even though the legal contexts are locally specific.

Lastly, one of the consequences of the PHA discussions was the realization of the need for a community of practice to share experience. Through this collaboration involving CEHURD and UCT, we anticipate being able to carry a nascent international network through the People's Health Movement, to lead a mapping process for social mobilisation approaches in different countries, with a view to sharing best practice more broadly. What we learn in this project will, therefore, hopefully have resonance in a much wider learning network in future.

Progress to meeting objectives is on track and we have not added any new objectives. However, CEHURD have partnered with other organizations on a Go4Health project which aims to surface community views about health needs that should be addressed in a post-MDG context. Similarly, the LN has secured an EU grant to expand the scope of its work in the Western Cape to include all Metro Health Committees and to involve comparative work in the Eastern Cape. We have thus been able to use the impetus of the Governance Project to leverage other project funding in parallel to this study.

At the national level in Uganda there has been adaptation of the right to health materials that had already been developed by the LN under creative commons licenses. Uganda now has six pamphlets covering the following areas; 1) What are Human Rights, 2) The Right to Health, 3) The patients Charter and redress for violations. 4. Right to Information, 5) Community Involvement and 6, Individual and collective rights. These have been written in very basic language and they target various audiences such as health professionals, district leaders, the community trainers and the community itself. The briefs cover experiences of good practice within the Southern and East African region which have been adopted from the Learning Network.

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[2]**Gaventa J. (2006). Finding the Spaces for Change: A Power Analysis.***IDS Bulletin* 37: 23-33

Related to this, CEHURD working with the Ministry of Health in Uganda and the WHO country office have successfully adapted a Health Human Rights Manual to be pre tested in selected districts in the country. The manual directs feeds from the LN developed a prototype Toolkit on health and human rights.

4.0 Project Implementation and Management

The project management is shared between the South African and Ugandan counterparts (Leslie London and Moses Mulumba) with respective local research teams and coordinators. LL visited Uganda in August 2012 to establish cooperation modalities with CEHURD, see first-hand the chosen study areas and to meet with local academics with the aim of encouraging recruitment of Ugandan students for the project. This was an important first step to getting the project going. In each site, project research teams meet regularly to review progress and identify next steps. The research coordinator in the South African setting is Ms Nicole Fick and Ms Hanne Haricharan is the lead researcher on the Health Committees' projects. In the course of 2012, we also recruited a coordinator for the LN, Mr Kanya Mdaka, and a further administrator will be appointed in March 2013 exclusively for the EU project support. The School provide research and financial administrative support with a Research Administrator and Finance Officer supporting the project work on limited part time basis. In Uganda in addition to Mulumba Moses, the project is implemented under the community empowerment program which has three staff and Juliana Nantaba is the designated project officer for this project. This team is supported by the administration, finance and communication team at CEHURD.

The programme of work in terms of this project is addressed below.

As part of developing and testing models of good practice for Health Committees in South Africa and Uganda, we undertook to pursue (a) training and capacity-building for health committee members; (b) building Civil Society networks in which Health Committees are supported by other Civil Society Organisations; (c) engaging with health officials and policy-makers to lobby for effective policies and structures to empower health committees; (d) developing and implementing training and support for health workers; and (e) testing of local systems to ensure health committee effectiveness.

Each set of activities is discussed below in turn in relation to implementation:

a) Progress on **training and capacity-building for health committee** members in the Western Cape has involved the development of a curriculum drawing heavily on results of the audit of Health Committees in the Cape Metro completed early in 2012 (Haricharan, 2012). The curriculum includes four broad areas (a) understanding the health system; (b) skills to act as agents of change; (c) understanding of health rights; and (d) meeting and procedural skills to support organizational work. The process of developing this curriculum has been supported by a visiting intern from a programme for minority students in the US run through Mount Sinai School of Medicine, and hosted locally by the Learning Network. It has also engaged with the Adult Learning Network as part of SANGOCO and with different providers to aim to develop SAQA accredited training that would be more readily transferrable and useful for a lifelong learning pathway.

The piloting and testing of the curriculum has been partly delayed by three factors. Firstly, the difficult of achieving health service buy-in to finalise the roles of health committees in the W

Cape. At the same time, we have expanded our involvement to include the Eastern Cape, which affords a wonderful opportunity for comparative work, but also introduces an element of trying to achieve a training tool more generically suitable. This has meant more time has needed to go in to training preparation. A workshop in mid-March will bring the W Cape and E Cape experience together to finalise progress.

b) **Building Civil Society networks** in which Health Committees are supported by other Civil Society Organisations has proven a useful strategy. The Learning Network held two Networking Meetings in March and June 2012, framed as Review and Reflect meetings, which provide the opportunity for organization to share and support each other in thinking through their health rights practice. We also used a Research Team meeting to conduct a reflection on the PHA.Additionally, The Western Cape branch of Epilepsy South Africa, and Women on Farms Project, as LN members, have both engaged with the Health Committees of the Cape Metro Health Forum, to explore strengthening of voice for their constituency groups. Further, WFP has been exploring establishing of rural health committees as a result of its links with the CMHF. Epilepsy South Africa has also been supporting Health Committees through engaging them on disability rights and awareness related to epilepsy and other disabilities.

c) The project has made some progress in **engaging with health officials and policy-makers** to lobby for effective policies and structures to empower health committees. Firstly, the LN held a successful symposium in May 2012, at which we hosted a presentation by PHM activist Walter Flores who spoke on"The evolution of social participation in health in Guatemala" as part of the ongoing community participation dialogues. Although modestly attended, there was representation from a key official responsible for policy in the provincial health department which was an important start to an engagement that otherwise had seemed very slow to get off the ground. Secondly, the LN was able to make a pre-emptive submission to the Provincial Health Department in relation to amendments to the Provincial Health Facilities Board, drawing on various pieces of research conducted through the LN to date. Because of its networks and links with members of the newly created District Health Council for the Cape Metro, opportunities have arisen to anticipate legal reform and to lobby key policy actors. As a result of its submission on the Act (see attached), the Health Impact Assessment Directorate has included elements of the submission into the Province's proposed 2020 planning documents. Further, one presentation was made to the HIA directorate and a further has been invited to follow up with a discussion in late February 2013, and a public health registrar (specialist in training) has been allocated by the directorate to work on the Health Committee projects of the Learning Network, reflecting a high degree of support from this particular structure in the health department.

A further engagement has been with the Chief Director (CD) for the newly created Office for Standards Compliance created in the National Department of Health. This Office will function as a semi-autonomous ombuds to oversee the quality assurance monitoring in the health services. Because of the CD's interest in the voice of the patient, she has invited the LN to partner with other projects funded by the EU to strengthen the demand for quality primary health care. At the moment, the LN is setting up an advisory body to give input to the work on health committees and this CD has agreed to serve on this advisory panel. This will be a high-level official engaged in the advisory board.

However, despite these positive developments, there have also been seemingly intractable delays in line managers taking seriously the need for finalizing a policy on health committees. For example, the Chief Director for the Cape Metro district, under whose authority all matters relating to community participation falls, has not engaged as hoped in the process of clarifying

health committee roles; rather, the establishment of the District Health Council structure has been substituted for local community participation in the discourse around community engagement, a strategy that potentially undermines meaningful community participation. This duality is a common thread running throughout the current engagement with policy makers[3]. On the one hand, an explicit elevation of the important of the patient experience and community participation as a strategic priority is evident in policy documents and in some managers' engagements, whilst, on the other hand, a desire to control the terms and form of such participation results is long delays in any movement towards institutionalizing community participation.

d) As a result, **training for health workers** in rights-based approaches to health and community participation has not taken off as rapidly as hoped. We are working with the DIALHS project but have not been able to move any faster in piloting materials because of the DIALHS project's own priorities and timelines. Further, the quite substantial post changes in the District Health System (the current DDG or head for the DHS is retiring), coupled with the creation of a District Health Council have delayed any progress on elevating community participation on health service agendas.

Nonetheless, the project has begun a process to map learning outcomes for health professional training through establishing a task group, and will be using medical students to develop visual interview material that can be used towards development of a training DVD in the course of 2013. In addition, a piece on health rights for the Democratic Nurses Association of South Africa (DENOSA)[4] newsletter has been accepted for publication in the first half of 2013. Through a gender activist contact involved with DENOSA's newsletter, we will have access to sharing and disseminating research findings to the Union's members. Lastly, we anticipate that the Masters student undertaking a study of facility managers will identify a number of 'best practice' opportunities for interview which we hope to capture on DVD towards the development of a training tool.

e) **Testing of local systems to ensure health committee effectiveness** is currently in development. Because of other related projects, we were unable to implement the model complaints procedure until these other projects were identified and clarified. One relates to work done by systems analysts within the Health Impact Assessment Directorate on complaints procedures in a Community Health Centre in Khayelitsha; the other relates to a project developed by an M-health NGO called Cell-life developing a cell phone based patient satisfaction survey under the EU-funded programme to strengthen demand for quality primary health care services. Now that we have met with Cell-life and the Khayelitsha pilot has been finalized, we have been given permission to go ahead with the complaints sub-study. The allocation of a public health registrar and the inclusion of this activity in the Provincial 2020 plans signals that implementation in 2013 will be much easier.

As part of disseminating experiences of good practice within the Southern and East African region, the project undertook (a) the production and distribution of materials on the right to health, both electronic and hard copy; (b) Hosting one or more meetings of participants from the region to share experiences; (c) Building strong local, national and regional networking on the right to health

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[3]See for example, Meier MB, Pardue C, London L. Implementing community participation through legislative reform: a study of the policy framework for community participation in the Western Cape province of South Africa. BMC International Health and Human Rights 2012; 12(1):15

[4] DENOSA is a trade union for nurses and a COSATU affiliate

a) **Production and distribution of materials on the right to health** has involved the translation of existing Toolkit on the right to health into Afrikaans and Xhosa for use in working class communities of the Western Cape; additionally, the Ugandan collaborators have used the LN pamphlets and adapted them to the Ugandan context producing locally useful tools for action; partners in Angola who attended the PHA have taken the Toolkit and translated it to Portugese with suitable local adaption for use in Angola with some interested from lusophone Mozambique as well. Approximately 100 toolkits and 100 of each of the right to health pamphlets were distributed to interested particiapntsat the PHA. Lastly, the LN has also produced a draft simple English pamphlet summarizing the findings from its audit of Health Committees (see http://salearningnetwork.weebly.com/resources.html). Further materials are anticipated to be produced in 2013.

b) The **Regional Consultation** which was planned as an activity in the first year will, in actual fact, only take place in the first few weeks of year 2 (28th Feb to 1st March). The reasons why it could not be held in the first year were related to the need to raise additional funding for bringing in participants from the Southern African region. In the end, we have linked the meeting to a project meeting of a CEHURD collaboration (Go4Health), so as to capitalize on the EU funding to bring participants to both meetings and so save on costs. The regional meeting will take place in a rural town in Kiboga district of Uganda, the site ofthe CEHURD field work, in order for partners to see the work in process and to involve local community members in the engagements. At present, it is planned that participants in the Kiboga meeting will share experiences from South Africa, Kenya, Uganda, Malawi, Zambia and Angola. The outcomes of the meeting will include a report, a shared dissemination strategy and a potential manuscript or plan to produce a manuscript from the meeting.

c) **Building strong networks on the right to health** has taken place at local, national, regional and internationallevels. At *local level*, the LN held a toolkit training workshop at the annual South African NGO Coalition (SANGOCO) NGO week –theme – uniting civil society to fight poverty and inequality, targeting local CSOs both within and outside the health field. The workshop was run in November 2012 and amongst the participants were a representative from the labour sector (Labour Research Services or LRS), People's Health Movement, Health Committee members and other health NGOs, including participants working in the Northern Cape. The LN has also participated in engagements with the People's Health Movement in the Western Cape and shared materials and plans for Health Committee strengthening, which has also been incorporated into the PHM plans for 2013. Materials to be developed in 2013 will raise awareness in communities of health committees and accountability structures available for community action so as to strengthen the links of health committees to their communities and increase community uptake of health committee roles.

The networks being developed at local level include both CSO and academic networks. Collaboration with the Department of Social Anthropology at UCT has enabled the LN to secure a small grant for a photovoice exhibition from a UCT institute (the Gordon Institute for Performing and Creative Arts, GIPCA), and to host a Masters student in Social Anthropoogy doing work on knowledge creation within the LN. Collaboration with School of Public Health at UWC has enabled engagement with the DIALHS project as outlined above. Lastly, we have engaged with a researcher based in the Childrens Institute at UCT (Mira Dutschke) who presented herAusAID-funded systematic review looking at the evidence that the establishment or use of community accountability mechanisms and processes improve inclusive service delivery by governments, donors and NGO's to communities. She is in the process of developing this

review, and used the seminar to get insights into the best inclusion and exclusion criteria for her research, with additional meetings planned for 2013.

At *national level*, the LN was a participant in the National Health Assembly held at the University of the Western Cape prior to the PHA in July 2012, funding participation of women from almost all the LN member organizations to be part of the NHA program. The NHA enabled participants to engage with, and understand some of the key policy reforms planned in South Africa and how to critically engage with these reforms. The LN involvement in the Eastern Cape (Nelson Mandela Bay Metro) has also helped to develop links between health committees from different provinces and the EU project will support short exchange visits between sites.

At *regional level*, the LN hosted a visit from the CEHURD project leader in April 2012 and will send two CSO activists (both women) to Uganda to spend 10 days with the CEHURD project as part of an exchange. Three Ugandans will visit in exchange (two funded from this project and one from Go4Health) and see the project work on the ground in the LN. The decision to send activists in pairs or small groups was made in preference to sending one participant a year, since the pairing would allow for more support and make the experience more worthwhile. The PHA has also led to involvement in the Health Committee and Right to Health work by activists in Mozambique and Angola. Lastly, through our links with academics in Kenya, the LN was invited to a meeting hosted by the British Academy of East Africa on the prospect of realising the right to health in Eastern Africa, and shared its experiences in strengthening health committees as vehicles for the attainment of the right to health. Although meetings were held at the Ugandan Christian University and Makerere University (see below – with both law and public health faculties), there have as yet been no student recruited. We hope these links will develop more strongly in the course of the project, reinforced by UCT's involvement in the Association of Schools of Public Health in Africa (ASPHA), for which UCT is convening a project on establishing core competencies for MPH graduates in the region.

Lastly, at *global level*, the PHA has firmly established international links with PHA chapters in other continents. The PHA exchange has advertised some of the LN materials and the work being pursued in this project. In May 2012, the LN hosted a presentation by PHM activist Walter Flores who spoke on "The evolution of social participation in health in Guatemala" as part of the ongoing community participation dialogues. The LN is in ongoing discussion with Walter about following up on the PHA workshop commitment to global mapping of social participation spaces, structures and processes. The LN also participated in a consultative meeting in Johannesburg in September 2012 of the Go4Health consortium developing a work programme to surface community needs and voice in shaping the post-MDG agenda.

At the same time, the LN has benefited from international academic networks. These have included long-standing partnerships with Professor FonsCoomans from the Centre for Human Rights at Maastricht, and Dr Maria Stuttaford of the Institute for Health at Warwick University. Both Prof Coomans and Dr Stuttaford have supported the work of the project, and visited in 2012, Prof Coomans in April, during which he met with students, gave a seminar, and visited some of the field work and training activities. Dr Stuttaford's preceded the IDRC grant, but gave rise to discussions about strengthening qualitative research capacity in the School (see below). She has also been able to participate in the project through Skype, teleconferencing and email and will be in Cape Town, along with Prof Coomans, in March 2013. Although Prof Richard Saunders at York University in Toronto, our initial collaborator on the IDRC proposal, attempted to submit a grant to support student and staff exchange with the LN, this was not successful, as a

result of which some of the activities related to curriculum development and student exchange have not been implemented.

5.0 Students and capacity building

Early in the project, the PI (LL) visited his counterparts in the Law and Public Health Departments at Makerere University and the Uganda Christian University (UCU) with the Ugandan lead (MM) to explain the project and lay the basis for student involvement. An advert for students was subsequently drawn up and distributed. It will be used in 2013 to recruit Ugandan students to the project.

Secondly, the involvement of Dr Stuttaford in the project has enabled the School of Public to explore setting up additional qualitative research modules on its MPH. Though Dr Stuttaford is not funded from this IDRC grant, her involvement with the LN and its Health Committee strengthening research, has made this opportunity available.

In the Western Cape, we have currently 4 postgraduate students registered on the project, 1 in the process of registering, and 1 postdoctoral fellow doing research related to the project. An addition Anthropology student is using a companion LN grant to research young women's reproductive health experiences. This is sumarised in the table below. Note that two of the students (Abrahams and Kunka) are completing their mini-theses as part of their MPH degrees. As such, there is a time lag between the students expressing interested in the projects (2nd half of 2012) and the finalization of their protocols (in early 2013) with implementation planned for 2013.

Table 1.0 Students on the Project (UCT)

Name	Gender/race	Degree	Topic and explanation
Wendy Nefdt	Coloured female	PhD	The role of Social Capital in the integration and implementation of Health and Human Rights programmes among CSO's. This project aims to capture how CSOs have changed or benefited from engagement in the LN. As the CMHF is one of the CSOs from whom data are being collected, it will provide insight into the way in which the CMHF has taken up rights issues. Student is registered and data collection ongoing.
Theo Abrahams	Coloured male	MPH (health systems)	How do Health Committees engage with disability in their roles and functions? This project explores the practice of health committees Student is registered but thesis proposal still in development
EvaristoKunka	Black male (Zambia)	MPH (health systems)	How do health managers facilitate or obstruct community participation in health? This project explores the receptiveness of health workers to health rights Student is registered but thesis proposal still in development
Nicole Fick	White female	MSc (Public Health)	How do women in communities understand and act for health rights? This project explores the use of photo-voice to give voice to women in communities to take action to redress health rights violations. Proposal is almost complete, after which the student will be registered. The student is also the project research coordinator.

Kerry Vice	White female	MA SocAnthro	Girls and Toilets: Menstrual Hygiene and Public-Private Spaces in an Informal Settlement. This project explores young girls' experiences of toilet arrangements in relation to menstrual management. Research ongoing. [related project]
Jen van Heerden	White female	MA SocAnthro	Collaboration and the co-production of knowledge in ethnographic research: An investigation into authorship, power and identity. This project explores the process of knowledge creation and power relationships within the Learning Network, working most closely with IkamvaLabantu. She is handing in her thesis in 2013.
Alex Muller	White female (German)	Post-Doc	How do health committees view the needs of gay and lesbian patients attending health facilities? This project explores issues of vulnerability and rights. Proposal is approved, data collection is ongoing.

Of the five students, one is a CSO activist, two are postgraduates recruited from the flagship programme in the School of Public Health and Family Medicine (the MPH), and one is a postdoc. We have had interest expressed by another postdoc to join the project and she has a likely interest in gender issues within the project. We will actively encourage her to seek out a postdoc award and will support her as needed.

No other funding support was available for Canadian partners. An application was made to an internal source in York University (Toronto), which was not successful. As a result, no work has proceeded further on the student placements or the Web-based teaching platform nor on the globalization and health module. We will still explore with Prof Saunders at York University opportunities to support module development on globalization and health.

In Uganda, following the circulation of the call for students, over 30 applications were received with a mix of legal and public health applicants. Three students have been selected to take part in the research from three universities: Makerere University, Uganda Christian University and the International Health Sciences University.

The first student (Nsereko Arthur Junior) is a Law student focusing on investigating the extent to which community participation has been effective in strengthening governance of the health system in Uganda. His study looks at the existing health guidelines intended to foster community participation, the implementation of those guidelines and the achievements and shortcomings of the implementation.

The second Student (Monica Wambugu) is an MPH student who will be investigating the contribution of community participation to the right to health. Her study will seek to establish the relationship between community participation and the right to health. Her specific objectives include investigating the current forms and levels of community participation in health, investigating the level of community awareness as a determinant to the right to health and determining the link between effective community participation and the right to health.

The third student (Mugero Jesse) a law student is focusing on the examination of the law relating to persons with physical disabilities in Uganda and how this law enhances community participation for people with physical disability in the health system. The study explores how a good legal environment promoting community participation could enhance the right to health of persons with disabilities.

In addition to the three students, a Doctoral Student (Mulumba Moses, the Ugandan project leader) has been registered at the Center for Human Rights at the University of Pretoria. His research focuses on Developing a human rights-based approach to community participation in the healthcare systems with special reference to Uganda' the study aims at developing a human rights based approach model for community participation in a decentralized health system and investigates the value of applying this model to ensure entitlements in a decentralized health system.

6.0 Technical, financial and administrative issues

Although there were some delays in the finalisation of the contract, there have been no undue difficulties in communication between IDRC and relevant administrative and financial staff at UCT, nor any problems in meeting the operational and contractual needs. The administrative and financial staffs at UCT are familiar with the needs of the project and are providing the requisite support.

The project is within budget for year 1 and will not need to revise its anticipated expenditures for years 2 and 3 at present. A more detailed narrative on the financial statement will be included with the financial report due in March 2013.

The Principal Investigator, Professor London, will be away on leave from the 1st April till end May, and then on sabbatical in the US (at Boston University) from 1st June to end December 2013. Dr Chris Colvin, an anthropologist currently leading the qualitative methods teaching in the MPH and a researcher linked to the LN will deputise for Prof London during this period. His contact details are Dr Christopher Colvin, phone + 27 84 684 7292 (mobile); + 27 21 406 6706 (work); email chris@capetorichmond.com.

7.0 Project Milestones – as per schedule

Project Milestones listed in the proposal for the two sites including shared activities are discussed in tabulated form below.

Table 2. Project Milestones, timing and achievements

Milestones	Timing	Comment: Achieved/Not achieved/Still to be achieved
Agreement from services for 2 sites to participate (SA and Uganda)	Month 6	Not possible to achieve in SA in first 6 months – reasons outlined in narrative above. Still ongoing and will be concluded in first half 2013; Ugandan sites chosen
Completion of first round of health committee training (SA)	Month 18	May only be completed by 20 months given delay
Completion of training and capacity building reaching majority of intact health committees (SA)	Month 36	On track for Month 36
Training for village health teams (VHT's) and parish development committees (PDC's) (Uganda)	Months 12 and 30	Identification of training needs and indicated in the community plan. Trainings will be happening in the next phase
Follow up meetings with the VCT's and PDC's together with the community (Uganda)	Month 36	On track for Month 36

Presentations to CSO networks at SANGOCO NGO week or equivalent (yr 3) (SA)	Month 34-35	Presentations to SANGOCO NGO week was done in year one and further presentations planned in year 2
Holding CSO meetings (Uganda)	Month 6, 24, 36	These are happening and will be ongoing
CSO activist internships: exchange 2 per year SA&Uganda for 2-3 weeks	Month 12, 24, 30	On track for Month 12, 24, 30
Dissemination of policy brief to key stakeholders in civil society and government (SA and Uganda)	Month 36	On track for Month 36
Presentations on health committees as vehicles for community participation in realising the right to health to Standing/Portfolio committees (SA)	By month 24	On track for Month 24 Colloquium on Health Committees planned for mid 2014 (approx Month 28) which will include (a) short course; (b) national colloquium; (c) visit by International partner (Walter Flores) to brainstorm global networking follow up.
Strategic lobby meetings with policy makers (Uganda)	By month 30	This has actually started with the district policy makers and will continue by month 30.
Implementation of training to providers and health workers on health committees as vehicles for community participation in realising health rights to staff in 2 sites	By month 24	On track for Month 24
Holding a Health workers training on the right to health (Uganda)	By 12 months	On track and already indicated in the community workplan for months 12 - 24
Agreement from services to pilot a 'model' complaints resolution system (SA)	By month 7	Agreement in principle from health department incorporated in provincial plan; still to identify pilot sites
Roll-out of the model to other sites and districts	By month 36	On track for Month 36
Sharing field findings and use them to lobby for practice and policy changes (Uganda)	By Month 36	On track for Month 36
Approach Law and Public Health Schools at Makerere and Ugandan Christian University to solicit involvement	By Month 6	Accomplished, we had meetings with the universities with Prof. Leslie London and as a result we are working with students recruited from these universities
Recruitment of at least four postgraduate students to work on the project	Two by month 7 and 2 more by month 19	Four postgraduate students and 1 post-doc working on the project (SA); more may still be recruited – specifically, we intend to recruit a student or post doc to focus specifically on gender in the project. A Ugandan PhD student has registered at the university of Pretoria and 3 other Uganda students are working on the project
Dissemination of pamphlet/s on health committees to Civil Society structures	By month 18	On track for Month 18
Regional stakeholder meeting of health and civil society	By month 12	Regional stakeholder meeting of health and civil society (SA and Uganda) to be held in month 13
2nd regional meeting of health & civil society	By month 24	On track for Month 24

3rd regional meeting of health and civil society	By month 36	On track for Month 36
LN participation in the 3rd People's Health Assembly with a focus on Health Committees as vehicles for realising health rights	Month 7	LN ran two sets of workshop at the 3rd People's Health Assembly in Month 6 – one on the toolkit and one focused on Health Committees as vehicles for realising health rights. Report available, international network established.

In general, the milestones are likely to be reached as originally intended, though with some delays in some of the activities.

8.0 Project Outputs – as per schedule

Project Outputs listed in the proposal for the South Africa site or as shared activities are discussed in tabulated form below. Specific outputs and dissemination activities are individually listed below the table.

Table 3.0 Project output, timing and achievements

Output	Timing	Comment: Achieved/Not achieved/Still to be achieved
Draft training programme and materials for health committees	Month 6	Curriculum outline finalised. Still to confirm training programme
Revised training programme and materials for health committees based on initial experiences and evaluation	Month 18	Will likely only be finalised by month 24
Web-based training module following feedback on curriculum	Month 18	Unlikely to be realised unless additional funding
Evaluation report on effectiveness of capacity building intervention for health committees (SA)	Month 36	On track for month 36
Adapting training materials on the right to health (Uganda)	Month 6	Six pamphlets have been adapted and the toolkit pre testing is scheduled when further funding is secured.
Narrative report on LN Review and Reflection process highlighting major learnings (SA)	Month 36	On track for month 36
Production of popular CSO materials (Uganda)	Month 30	On track for month 30
Policy brief on health committees as vehicles for community participation in realising the right to health	Month 18	Probably likely to be finalised by month 24 in synchrony with presentation to portfolio committee
Production of popular materials targeting policy makers (Uganda)	Months 12 and 30	On track for months 12 and 30
Training programme and materials for health workers on health committees as vehicles for	Month 12	Will likely only be finalised by month 24

community participation in realising the right to health		
Training DVD for health workers on health committees as vehicles for community participation in realising the right to health	Month 18	Will likely only be finalised by month 24
Evaluation report on effectiveness of training to providers and health workers on health committees (SA)	Month 36	On track for month 36
Systems and procedures written up into a protocol for managing complaints in two sites (SA)	Month 12	Protocol in development; likely to be complete by month 15
Evaluation report on success of the pilot 'model' complaints resolution system (SA)	Month 24	Will likely only be finalised by month 27 since the pilot will need to run for 6 months
Report on Field Assessment for local systems for health rights (Uganda)	Month 30	On track for month 30
Materials for an MPH module on globalization and health developed	Month 12	Unlikely to be realised unless additional funding
Development of an IT platform for web-based teaching	Month 12	Unlikely to be realised unless additional funding
Postgraduate student research theses finalised (SA and Uganda)	By month 36	On track for month 36
One or more pamphlets explaining and promoting the role of Health Committees in realising health rights (SA)	Month 12	Pamphlet on health committees distributed to CMHF Draft pamphlet on Health Committee audit in plain English being finalised
2nd edition of the Toolkit on Health and Human Rights for CSO's incorporating regional rights commitments and constitutional provisions on the right to health (SA and Uganda)	Month 24	On track for month 24
Version of the toolkit adapted for use in Uganda (Uganda)	Month 12	The tool kit was successfully adapted and it just the pre testing pending securing further funding as its not funded under this current IDRC grant
List servers of PHM, Section 27 and UCT HHRP used to disseminate information (report) (SA)	Month 36	Some list servers in use already
Functioning website for the project accessed for materials and resources (SA)	Month 36	Website in process of including project materials On track for set up before month 36

In general, the outputs are likely to be reached as originally intended, though with some delays in some of the activities.

9.0 Specific Outputs

1. Reports: Haricharan H. (2012). Extending participation: Challenges of health committees as meaningful structures for community participation. Learning Network for Health and Human Rights; URL: http://salearningnetwork.weebly.com/resources.html
2. Policy inputs
   a. Cape Metropolitan Health Forum and the Learning Network for Health and Human Rights. Submission to the Western Cape Government Health Department: Amendments to the Western Cape Health Facilities Board Act, 2001. Unpublished report, 2012.
   b. Extracts from the above included into Provincial Health Plan for 2020
3. Popular outputs: Health committee report in pamphlet form (layout in process).
4. Internships: Two CSO activists (L Sigasana and D Fritz), both of whom attended the PHA will be spending 10 days with CEHURD in Feb/March 2013. The original plan was to exchange one activist per year but the project decided it would work better to send two activist as a pair, so the SA to Uganda exchange will take place in early March 2013. The reciprocal exchange will take place later in 2013 with two activists to be hosted for 10 days in the Western Cape. A third CEHURD member will join the pair, but funded from another CEHURD grant, to intern at the Legal Resources Centre in Cape Town (since he is a litigation expert for CEHURD and will benefit by seeing public interest law activities at the LRC).
5. Pamphlets adopted on the right to health for use in Uganda

Planned outputs in process include two manuscripts in development from Extending participation: Challenges of health committees as meaningful structures for community participation; a manuscript exploring the place of social solidarity in rethinking conceptions about the right to health; and the paper for the Conference proceedings for the Conference on "The Prospect of the Right to Health in Eastern Africa" under the auspices of the British Institute in Eastern Africa (see below).

10.0 Specific Dissemination Activities

1. Training workshops:
   a. Photo-voice workshops with participants from three TWC circles (Hanover Park, Athlone and Delft) from June to November 2012 (total of 37 sessions).
   b. Workshop on Using a Health and Human Rights Toolkit at the SANGOCO NGO week themed "Uniting civil society to fight poverty and inequality", November 2012. [14 participants]
   c. Workshop on Using a Health and Human Rights Toolkit for Sign Language Interpreters and participants from the Deaf Community of Cape Town (with Sign Language Translation) over a period of four weeks, June to July 2012. [10 participants]
   d. Workshop on Using visual materials to mobilise for the Right to Health, People's Health Assembly, University of the Western Cape, South Africa, July 2012. [+/-40 participants]
   e. Workshops on Community Participation in health for the communities in Kiboga and Kyakwanzi District for the identification of community participation

challenges and development of a workplan for actions prioritized by the communities.

    f. Development of popular messages and some printed on T-shirts as requested by the communities on the aspects of community participation.

2. Conference presentations:
    a. November, 2012: British Institute in Eastern Africa, Nairobi, Kenya: The Prospect of the Right to Health in Eastern Africa. Paper presented: Hanne Haricharan. Extending Participation: How Can Health Committees Become Effective Vehicles for Realizing the Right to Health Through Participation.
    b. July 2012: People's Health Movement, Global Health summit, Cape Town, South Africa. Paper presented: Hanne Haricharan. Extending Participation: Challenges to Health Committees as Meaningful Structures for Community Participation.
    c. July 2012: People's Health Movement, Global Health summit, Cape Town, South Africa. Paper presented: Mulumba, Moses. Community Participation in Uganda's decentralised health system: Challenges and Opportunities
    c. February 2013: Abstract accepted for International Congress of Qualitative Inquiry Conference, to take place in May 2013 in Urbana-Champaign, University of Illinois at Urbana-Champaign, USA: "Reflections on a Collaborative Research Project to Strengthen Community Participation."
    d. October 2012: N Fick. Nicole to qualitative health research conference – presentation on Using photo-voice as a method in qualitative health research, presented at the18th Qualitative Health Research Conference, University of Alberta, Canada.
    e. Maria Stuttaford, Damaris Fritz, Leslie London, Wendy Nefdt, Vanessa Reynolds, Glynis Rhodes, and Lulama Sigasana. Weaving Conceptual Threads to Illuminate Implementation of the Right to Health: the Learning Network for Health and Human Rights, Western Cape, South Africa.Paper presented at International Interdisciplinary Colloquium on Law and Global Health, University College London Laws, UK, July 2012. [Due to be considered for inclusion ina Conference Monograph currently in process.]

3. Other seminars, collaborations and academic activities
    a. FonsCoomans: Human Rights: Collaborations involving customary law and the right to health. Co-hosted with the NRF Chair on Customary Law, Professor Chuma Himonga, UCT, 17th April 2012.
    b. GO4HEALTH: Community Consultations for work package 2 of a European Funded project on formulating new goals for health.

11.0 Impact

It is too early to measure impact of the research at the moment, though it is clear that there is much contestation of power in relation to community participation. However, there is also high level interest and inclusion of elements of the LN programme to empower health committees into the Provincial Health Plan.

The work conducted with the Health Committees is linked to enhancing the capacity of marginalised social groups in multiple ways – training for deaf persons and their interpreters; engagement with health committees to explore their approaches and engagement with the needs of disabled persons, gays and lesbians and rural farm residents; promoting stronger patient voice in the public health services, which serve predominantly poor and working class patients.

Similarly though its early to talk about the impact of the project in Uganda, its interesting to note that there is more attention to community participation and local leaders are beginning to find space in critical processes at the local government level such as the budgeting process. Networks are beginning to form across the local NGOs doing community health rights work and community participation is getting integrated into their areas of work. It is also visible that VHTs and PDCs are working more closely with the local leaders to enhance participation in health decisions making. The talk of human rights is beginning to take shape at the lower health facility level and the health professionals are asking for refresher trainings in human rights as part of promoting community participation.

12.0 Gender

In terms of gender considerations, the project has established two directly linked projects – one aims to surface the experiences of women in process of building capacity for rights. It is envisaged as an ethnographic study. The second is to explore the willingness of health committees to address health needs of their communities within a gender lens. For both projects, we were unable to recruit students in the first year of the project. One reason was that a potential student interested in doing the former project as her PhD was unable to secure a PhD bursary from our other (South African) funder because she was a Lesotho national. She then chose to pursue a different topic for her PhD. We will still seek to recruit students for both these areas. Additionally, we are hoping to recruit a post-doc who is currently in the process of handing in her PhD (on gender issues affecting HIV and sex work) to join the LN and the Women's Health Research Unit in the Department later in 2013. Should this development transpire, we will be in a far better position to pursue a number of studies addressing gender and women's health.

A related development outside the IDRC project, but linked to the LN's health rights focus, was that the LN was able to support an anthropology student doing work on young women's experiences of menstruation in relation to lack of basic services in a township in the Western Cape. This study, for her MA in Social Anthropology, is ongoing but raised important issues about safety, identity and lack of access to services for a particularly vulnerable group. Because of our LN engagement on health rights, we were able to leverage a bursary for this student, even though she is not working directly with health committees.

Lastly, the return of Dr Chris Colvin, who has been on sabbatical in 2012, to rejoin the Learning Network, has expanded our capacity for social science research. Dr Colvin has an interest in masculinities and health, so this will complement much of the work on women's health in different contexts. He will also deputise for the PI whilst Prof London is on sabbatical.

13.0 Recommendations

Research recommendations will emerge from the various sub-studies. At this stage, we would not want to commit any definitive directions. In terms of feedback to the IDRC with respect to the administration of the project, there are no concerns to raise at this stage.

Submitted jointly by:
1. The Cape Metropolitan Health Forum
2. The Learning Network for Health and Human Rights (represented by the School of Public Health and Family Medicine at UCT)

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19th November 2012

Background

Community participation is widely recognized as a pillar of the Primary Health Care approach, and as instrumental to the right to health[i]. Further, community participation in health has been argued to improve the effectiveness and sustainability of health interventions, programs and services in various ways – for example, by lowering costs for service delivery through voluntary community efforts and mobilization of resources from outside the health sector[ii], increasing service responsiveness[iii], enabling more equitable client-provider relationships with improved feedback[iv]; and increasing a sense of responsibility for health and ownership amongst community members resulting from new skills and securing control over resources[v]. Community participation in health has been shown to improve health outcomes and ensure more equitable access to health services.Research in Zimbabwe[vi] has shown improved health outcomes where structures for community participation in health are functioning well. A systematic review conducted in 2011 found that there was some evidence of the effectiveness of Health Committees in contributing to improving the quality and coverage of health care, and impacting positively on health outcomes[vii].

Successful implementation of community participation therefore has the potential to strengthen the health system and to have positive impacts on trust and relationships between patients and health workers. It allows communities to participate in defining models of care and resource allocation in health and for communities to become involved in dealing with the social and economic determinants of health. It provides a structured framework for accountability. With effective community participation, community members are no longer passive recipients of health care, but actively participating in the creation of a health care system that serves their specific needs[viii].

In addition, work emanating from the office of the UN Special Rapporteur on the Right to Health[ix] has proposed a range of indicators for measuring the right to health in a health system perspective, amongst which are measures reflecting the extent to which health systems actualize community decision-making in health. This work reflects growing international interest in making the concepts adopted in the Declaration on Primary Health Care (PHC) at Alma-Ata in 1978 realizable in practice.

A conceptual framework proposed to benchmark health facility committee performance[x] highlights the role of health facility factors (staff attitudes, skills and resources), health committee features (clarity on roles and functions, on mandate and authority, accountability arrangements, and capacity and resources), and community factors (social, political, cultural and economic). This framework provides a useful starting tool to develop interventions and monitoring indicators to assess effectiveness of participation (see Figure below).
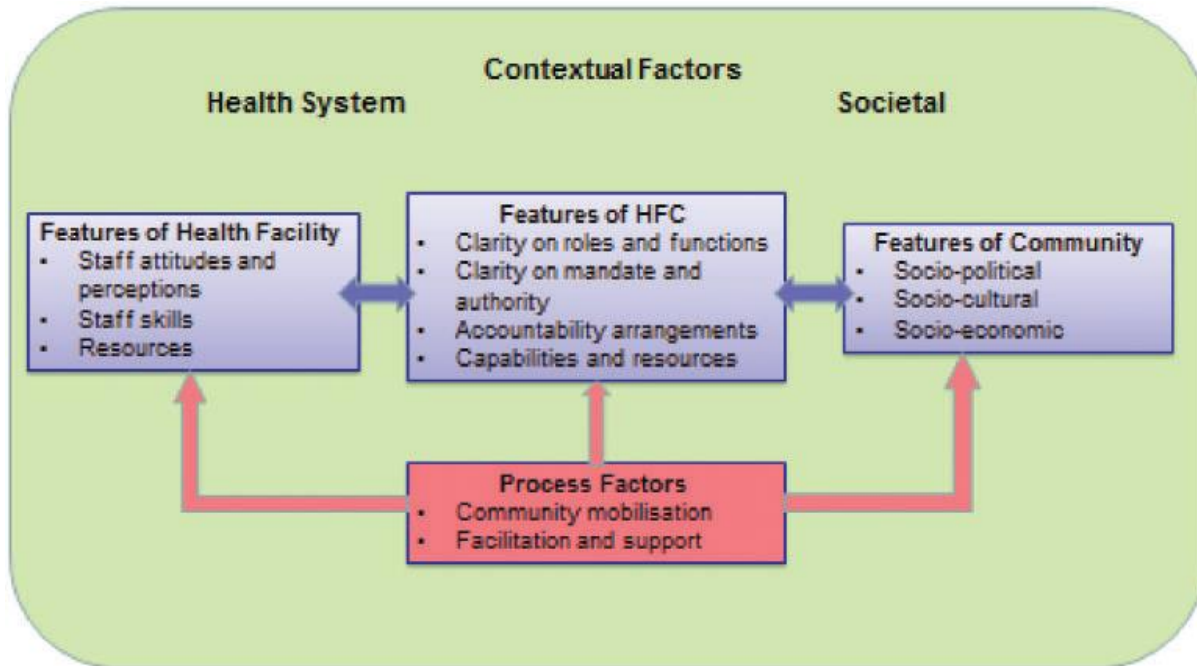
Figure: Conceptual framework for the determinants of health facility committee performance (From: McCoy et al, 2011)

The South African legislative and policy framework

The National Health Actis the bedrock of our Health System. As stated in its preamble, it provides a "framework for a structured uniform health system within the Republic, taking into account the obligations imposed by the Constitution and other laws…"

The importance of community participation is evident in different places in the Act.

Firstly, the Act speaks of Primary Health Care services. Though not elaborated in any detail within this Act, the concept of Primary Health Care made community participation a central pillar of the PHC approach. By implication, planning for a health system based on Primary Health Care services implies recognition of the place of community participation in health, a position confirmed in the White Paper on the Transformation of the Health System (1997)[5]. This is further reinforced in section 30 which deals with the division of health districts into sub-districts. In this section, the relevant MECs (for Health and for Local Government) are expected to "pay due regard to … Constitutional principles …" and relevant legislation, inasmuch as they relate to various principles, one of which is that of community participation. [Section 30(c) (2)].

Secondly, the Act imposes responsibilities on both national and provincial health departments to "promote community participation in the planning, provision and evaluation of health services", in sections 21.2(h) and 25.2(t), respectively.

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[5] The White Paper states in its discussion of the Mission of the Department of Health in relation to the people of South Africa, that "without their active participation and involvement, little progress can be made in improving their health status." It also includes as one of the objectives of the health system – "To foster community participation across the health sector" which includes involving "communities in various aspects of the planning and provision of health services" and establishing mechanisms to improve public accountability and promote dialogue and feedback between the public and health providers", as well as encouraging "communities to take greater responsibility for their own health promotion and care." Lastly, it confirms community participation as one of the principles for a transformed District Health System.

Thirdly, the Act explicitly creates structures for community participation. In the case of hospitals, Section 41(4) to (9) deal with the establishment of hospital boards and Section 42 (1) to (3) deals with clinic and community health centre committees. However, the Act stops short of indicating the precise roles and functions of any of these structures, leaving to designated authorities to finalise these roles. In the case of central hospitals, the functions of their hospital boards are designated as to be prescribed by the national Minister of Health, whereas in the case of other hospitals, community health centres and clinics, to be promulgated through provincial legislation. The Western Cape took the step of regulating roles and functions of its hospitals in the Western Cape Health Facilities Boards Act of 2001. However, as will be explained below, this Act is poorly adapted to serve as the regulatory framework for the Health Committees described in Section 42 of the NHA and existing in the Cape Metro currently.

Lastly, section 31, which follows immediately and which deals with the establishment of District Health Councils is entirely silent on the matter of Community Participation. Section 31.3 describes the role of a district health council as being too "*(a)* promote co-operative governance; *(b)* ensure co-ordination of planning, budgeting, provisioning and monitoring of all health services that affect residents of the health district for which the council was established; and *(c)* advise the relevant members of the Executive Council, through the Provincial Health Councils, and the municipal council of the relevant metropolitan or district municipality, on any matter regarding health or health services in the health district for which the council was established."

Inasmuch as community participation can be subsumed under "any matter regarding health or health services", it is not inappropriate for the DHC to address mechanisms for community participation; however, it is not explicitly stipulated. This is a weakness both of the NHA and of the Western Cape District Health Council Act. As argued below, the intent of the NHA and the White Paper for the Transformation of the Health System are to set up effective structures for community participation, but these structures lack clear roles, articulation with the District Health Council, and an overarching framework in which to operate, which seriously undermines the possibility of realising effective community participation. This is the focus of this submission on the Western Cape Health Facility Boards Act.

It is the case that a Draft Policy Framework for community participation/governance structures for health was developed in the Western Cape in 2008 but has never been formally adopted. The policy framework responds to many of the drivers identified in national legislation and in national policy, but predates the more recent adoption of the District Health Councils Act.

Experiences of Community Participation in the Western Cape – what evidence can we draw on?

A limited number of studies are available on the effectiveness of health committees as community participation structures in South Africa[xi]. Of these, three examined different aspects of health committee effectiveness in the Western Cape Metro. Glattstein-Young compared three health committees with different levels of functioning in the Cape Metro. Her main finding was that participation by and attitude of facility managers and ward councillors were critical to the success or failure of health committees. Haricharan identified the critical need for clarity on roles and functions of Health Committees so as to inform capacity building; and, in the absence of any guidelines, great variability in how committees were constituted, with one extreme including appointment of members by the facility manager, which seriously compromised the committee's credibility in the community and, hence, their effectiveness in terms of community voice. Lastly, Purdue et al, identified the policy hiatus that needs to be addressed to ensure that health committees have meaningful input to decision-making in health. In particular, the latter two studies showed how Health Committees exist in a policy vacuum, and that they need to be located in policy framework that enables health committees to have a structured articulation with other community participation structures (Hospital Boards) and with the District Health Council. Taken together, these three studies indicate that there is an opportunity to create synergy in setting up a new policy framework that makes community participation through health committees effective. This is one of the main points made in this submission.

The studies are attached as annexes to this submission for information.

Proposals for revision of the Health Facilities Board Act

Given the need for legislative changes to bring health committees into a framework for community participation, we make proposals for revision of the Health Facilities Board Act. We do so, first, by identifying elements within the existing Act that require attention/revision/rewriting if health committees are to be included in the ambit of the Act, and propose how the Act might be changed to address these problems. Thereafter, proposals are made for additional clauses or elements needed. Lastly, a set of implementation activities to support changes in the Act are also detailed.

1. The current Act: Changes needed
   a. Firstly, it should be noted that. Although section 5 of the Act implies 'any health facility' could fall under the ambit of the Act, it is clear that the Act is primarily intended to address Hospital Boards and is poorly adapted to Health Committees. Indeed, the section outlining repeals of other legislation refers to a previous Hospital Ordinance, indicating the concerns of the Act to bring hospital governance into line with the provisions of the National Health Act. However, the NHA clearly distinguishes Hospital Boards from Health Committees. The terms used in the Act therefore need to accommodate both.

      Action: The overall structure of the Act should be amended to target (all) "Health Facilities" and these should be defined in the beginning of the Act as including hospitals (one group) and clinics and CHCs (another group). The Act can then refer to Health Facilities when speaking in general and to each group when provisions are specific to either hospitals (boards) or, one the other hand, to clinics and CHCs (committees).

   b. The Act currently provides for Ministerial appointment of Boards (section 6). This would not be entirely appropriate for local structures intended to represent the community, where the emphasis should be on election rather than appointment. Not only would this defeat the purpose of community participation, but it would, in all likelihood be unworkable to expect the MEC to have the time to apply his or her mind to the composition of 70+ health committees in the Cape Metro. The research referred to above indicated that the functioning of some health committees was, in part, adversely affected by a lack of legitimacy in how they were established. The process of setting up a new health committee, or re-electing its membership should be such as to strengthen its role and mandate.

      Action: The Act should specify in broad terms that membership of a Health Committee should include a majority of elected member from the local community, with some designated appointments ex-officio (ward councillor, facility manager). The Act should defer the details of how those elections take place and the constitution of health committees to regulations which could be promulgated after some pilot work establishes the best options for such procedures (see 3.1 below).

   c. The composition of health committees is stipulated in the NHA as including the ward councillor, facility manager and one or more representatives of the community. The current section dealing with composition of hospital boards (section 6) is appropriate for large hospitals but is not suited to health committees for CHC and clinics because of the diverse range of persons stipulated.

      Action: A separate section needs to be included specific to health committees and reflecting the contents of section 42.2 of the NHA. This would allow for separate processes to be followed for Hospital Boards and for Health Committees – both for election/nomination and for filling of vacancies (section 8).

d. The functions identified for Facility Boards are more or less suited to a health facility environment, whether hospital or clinic/CHC. There are 10 functions listed in Section 9, and all the functions identified in the Draft Policy Framework for community participation/governance are covered by these functions. However, the strength of health committees as vehicles for community participation lies in their local representivity and engagement. For that reason, we would propose that clause 9(f) ensure that health committees are expected to participate in the resolution of complaints (and would be empowered to do so). This would be consistent with the revised National Complaints Management Guideline released recently by the National Department. Section 3.2 below proposes pilot work to establish how best to effect such participation.

Action: Clause 9(f) should be amended to include explicitly the participation by the Board or Health Committee in the resolution of complaints.

e. Further, consideration could be given to a more active role for Boards and Health Committees in relation to formulation of strategies and policies, and mission, vision, and values. Health committees are ideally suited to help contribute to the identification of community needs. Rather than merely approving or advising, meaningful community participation could include active participation by representative and competent Health Committees in the shaping of these elements.

Action: Clauses 9(a) and (b) should be amended to include the role of providing input to shaping mission, vision, value, policies and programmes.

f. A second problem in the functions identified for Facility Boards is in clause 9(h). The role of a Board (or Health Committee) should not be to raise funds for the Board (or Health Committee) but for the facility, or for specific health projects. The funding of community participation structures must be a departmental responsibility, given the NHA's very clear mandate which obliges the national DG for health and the provincial Heads of Health to promote community participation (sections 21.2(h) and 25.2(t)).

Action: Amend Clause 9(f) to reflect a function in which the Board or Health Committee is empowered to raise funds for the facility or for defined health projects.

g. Section 13 correctly points to the importance of cooperation between boards and facility management, since, without good cooperation, the value of community participation is greatly reduced. The same measures should apply to Health Committees at Clinic and CHC level.

Action: The Act should identify the same importance accorded to good cooperation between facility managers and health committees, with measures to resolve any problems arising. Moreover, this implies consistent investment in capacity building, both of providers/managers and health committees to ensure good relationships can be built based on a shared vision. (See 3.3 and 3.4 below).

2. Additional   Comments

a. The Act is silent on the place of groups of health committees in a sub-district. Although it refers to the possibility of groups of facilities forming a Health Facility Board (Section 5.1), this is not the same as a group of facilities, each of which has a Board (or its clinic or CHC equivalent of health committee) and which function in a sub-district. Notably, the NHA recognises that there might be a need for sub-districts and considers community participation as one of the criteria to determine how those sub-districts are formed (in section 31.3 of the NHA). It is therefore important to establish a community participation structures contiguous with these sub-districts.

Action: The Act should recognise sub-structure aggregations of health committees.

b. A second reason why sub-district aggregation of health committees would be helpful relates to the value of sharing of experiences amongst health committees, with a view to identifying best practice. It is not only cooperation between boards/committees and facility managers (Section 13) that is desirable, but also cooperation between clinics, between boards and between clinics and boards. A platform at which health committee and facility board experience can be shared, problems clarified and solutions identified would be in the interest of a responsive health   system.

Action: The Act should add a set of structures in which committees and boards are able to come together. Whether this is similar to the existing Cape Metro Health Forum in the Metro district, or adapted to take account of hospital boards may need to be discussed further.

c. A third reason why a structure akin to the Cape Metro Health Forum may be important is in resolving the policy gap between the intent of the NHA to "promote community participation in the planning, provision and evaluation of health services" and the failure of the Western Cape District Health Council to speak to the structures established in Sections 41 and 42 of the NHA. Given that the DHC has key responsibilities in overseeing the planning of health services and approving budgets, the place of community participation should be structured consistent with the intent of the NHA that facility boards and health committees act as vehicles for community participation. Such structures are important to ensure proper feedback between different levels of governance so as to ensure that issues that are identified at a 'local' level   are   addressed   at   a   'higher'   level.

Action: The Act should include reference to community participation structures being represented on the DHC. This should be included as an additional function in section 9, as well as meriting a special section to explain how the structures articulate with the DHC.

To achieve the intended policy intent of the changes proposed above, a set of implementation activities would be helpful, either to provide evidence for guidelines or regulations, or to strengthen capacity to manage community participation in the services. These are outlined below. The LN is developing a research and evaluation programme under the auspices of a EU-funded project related to enhancing the patient experience through community participation, which give us the opportunity to test out many of these ideas in support of legislative reform to enhance community participation.

3. Implementation   possibilities.

a. Establishment   of   Health   Committees   (point   1(b)   above): To develop the evidence for the best methods of establishing health committees, we propose that evidence be tested in one or more pilots in different setting. Different provinces have adopted different approaches to the establishment of health committees and the Learning Network is in the process of assembling experiences from different provinces as to how they have gone about it. The LN would also like to test out different approaches to setting up a new health committee to identify what steps would be most helpful in establishing credibility with both communities and providers. A current partnership project is reviewing the experience in the Nelson Mandela Bay Metro in setting up health committees, which will be shared locally as   part   of   identifying   best   practice.

b. Complaints procedures (point 1(d) above):

The APP currently contains an indicator for the resolution of complaints, but it is well recognised that the validity of this indicator is unknown. Partly for this reason, and because of the provincial commitment to enhancing the patient experience, the Health Impact

Assessment Directorate has been working with selected facilities to enhance the effectiveness of complaints systems. The LN has also intends to propose two pilot projects in which a structured engagement of health committees with health facility mangers in the identification and resolution of complaints is tested over a 6 month period. The focus of this pilot would be to identify the health system gaps that give rise to the complaint and opportunities for resolution. The rationale is that local collaboration with community structures, that is seen to result in changes, however large or small, that contribute to avoiding a recurrence of the problem, can trigger a 'virtuous cycle' and build mutual trust between the community and the services. Too often, complaints are reduced to adversarialist conflict, which is unlikely to move a problem towards resolution or help build long-term system sustainability. This pilot work can contribute to developing SOPs for facility mangers and health committees so that complaints are managed in an agreed and structured way, with real changes representing an enhanced degree of service responsiveness.

The newly release revised National Complaints Management Guideline from the Department of Health recognises the potential for Health Committees and Hospitals Boards to be part of complaints resolution.

c. Training and capacity building health committees (point 1(f) above):

To be able to implement the many functions identified in Section 9, Health Committees will need to be capacitated. Many of these training needs have been identified in previous research. Confirmation of the roles and functions of health committees will need to inform the training required. Support for health committee capacity building is also part of the proposed programme of work for the LN, which we aim to implement in collaboration with the CMHF and with the Health Department.

d. Training and capacity building of facility staff (point 1(f) above):

Similarly, for systems of community participation to work, health workers and managers need to be supportive. Training and capacity building of health workers and managers therefore will need to be in place. Support for health worker / manager capacity building is also part of the proposed programme of work for the LN, which we aim to implement in collaboration with the Health Department. Some pilot work in this regard has already been taking place in collaboration with the DIALHS project in Mitchells Plain.

14.0 Conclusion:

The opportunity to amend the Western Cape Health Facility Boards Act provides an opportunity to give effect to the intent of the National Health Act and the White Paper on the Transformation of Health Services with regard to community participation. It also provides an opportunity to fill the policy gap between the District Health Council and those structures created by the NHA precisely for the purpose of community participation – health committees. These are structures which have a long history in the Western Cape and with whom the Health Department has travelled a long journey, and in which considerable efforts have been invested to date. These proposals aim to capitalise on what strengths we can draw from this history. We would urge that the Department ensure there is an adequate process for consultation on the revisions of the Act, which is well communicated to communities, with adequate time for inputs.

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