

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 second year has been on deepening our understanding of how community voice can be articulated with claims to health rights in participatory structures in both countries and using that understanding to develop and implement training for members of community participation structures. A set of participatory research activities in Kiboga and Kyankwanzi sub-counties in rural Uganda have formed the basis for training of local Village Health Teams (VHTs) and Health Unit Management Committees (HUMCs) in Uganda, while the findings of an audit of Health Committees in the Cape Metro were used in the development of a manual and instructor's guide for training of Health Committees in a sub-district in Cape Town. The work in South Africa has also extended to training in another urban site in the Eastern Cape. Both sites have shared resources and instruments for the development of training tools on health rights and participation, and materials in Cape Town have been further developed to address issues of diversity, race, gender and sexual orientation. Novel developments have included the introduction of Learning Circles for Health Committees in Cape Town and exploration of Training-of-trainer approaches to address the need for ongoing support, mentorship and sustainability. In both sites, facility-based health workers linked to participation structures have been included in training, though institutional support from the W Cape Health Department has been uneven, and limited the potential to mainstream such training in ongoing health worker capacity building. In contrast, in Uganda, strong ministerial support, linked to WHO interest, has opened the door for CEHURD to play a key role in developing training material for health professionals on human rights and maternal health, within which community participation is nested. Through this partnership, CEHURD has been able to pre-test the Health and Human Rights Manual in six other districts and held a National Meeting to validate the final draft of the manual. The development of models for participation is ongoing in both sites.

What has emerged is how critical the policy context is for effective participation. In the Western Cape, despite high level commitments to participation, there has been no progress in institutionalising structures for participation, nor reaching clarity on the roles of Health Committees. This is despite individual managers' support for health committees and draft national guidelines outlining a strong governance role for health committees. The project has been active in advocacy to reach agreement on roles and functions of Health Committees, which would need to be issued as regulations, both in the W Cape and nationally. In contrast, in the E Cape, official policy is clear on recognising Health Committees but lacks practical expression in terms of resource allocation and support. In the Ugandan context, the decentralised health system affords local officials and officers extensive powers to shape the contours of participation despite official policy. While most interviewees expressed support for the idea of community participation, there was little evidence this support was carried through in practice. As a result, participation has to be built from the bottom up, through empowerment of VHTs and HUMCs to be active agents on behalf of their communities and building strong civil society interventions.

Building civil society networks at local and national levels has helped to strengthen the work on the ground in different ways. In Cape Town, a set of activities within the Learning Network, involving Network members, has enabled capacity building for health rights and strengthening of the lobby for participation in health, for example in rural areas, where health committees have historically been absent. Linking with the People's Health Movement has expanded the call for

participation and national networks in South Africa have developed to work on Health Committee policy. In the Ugandan site, working with other local CSOs has strengthened local capacity and the ability to take community voice, using the lessons of this project, into other avenues of advocacy for the maternal health rights, has been an invaluable spin-off of the work. An important strategy for building CSO capacity has been the successful completion of exchange visits involving activists from each of the two sites in year 2, where the participants have been able to implement learnings from their visits in their own work on return. Regionally, civil society networking on participation in health has been supported by a number of complementary activities: (i) a two-day regional meeting organised in Kiboga by the project in March 2013; (ii) a Participation, Reflection and Action (PRA) training organised by EQUINET in October 2013; (iii) a regional meeting on Health Committees organised by EQUINET in January 2014. Through these meetings, the partners in this project have been able to share experiences and build regional networking to enable support for wider health system interventions to support community participation in health. Both the partners are also participating in a four-country study of participation to expand our understanding of the nature of power in participatory strategies, a project that picks up on plans made at the 2012 People's Health Assembly under the People's Health Movement, and the Ugandan partners remain involved in a global consortium, GO4HEALTH, to explore priorities for the post MDG period and how community voice can influence these developments.

A wide range of dissemination activities have been undertaken. These have included the development and distribution of materials (pamphlets, briefs, posters, reports, training manual and toolkit on health rights), hosting of a Regional Consultation and participation in two other regional meetings at which presentations of ongoing work were shared, presentations to a national consultative meeting on Health Committees in South Africa, and a wide range of capacity building activities (workshops, advocacy events, exhibitions) with other Civil Society organisations. A number of abstracts have been submitted to the forthcoming Global Health Systems Research (GHSR) conference to be held in Cape Town in September/October 2014 and presentations made at conferences in the US and South Africa. Two papers are in press and three under review with the journal Health Policy and Planning for a special issue linked to the GHSR conference.

The project has generated a wide range of research and capacity-building opportunities twelve students are working on aspects of the project, including four from Uganda and eight registered at UCT, of whom two are MPH students from other African countries. We are particularly interested in how questions of vulnerability (disability, gender and sexual orientation) are being played out in context of participation and these are being examined in different ways in these studies, amongst other topics. Additionally, the Ugandan PI is registered for a PhD at a South African university (Pretoria) examining the legal basis for participation in health and the South African PI has initiated a linked study examining motivations of health officials who have to deal with community claims for rights. Through our international links, we have been able to draw on international partners to strengthen the teaching of qualitative methods at UCT and host various academic visitors for seminar activities.

The project continues to create new knowledge in an under-researched field. We are testing out different approaches to best practice in community participation as a vehicle for realising health rights and learning important lessons for health systems strengthening.

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:

The project began with a focus on the question of how to operationalize community participation in health and characterizing how this participation enables communities to claim their rights to health. In both sites, preliminary research has indicated serious problems in the structures and system for community participation which limit their effectiveness as agents to advance health rights. Further, in both sites there is some evidence that where strong or active civil society groups support community participation structures, the quality of that participation is enhanced, when compared to state-initiated participation structures. For example, in Uganda, in those sub-counties where civil society had emerge to support the Village Health Teams (VHTs), the VHTs were more active and achieved greater progress in providing services for their respective communities, even though they were not a structure for participation, when compared to sub-counties where VHT's had been established by government independent of civil society. Civil society agency in strengthening participation is thus key.

The conceptual framework for the project is provided by an analysis of the relationship between health equity and human rights, in which inequity in health is common to both sites (South Africa and Uganda) and for which a human rights approach offers the possibility of addressing inequities. This is because human rights approaches create the space to challenge the powerlessness that renders communities and individuals vulnerable to factors that lead to ill-health. Participation provides a means to challenge the race, class, gender and other gradients in the distribution of social determinants of health and to make the health system more responsive and accountable. 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. More responsive governance mechanisms at local level are more likely to be effective in reducing health inequities.

The fundamental challenge is therefore how to enhance community capacity to engage with providers, and to assert health rights within structures intended to be vehicles for community participation, and how the capacity of service providers and managers to be more responsive to community needs can be supported.

Through our engagement with communities and services, we have come to realize that the challenge of participation and its contribution to realization of the right to health requires a deeper analysis of power and how power is exercised in different ways, at different levels and in different kinds of spaces. The differences in health systems with regard to the degree of decentralization generate additional complexity to examining community participation. In Uganda, for example, health governance is highly decentralized with the result that practices and how power is organized may differ widely across different districts. It also poses questions about how structures established for community participation articulate with power and how different kinds of vulnerabilities are inserted into the work of these structures. Indeed, the question of power also inserts itself into the very research process with questions around how knowledge creation acknowledges and involves those amongst whom the research is conducted. These analyses are currently underway through various collaborative research activities and through postgraduate student research.

The threads identified in the first year of the project remain under exploration: Vulnerability as a central concept in linking participation to rights is the subject of three postgraduate research projects in Cape Town (how disability, sexual orientation and gender interact with the work of Health Committees); the non-linear and multidimensional nature of policy formation which requires more reflexive and adaptive strategies to achieve objectives; and the unexplained

tension between oversight (governance) roles and direct provision of support services remains a subject of ongoing policy analysis and a challenge to capacity building activities.

Additionally, a better understanding of power and how power shapes and is shaped by community participation is helpful to understand successes and failures of community participation initiatives. We have found very useful the model developed by Gaventa (2006¹) in which power is conceived in three axes – level (local, regional and national or international), the nature of power (hidden or explicit) and the space in which power is exercised (invited or claimed). In both Uganda and South Africa, these analyses resonate with experiences in trying to engage with local and national decision-makers and freeing up space for communities to take action on their health rights. This will form the basis of a developing piece of research using the two research sites (Cape Town and Uganda) as case studies for mapping power in the participation process.

Secondly, a realisation emerging in the South African context, in particular, is the critical role of gatekeepers (so-called street level bureaucrats and those at higher level) whose own activist background may be a key determinant of receptivity to community engagement. This is also providing a basis for a piece of work in South Africa looking at how public health officials and elected representatives who are faced with community claims for health rights, respond and how their activist and/or professional background mediates these responses. The key role of elected officials as gatekeepers in the decentralised health system in Uganda has also emerged very strongly in preliminary research findings. Here, it is not so much an activist orientation that is important to consider, but the trappings of local governments political power.

Lastly, in the both settings, a new insight has been the importance of reconceptualising the right to health as being linked to collective entitlements of groups, rather than as individual claims for individualised benefits. The basis of much of public health and health systems development is premised on ideas of the social good and rely on principles of social solidarity. Where rights operate as liberal values that focus only on autonomous individuals, their application runs the risk of undermining health systems strengthening approaches. Exploration of the right to health within a more collectivist context has formed part of work in the LN in the past to draw on ideas from African philosophy, and this work is being taken forward in the thinking around how to empower health committees as agents of change.

These insights enrich the ongoing work under the original research planned, providing more diverse perspectives for analysis and write-up and are reported upon further below.

3.0 Research Findings

The overall objective for the study remains unchanged - to explore the hypothesis that building civil society capacity to participate in health (both 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.

Research is ongoing in both sites as outlined. However, preliminary findings are can be identified in brief:

1. Structures for community participation are vulnerable to displacement by cadres of community-based health workers in both sites. In South Africa, Community Health Workers (alternatively known as Community Care Workers or Home-Based Workers) are

¹ Gaventa J. (2006). Finding the Spaces for Change: A Power Analysis. *IDS Bulletin* 37: 23-33

often subsumed in the same breath as Health Committees, as if these cadre of health workers could substitute for community participation. Similarly, in Uganda, Village Health Teams (VHT's) have emerged as the service equivalents of CHW's, substituting for the weak but more institutionally appropriate Health Unit Management Committees (HUMCs). This slippage between CHW/VHT and HC/HUMC represents a potential backsliding by policy makers on any commitment to true community participation. In practice, members of community participation structures often are also Care Workers in some form, and sometimes join participation structures in the hope of securing paid employment as Care Workers. This undermines the oversight function of participation structures if committee members are also active delivering services.

2. Secondly, community awareness and engagement with the structures intended to be their vehicle for participation is variable. The legitimacy of these structures is dependent on a number of factors, including the process by which these structures are created, their efficiency in generating benefits for their communities and their ability to engage the full breadth of interests in the communities. This reinforces the need to ensure that participatory structures are able to engage with issues of diversity in the fullest sense. Further, the composition of such structures is crucial, given the role of power in participatory politics.
3. The question of incentives for participation remains a complex one but critically important for sustainability of participation processes. Different models are in use and inconsistently so. Further research to tease out the best practice available is critically needed.
4. The value of participatory approaches in research has emerged in both sites, with information being generated that would otherwise have remained invisible. Through the detailed and careful focus group work in rural Uganda and the novel work on photovoice in the poverty-stricken urban areas of Cape Town, the researchers involved have been able to find ways to give voice to those most affected by human rights violations – in narrating their stories and needs in calling for strategies to redress their vulnerability. These findings confirm that agency on the part of those most affected is a key principle of a human rights approach to health.

4. Project Implementation and Management

The project management continues to be shared between the South African and Ugandan counterparts (Leslie London and Moses Mulumba) with respective local research teams and coordinators. Regular communication through email and skype has been used to ensure consistent adherence to project timelines, discuss new developments and review progress and findings.

In 2013, Moses Mulumba registered for a PhD at the Centre for Human Rights at the University of Pretoria. To manage his investigator responsibilities to the IDRC work, CEHURD hired a Technical Collaborator (TC) to work closely with field teams as well as the project officer. The TC and project officer ensured that all data was transcribed at each stage of the investigations. This data was shared with the Uganda principal investigator (Mulumba Moses) to enable him have a feel of the raw data before further analysis. Additionally, the project officer, TC and field teams held pre- and post-field visit meetings with principal investigator to agree on and update each other on field visit objectives and also to evaluate and monitor their activities and field interventions during and at the end of each field visit. Principal Investigator is writing a thesis on the same subject and spends time in the field with the team.

In April 2013, Leslie London undertook a 9 month sabbatical in the US, partly to pursue research linked to the current project, and appointed Dr Chris Colvin to manage the day-to-day aspects of the IDRC work whilst he was away. Although out of Cape Town, Leslie London continued

participating and liaising with the Ugandan colleagues whilst on sabbatical although the day-to-day management responsibilities were shouldered by Dr Colvin. Dr Colvin has handed back responsibility in January 2014.

The research teams have been stable in both sites, with Nicole Fick continuing as the research coordinator in the South African site and Juliana Nantaba as the designated project officer for this project in the Ugandan site. CEHURD also employed the services of a TC to provide Technical support on the project. CEHURD also benefited from the technical skills and support of a Center for Disease Control (CDC) Fellow currently hosted at CEHURD for two years from the Makerere School of Public Health. Research and financial support from the School of Public Health and Family Medicine at UCT continues to be provided through designated staff in the school, while in Uganda, administrative, finance and communication support is provided by the team at CEHURD. In 2013, because of additional research activities and additional funding from an EU grant to do work in South Africa, an administrator was appointed in who has been able to provide additional administrative support to the IDRC work in Cape Town. Consistent with project plans, two trainers have joined the project in Cape Town to implement the training components of the study.

Progress on the programme of work for this project is outlined below. Each set of activities is discussed below in turn in relation to implementation:

a) Training of community structures has been a key feature in both sites. In the Western Cape, we have developed and implemented a curriculum for health committees. This has been done through a task team established with the Cape Metro Healthcare Forum, through which a training guide and instructor manual has been developed which includes five chapters on Community Participation, what is a Health System, Human Rights, Effective Health Committees and Leadership. Two trainers were appointed in the course of the second year in the Western Cape, and, thus far, we have trained 55 Health Committee members from 9 committees in the Klipfontein sub-district and 18 representatives from 7 sub-districts within the Cape Metro district using these materials. Additionally, we have used these materials to train approximately 190 members from 49 committees in a short refresher course and 9 committees with more in-depth training in the Nelson Mandela Bay Metro district in the Eastern Cape, through the EU grant. Linked to the training has been the development of other tools, including a Health Committee checklist and template Health Committee agenda to support Health Committees in their ongoing work. Evaluation of the training is the subject of MPH student mini-dissertations in both the W and E Cape (see section below on student involvement) and will be reported on in more detail in the final year's report. The evaluations will include examination of questions related to the role of incentives in the sustainability of participation initiatives, and the gender issues inherent in the caring and advocacy roles required from health committee participants.

What has emerged from the W Cape experience is the need for ongoing support and mentorship of trained health committee members, and the adoption of a training model that establishes Learning Circle to follow up with trained committee members. Thus far, 12 participants have been involved in Learning Circles providing ongoing support and responding to new training needs identified. Also, we are pursuing a Train-the-Trainer approach in further follow up, in which new materials, identified as a need by trainees, is workshopped. For example, the current manual has been supplemented by materials on diversity, race, gender and sexual orientation and is planned to include additional materials explaining some of the key planning and monitoring tools used in the health department to empower committees to engage more meaningfully with these functions.

The training to Health Committees is certificated, but we have not succeeded in securing SAQA accreditation for the training that would enable transfer for a lifelong learning pathway because of the difficulties of negotiating the SAQA system.

As reported last year, the implementation of the training of health committees was delayed by changes in the policy context in the Western Cape, in terms of which the Health Department has essentially stepped back from its support to existing structures of Health Committees. There is no consensus at provincial level regarding the roles of health committees in the W Cape and, seemingly, no political will to address this amongst key line managers. For that reason, service buy-in to the training in the Western Cape has not been established. However, with the process of developing the new Provincial Plan (Vision 2030), we are hopeful this will open the door to progress on Health Committee policy, given signals from the policy and planning directorates in the services. The extension of training and the use of the manual in the E Cape has also been more feasible because policy support has been more forthcoming from the Nelson Mandela Bay Metro health department. It has also opened the possibility of implementing in a different site if the policy door remains shut in the Western Cape (see below).

In Uganda, training of members of community structures was preceded by a set of Focus Group interviews, both with Village Health Teams (VHTs) and Health Unit Management Committees (HUMCs). These FDGs helped identify a number of issues including the capacity gaps and existing challenges and how they could be addressed. Training and capacity building on rights based approaches to health and community participation was then undertaken in each of the two target districts, Kiboga (50 participants) and Kyankwanzi (60 participants). The groups trained included HUMCs, VHTs and health professionals. CEHURD developed the training curriculum from the right to health pamphlets that were adopted in the first year and from a training manual titled, “Gender and Human Rights for Health professionals” that was developed for health workers and professionals. This was part of a collaborative project undertaken by CEHURD with the Ministry of Health and World Health Organization country office. CEHURD conducted training for health workers and professions in each of the districts of Kiboga and Kyankwanzi. The trainings also were opportunities to have trainees share their share experiences in light of the concepts of the right to participation and community participation. Numerous difficulties in the working conditions of VHTs and in the ability of HUMC members to be effective community representatives were identified in the training

As pointed out in the previous year’s report, the possibility of using internet-based training has been precluded by the failure to secure additional support for York university input to this aspect. Moreover, the practicability of internet access for community members remains a challenge, not only in rural Uganda but even in urbanized Cape Town.

b) **Building Civil Society networks** in which Health Committees are supported by other Civil Society Organisations continues to be an important focus. In the South African site, this has continued through different strategies. Firstly, within the Learning Network, 2 Review and Reflect meetings were held in year 2 to provide opportunities to share and support organisations within the LN in learning from their health rights practice. The meetings also helped to identify materials needed for civil society advocacy and planned engagement in the GHSR meeting in 2014. For example, in the rural W Cape, we have seen the successful establishment of a health committee in the rural town of Klappmuts, partly through discussions within the LN about the role of health committees and there has been further engagement through Women on Farms Project in setting up health committees in other rural sites in the province. A study of denial of access to health care amongst farm workers during the 2012 farm worker strikes by a visiting intern recruited through the LN was presented to the Health Department in 2013 and included recommendations for the establishment of and better use of Health Committees for rural communities. This piece was also published in a debate in a weekly newspaper as part of an

advocacy strategy by the People's Health Movement with whom the LN has engaged around health committee support. Women on Farms has been successfully using the toolkit as a mobilizing and action-generating strategy in its work in empowering farm women to be agents of change. In the course of the year, approximately 70 farm worker women were trained with the toolkit, and the activism of their work reinforced. Support was also provided to The Women's Circle for their Women's Day activity focused on combating violence against women, at which there was wide dissemination of the LN Right to Health pamphlets.

Other ongoing intra-LN work has included engagement by the Western Cape branch of Epilepsy South Africa with health committees in local facilities to raise issues of disabilities, and by Ikamva Labantu, in accessing service opportunities in Khayelitsha. The LN toolkit and pamphlets are widely used by member organizations. For example, Ikamva Labantu has trained about 800 people in a 9-month training cycle while the Cape Metro Healthcare Forum has reached about 120 members through toolkit training. Through reflection in the LN forums, better strategies around health rights can be developed and implemented. The third year of the project will also see exchanges implemented between health committees in the Western Cape and the Eastern Cape, so as to share experiences in how models work in different settings and how obstacles might be overcome.

Externally, the project has linked up with other CSO's active in this area through participation in policy forums and advocacy actions. The Black Sash, Cell-Life and the Health Systems Trust are all active in different aspects of strengthening patient voice and monitoring systems in health nationally and we have been exchanging materials and tools. In September 2013, the LN shared a platform with the Metro Health Care Forum at a public meeting organized by the South African Human Rights Commission in the West Coast District of the Western Cape Province aimed at advancing communities' understandings of the right to health and the role of participation structures in realizing health rights. In September, the LN ran a workshop at the Public Health Association of South Africa Conference on participatory methods for community mapping, based on some of the experiences of LN researchers and in preparation for the Harare meeting on participatory approaches in research.

In Uganda, the project has engaged with local NGO's and civil society groups in Kiboga to strengthen the impact of training with HUMCs and VHTs. In particular, working with World Vision, CEHURD has started to explore sharing of curricula and training materials to strengthen local access to services. Given preliminary evidence that where civil society is active, community structures are more effective, this strategy is likely to multiply benefits for local communities.

Internships were implemented in year 2 for participants in the health committee work from both South Africa and Uganda. Two Cape Town-based members of the LN spent 10 days in Uganda hosted by CEHURD following the regional meeting in March 2013 (see point h below) during which time they visited the field sites in Kiboga and Kyankwanzi and interacted with local project participants. The interns also visited Gulu district in northern Uganda with an aim of comparing how the different sites in the health systems operate with respect to community participation. The reciprocal visit in year 2 from two CEHURD members took place in April 2013 over a 10 days period during which time, they visited 3 local health facilities, met a primary care service director to discuss participation structures, visited parliament and engaged with local CSO's to share experiences.

Regionally, there have been valuable networking opportunities to strengthen Health Committee work. The LN participated in a regional activity held under the auspices of EQUINET from the 30 January - 1 February 2014 in Harare, which was specifically geared to strengthening health committee work in the region. This workshop was for organisations involved in training and strengthening Health Centre Committees in east and southern African countries. The outcomes of

the meeting highlighted the need for strengthening the effectiveness of Health Committees, sharing resources and good practice, and building supportive networks. Although CEHURD was meant to attend the meeting, it was not able to make the meeting, but did get feedback from the Ugandan participant at the meeting. The meeting committed to ongoing regional exchange to share experience, promising practice and resources and to future review meetings. As a result, the project intends to host its next regional meeting as a larger activity piggy-backed on to the Global Health Systems Research meeting in Cape Town in September 2014 (see point (h) below) to provide a platform to take forward the recommendations made at this workshop. (See report at <http://www.equinetafrica.org/bibl/docs/EQ%20HCC%20Mtg%20Rep%20FEB2014.pdf>).

A second related regional networking activity was the participation of the LN and CEHURD in an EQUINET workshop to explore how Participatory Reflection and Action (PRA) approaches could be used to raise community voice in strengthening the functioning and resourcing of primary health care (PHC) systems in the region (see report at <http://www.equinetafrica.org/bibl/docs/PRA%20Reg%20Mtg%20Rep%20Oct2013.pdf>). This meeting was held in October 2013 and contributes directly to the engagement with Health Committees in both countries through facilitating reflective processes to strengthen community voice. These skills have been incorporated in the work in both sites through reflective research and documentation processes.

Lastly, at global level, the People's Health Assembly (PHA) involvement by CEHURD and LN proposed some global networking through PHM. Whilst on sabbatical in the US, the PI (LL) follow up on a collaboration with Dr Ben Meier at the University of North Carolina in Chapel Hill which would take the PHA plan further, in the form of a four-country case study of social participation. The participants in this project are the LN and CEHURD, Walter Flores, a PHM activist from Guatemala, and Ben Meier, leading a case study from Vermont, USA. This project is funded by a small grant at UNC, but complements the work with health committees in Uganda and South Africa by juxtaposing the experiences in South Africa with other international contexts.

Regional and global activities related to work around strengthening civil society engagement in health rights more broadly are detailed under point (h) below.

c) Progress in **engaging with health officials and policy-makers** to lobby for effective policies and structures to empower health committees has been uneven.

In the Western Cape, the policy gridlock remains unchanged despite inclusion of the important of the patient experience and community participation as a strategic priority in provincial policy. No progress has been made on finalizing a Health Committee policy, nor in developing regulations as required by the National Health Act. The LN and CMHF submitted comments on the first draft of the Provincial Health Plan in November 2013, which emphasized the governance role of Health Committees and their involvement in local systems to give community voice. Although included in earlier drafts of the Plan as it evolved, these specific suggestions were removed from later drafts of the plan issued for public comment and community participation was left at a general level in the document *Vision 2030: The road to wellness*². The establishment of the District Health Council structure has continued to serve as the substitute 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

² For example, the text describes on page 35 a commitment to making community participation structures “more functionally effective as conduits of community concerns” and to “more effective communication and information sharing, capacity development within these structures and deepening of the relationships between them and the Department, based on trust and mutual respect.”

throughout the current engagement with policy makers, evident in a desire to control the terms and form of such participation that results in long delays in any movement towards institutionalizing community participation.

Despite this, some of the key managers within the Provincial Health Department and within the City of Cape Town have been very supportive of the work, welcoming inputs to internal policy discussions (e.g. two presentations within the Health Impact Assessment Directorate, in November 2012 and in March 2013) and, in the latter case, offering access for some of the piloting work, as detailed below (point (e)). A dialogue on community participation was held in March 2013 at which officials from both the City of Cape Town and the Provincial Health Department presented positions on community participation and the role of Health Committees. Although both were supportive of engagement and the principles of community participation, this has not reflected in progress in actual policy and support for Health Committees.

In contrast to provincial level, the National Department of Health has been much more interested in advancing the status of Health Committees. In August 2013, the LN was invited to a national workshop to develop guidelines for Health Committees. At the workshop, the LN presented a national rapid appraisal of health committees and there was discussion of different participants' experiences and recommendations and a draft guideline released for comment. The LN also presented on its current training model and the LN facilitated participation by Health Committee members. The LN submitted comments and the process of finalizing these guidelines is continuing. More recently, the LN has been invited, through the Health Systems Trust, to co-author a chapter of the South African Health Review on Health Governance, on the advice of key advisors within the National Department of Health. The invitation from the South African Human Rights Commission to the LN to co-host a workshop in the West Coast district for local health care providers signals also some level of acceptance in other policy and advocacy structures of the importance of community participation in health.

A policy brief based on the findings of the research in the Western Cape with Health committees has been distributed to Health Committees and will be submitted to policy-makers once there is more clarity on the direction of national health with regard to community participation structures.

We have continued to liaise with the Chief Director (CD) for the newly created Office for Standards Compliance (OSC) created in the National Department of Health, as a result of which training on understanding the set of standards used to audit health facilities is to be included in updated modules for health committee training. It is envisaged that if community oversight structures understand and are empowered to engage with services, they can use the National Core Standards and the audits using these standards under the OSC to enhance service accountability and responsiveness at a local level. The LN has also set up an advisory body to give input to the work on health committees with high-level health department participation in the advisory board.

In Uganda, the training of VHTs and HUMCs has been followed up by an extensive programme of meeting local leadership. This has included meetings with the District Health Officer, District Health Inspector (DHI), District Health Educator, Medical officers from the Kikolimbo Health center, the HUMC chairperson for the Kikolimbo health center II, the Chairperson LCIII and the sub-county chief of the Wattuba sub-county in the Kyankwanzi District. In the Kiboga district, a similar set of local officials and elected officers were canvassed, including the health in-charge at the Nyamiringa health center II, the Chairperson LCIII Kapeke sub-county and the District Health Officer (DHO) for the Kiboga District. In general, while most officials and officers were supportive of community participation, in practice, there was little practical support in terms of providing resources, considering community views, and ensuring functionality of the community participation structures. Thus commitment to community participation in health governance remains largely token which presents an opportunity for Civil Society intervention.

d) **Training for health workers** in rights-based approaches to health and community participation has been uneven in the two sites.

In the Western Cape, service reluctance to commit has delayed access to staff for purposes of training. Although collaborative relationships have been set up with the District Innovation and Learning in Health Systems (DIALHS) project, we have not been able to move any faster in piloting materials because of the DIALHS project's own priorities and timelines. The Masters in Public Health student doing his dissertation on facility managers' engagement with participation structures, who may have identified 'best practice' opportunities for interview, is still finalizing his protocol because of delays caused by work obligations in his home country, Zambia. Because of these delays, the intended plan to produce a training DVD by the end of year 2 has not materialized. However, we intend to locate an appropriate base to complete this by year 3 of the project and will carry budget forward for this purpose.

Nonetheless, there has been some training of health facility managers in the Eastern Cape as participants in Health Committee training. Moreover, the LN has collaborated with the DIALHS personnel at the University of the Western Cape to plan a Winter School course on health committees targeting providers and managers. This was meant to be held in 2014 but will be held over to 2015 because the UWC organizer is ill and will be unable to host the course in 2014.

In Uganda, it has been easy to access health workers in the two study sites and training with health workers using the Ugandan manual has been successfully completed in both sites. The pretesting process of the Health and Human Rights Manual developed in the first year provided an opportunity to train over 150 health workers in over six districts. The health workers also provided feedback on the content of the manual including particular case studies to include in the training guide of the manual. CEHURD has also been invited to inform the revision of the medical curriculum to include a right to health component in the medical school. This process has involved the training of various lectures in the medical and public health schools.

e) **Development of local systems to ensure health committee effectiveness** is ongoing but challenging. In the Western Cape, we are working with one health committee in Salt River, building a relationship with a view to strengthening their capacity to jointly manage complaints with the facility staff. Because of reluctance from the Chief Director, we have been unable to implement fully the idea of a "public health" ward round first envisaged for this activity. A second strategy to be pursued in the third year will be to document health committee practice where complaints management does form part of the Committee's work. Albeit a minority of committees in the Western Cape, there are some committees that do report active engagement in the complaints process. We aim to identify potential lessons for other committees from this review, whilst actively testing the potential for deriving a systems understanding from review of complaints in the Salt River facility.

In Uganda, we established that HUMCs are the key structure for community participation given that VHTs, although established as a community participation structure, mostly work as service providers. Working with the trained HUMCs will enhance their ability to hold services accountable. The project will be monitoring the ability of these structures to engage with and manage complaints following their training. CEHURD has also been requested to facilitate the process of re-orienting the HUMCs in some sub counties of Kyakwanzi district with a specific focus on their Terms of Reference and also engage the appointing authorities to fill some of the vacant position in Health Facilities where the vacancies exist.

Dissemination of experiences within the Southern and East African region has taken the form of the production and distribution of materials on the right to health, both electronic and hard copy;

hosting of a regional meeting to share experiences and plan a dissemination strategy; and building strong local, national and regional networking on the right to health generally.

f) By year 2 of the project, the LN toolkit on the Right to Health had been translated into Xhosa and Afrikaans (local W Cape languages) and, in the course of 2013, was further translated into Portuguese for use in Mozambique and Angola, by an attendee of the PHA based in Angola and can be found on the LN website. Plans in 2014 include re-working of the toolkit into an advocacy tool for civil society. Additionally, the Ugandan collaborators have used the LN toolkit and adapted them to the Ugandan context producing locally useful tools for action; Approximately 50 toolkits and over 10 000 right to health pamphlets were distributed to other CSO's. As a result of increased demand, an additional print-run of 50 000 copies of the series of right to health pamphlets for distribution in communities was completed.

The LN also printed an English-language pamphlet summarizing the findings from its audit of Health Committees (see <http://salearningnetwork.weebly.com/resources.html>) and is producing a poster which could be displayed at health facilities to popularize health committees in local communities. Future work will translate these into other local languages.

Other materials produced in 2013 include a training manual and facilitators guide for the training programme underway, and in the latter part of 2013 and early 2014, additional training materials on race, gender and sexual orientation, materials prompted by progress in the Learning Circles set up after training. Additionally, a set of 20 public banners capturing women's experiences was developed within a Photovoice project. In the project, women from 3 chapters of The Women's Circle were given disposable cameras to take pictures in their communities, firstly, of what the right to health means, and secondly what human rights mean to them. Women's narratives about the pictures they took was carefully captured as part of a photovoice research activity and incorporated into the display banners to produce a visually appealing but narrative account of the challenges faced by LN members in realizing the right to health.

In Uganda, CEHURD has been instrumental in developing a training manual on human rights and gender (based on the LN toolkit) aimed at health professionals, which was done in collaboration with the Ministry of Health and WHO. CEHURD spear headed the pre-testing process for the manual through training and consultative workshops with health professionals at the local government level from over 6 districts (not including the project districts) so as to ensure the participation and contribution of health professionals to the formulating of the manual. At the national level, a national level consultative meeting was also conducted to validate the document. We anticipate that this document will be published in 2014 and made an official national document. The pamphlets developed have also been disseminated in the districts of focus during the trainings. A Discussion paper has been developed on the preliminary findings of the project life so far. After the editorial work, this will be posted on the website and shared widely with the regional and global partners.

g) The annual **Regional Consultation** was held in the first few weeks of year 2 (28th Feb to 1st March), so as to piggy-back the meeting onto another event taking place in Kampala around that time. The Regional Consultation took place in Kiboga district of Uganda, the site of the CEHURD field work, and was linked to a day of field visits to engage and interact with local stakeholders. The meeting heard presentations from participants from South Africa, Kenya, Uganda, Malawi, Zambia and Zimbabwe. While there were many similarities, there were also key differences in the relationship between health committees and facilities, and the extent to which they became involved in service delivery rather than oversight. A report from the meeting is on the LN Website (at URL <http://salearningnetwork.weebly.com>) and continues to guide regional collaboration in the area of Health Committes. The meeting helped to provide the basis

for an EQUINET conference on health committee, sponsored by Medical International, and one in which participated representatives from Zimbabwe, South Africa, Uganda, Zimbabwe, Kenya, Democratic Republic of Congo and Malawi.

h) **Building strong networks on the right to health more generally** has taken place at local, national, regional and international levels.

At *local level*, the project has undertaken a number of activities aimed at building Civil Society capacity to address the right to health more generally.

In South Africa, the LN has run training on the use of the Right to Health toolkit, reaching 39 participants from 22 civil society organizations in a workshop held in March 2013 and continuing to support these CSO's in their subsequent use of the toolkit. The LN also co-hosted with the People's Health Movement a public event examining the role of Health Committees as agents of change in October 2013. The public event, attended by about 170 participants from a range of academic, service and civil society contexts, combined the launch of the Photovoice exhibition in which women from a LN member organisation, The Women's Circle, presented their photos about health and rights, with PHM-linked advocacy for health rights and community participation. Since hosting the exhibition, the banners with the photos and narratives has circulated through the townships in Cape Town where the photos were taken with a view to prompting reflection the question of health rights. The exhibition has also been presented in other forums, such as, for example, a symposium on health innovation at the University of the Western Cape in October 2013. The photovoice exhibition represented the outcome of a collaboration with Social Anthropologists to bring the exhibition to fruition, a collaboration which is ongoing, and, more recently has contributed to a Medicine and Humanities course running at UCT, developed as precursor to multidisciplinary Masters in Medical Anthropology.

Additionally, the LN presented at a South African Human Rights Commission organized intervention aimed at enhancing stakeholder understanding of the right to access health care in a rural district of the Western Cape in October 2013. However, this has not been followed up in any systematic way.

At *national level*, the project has contributed to building **strong networks on the right to health in the following ways:**

In South Africa, the LN organised a national meeting to discuss a draft Health Committee policy in August 2013 attending by other Civil Society and Research groups including the Black Sash, Treatment Action Campaign, People's Health Movement (PHM) and the Health Systems Trust (HST). The outcome of the meeting was a joint submission on the Health Committee policy between the LN and HST, and the start of a loose network of organizations working on similar issues related to Health Committees,. Linked to this discussion was a decision to hold a week-long short course at the University of the Western Cape Winter School in July 2014 and a draft outline and plan for this course was developed in the course of the year. However, because of illness of one of the key organizers at UWC, the course will held over to 2015. The course will serve as an important avenue to consolidate the network of groups working on community participation as a health rights issue, as well as providing skills to manager and front line workers in the field. The course will also provide another platform for civil society engagement with the services to strengthen the health system.

A second stratagem being developed in year 2 but to take place in year 3 is the idea of a national colloquium on health committees, which will be time to piggy-back onto the Global Health Systems Research conference in Cape Town in September 2014. Planning has already begun for this national meeting to advance consensus on the roles and functions of health committees.

In Uganda, CEHURD remains committed to a range of activities involving civil society action for the right to health. These include litigation campaigns in regard to maternal health, and pressure on issues such as access to abortion, access to essential medicine and challenges to restrictive intellectual property rights measures, access to information and access to pain treatment.

What is relevant is that CEHURD has used lessons learnt during the second year of the project in its other ongoing advocacy. For example, it has taken up a campaign to improve access to essential medicines by influencing positive change in intellectual property rights legislation and engaging community and civil society stakeholders around issues relating to the right to health. This work assessed elements of access to HIV medicines and other essential medicines at the community level in Buikwe district, central Uganda, as an initial part of a process of engaging community stakeholders around issues of access to essential medicines as a fundamental aspect of the right to health. The rationale of this work was to give communities an opportunity to contribute to, and participate in, setting an advocacy agenda to improve access to essential medicines at the community, district and national levels. In this work, community stakeholders reflected on their experience with the existing medicine access structures and systems and started to dialogue on issues relating to their health. The participatory methods learnt in this project helped to strengthen that campaign and ensure civil society input to an important health rights campaign.

As outlined above, at *regional level*, there have been a number of important regional networking opportunities. The LN and CEHURD participated in a regional workshop in October 2013 under the auspices of EQUINET on Participatory Reflection and Action (PRA) approaches, the lessons of which are now being built into the work of the partners. Additionally, a regional meeting under the auspices of EQUINET was held in January 2014, attended by the LN, to explore strengthening of health committee work in the region, one outcome of which was a commitment to building supportive networks of organisations involved in training and strengthening Health Centre Committees in east and southern African countries. We therefore plan to consolidate this through a regional follow-up workshop piggy-backed onto the Global Health Systems Research (GHSR) conference in September 2014, which is focused on people-centred health systems. Lastly, the LN and CEHURD are collaborators in a four country study of social participation initiated through a partnership between the LN and researchers at the University of North Carolina in Chapel Hill, which will further consolidate joint work on the project. These are regional networking activities all directly linked to the content of the current project on Health Committees.

Additional to these activities, we have revisited previous collaboration between the LN and the PI for CEHURD on a project investigating the role of parliamentary committees on health in East and Southern Africa in advancing health rights. This work was conducted for EQUINET in 2008 and raised important questions about the engagement of Civil Society and the legislatures in the region, which are beginning to emerge in this project as potential obstacles to advancing community participation as a vehicle for health rights. The data from that study (see <http://www.equinet africa.org/bibl/docs/DISS74parlrights09.pdf>) have been reanalysed and submitted for presentation at the Global Health Systems Research Symposium in Cape Town, September 2014, and as a manuscript to a special edition of Health Policy and Planning for the conference.

Lastly, at *global level*, the project has been active in building networks in the following ways. The follow up to the PHA involved a plan to map social participation across PHM members. We have been able to undertake a small aspect of this ambitious plan through a small grant of Ben Meier, a researcher at the University of North Carolina in Chapel Hill, which will bring together case studies from Guatemala, Uganda, South Africa and the US in a shared research activity

examining the role of power in participation. The outcome of the activity will be shared with PHM as part of its organizing between PHA's and disseminated via its PHA-Exchange listserv.

We had hoped to be able to host a workshop at the GSHR but the proposal for a workshop on community participation was not accepted by the GSHR scientific committee.

The project remains one which attracts international visitors. In April 2013, a visiting research from the University of Coimbra, Portugal, Alice Cruz spent time with the LN in Cape Town as a precursor to a longer visit planned in future. We continue to enjoy the benefits of international academic networks. Professor Fons Coomans from the Centre for Human Rights at Maastricht visited in March 2013, met with postgraduate students and ran two seminars, one on the Right to Food in International Human Rights Law, and one exploring the dimensions of the Right to Benefit from Scientific Progress. Our other visitor was Dr Maria Stuttaford of the Institute for Health at Warwick University in February 2013 during which time she met with students, engaged with staff in further developing qualitative methods teaching and presented a seminar on "The Right to Health and Plural Health Seeking Behaviour." She is also leading a linked project that is proposing a new international collaboration related to the right to health, participation and evidence. This will be a spin-off of the current work on participation. The Project PI also initiated a study of health manager's orientation towards community claims for rights as part of his sabbatical in the US in 2013, with a comparative study of health officials in the US and in South Africa that will continue with South African data collection in 2014.

Another area in which CEHURD has used the project as a platform to build strong networks on the right to health more generally, has been through its engagement with the GO4HEALTH consortium, an EU-funded project to examine the prospects and options for post-MDG global goals. One of the domains of inquiry for the GO4HEALTH project is, "community participation in health." CEHURD led community consultations on the post 2015 MDGs Agenda under the GO4HEALTH and co-ordinated the three African country studies in South Africa, Zimbabwe and Uganda. This project was able to generate the base for methods and information needed for this GO4HEALTH consultation, and enable consolidation of international contracts around the right to health for the CEHURD participants.

5.0 Students and capacity building

Students are active in both Cape Town and Uganda on the project. Funding has been made available to provide bursaries for many of these students to cover fees. In other cases, students have been able to access other sources of support for their participation.

In total, there are 12 students currently working directly on the project, and 2 students and a post-doc working on related activities.

Of the students on the project, 9 are registered in South Africa (8 at UCT, and one, a PhD, at the University of Pretoria) and 3 registered in Uganda (1 each at Makerere University, Uganda Christian University and the International Health Sciences University. In Uganda, the findings from our student research have also contributed to informing our community engagements planned for the last year of the project. Students will also be engaged in CEHURD's activities to share experiences on their research especially on community participation for marginalized groups (PWDs) and that of Urban-poor settlements.

There were two approaches to the project to pursue a PhD to explore gender issues and from a post-doc interested in gender and rights. However, neither approach has been followed through.

The prospective PhD student changed her mind about relocating to Cape Town and the post-doc was unable to find funding commensurate with her needs to take a post-doc position.

There have been a number of spin-offs in terms of capacity building.

Firstly, Dr Stuttaford has continued to develop qualitative research capacity at UCT and has helped to set up an additional qualitative research module on its MPH. Secondly, Dr Muller, the post-doc working on issues of sexual orientation has made proposals within the UCT Health Sciences Faculty regarding undergraduate teaching and has received funding to hold a conference in 2014 on "Heteronormativity and Health: Education and Practice", to strengthen LGBT people's health rights through introducing the issue to health care workers' practice and education. Thirdly, the Ugandan PI, Moses Mulumba, has been able to access a doctoral programme at the University of Pretoria (Centre for Human Rights) with Prof Ngwenya as supervisor.

As pointed out in the year 1 report, no other funding support was secured for Canadian partners. Prof Saunders at York University has been unable to secure funding to support development of a globalization and health module. It is therefore unlikely this output will be achievable in this grant.

Table 1.0 Students on the Project as at Feb 2014

Name	Institution where registered	Gender/race	Degree	Topic and explanation
Wendy Nefdt	University of Cape Town	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	University of Cape Town	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 and has started data collection
EvaristoKunka	University of Cape Town	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
Nkandu Chikonde	University of Cape Town	Black Male	MPH (health systems)	The effectiveness of health committee training in the W Cape (title still in development). This project will evaluate the effectiveness of health committee training in the W Cape and the motivations of health committee participants. The student is still

				developing the proposal.
Carmen Gerber	University of Cape Town	White female	MPH (General track)	The effectiveness of health committee training in the E Cape (title still in development). This project will evaluate the effectiveness of health committee training in the E Cape and the motivations of health committee participants. The student is still developing the proposal
Janet Austin	University of Cape Town	White female	MPH (General track)	The role of gender in the work of health committees <title still in development> This project will evaluate how health committees engage with gender issues in their roles. The student is still developing the proposal
Gimenne Zwama	University of Cape Town	White female	MPH (General track)	Evaluation of training to health care workers The student is still developing the proposal
Nicole Fick	University of Cape Town	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, who is also the project research coordinator, is registered and is in the process of data collection.
Kerry Vice	University of Cape Town	White female	MA SocAnthro	Girls and Toilets: Menstrual Hygiene and Public-Private Spaces in an Informal Settlement. This project explores young girls' experiences of menarche in the context of inadequate sanitation facilities in the township near Hermanus.
Jen van Heerden	University of Cape Town	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 completed her thesis in 2013.
Alex Muller	University of Cape Town	White female (German)	Post-Doc	How do health committees view the needs of gay/ lesbian patients attending health facilities? This project explores issues of vulnerability and rights. Proposal is approved, data collection is ongoing.
Nsereko Arthur Junior	Makerere University	Black Male	Masters in Law	Assessing the Role of Community Participation in Governance and Health Systems In Uganda; A Case study of Kyankwanzi District; Study completed.
Monica Wambugu	International Health Sciences University	Black female	MPH	The Right to Community Participation as a tool for Realizing the right to health for persons with disabilities Study completed.

Mugero Jesse	Uganda Christian University	Black male	Masters in Law	The Contribution of Community participation to the realization of the right to health; A cross sectional study of selected Urban settlements in Kampala, Uganda*. Study completed.
Moses Mulumba	University of Pretoria	Black male	PhD	The legal basis for community participation in health; Student registered; proposal to be presented in April

* Note: Student changed topic in 2013 on advice from supervisors – not same as reported in year 1 technical report.

6.0 Technical, financial and administrative issues

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 staff at UCT are familiar with the needs of the project and are providing the requisite support. Communication between the South African and Ugandan partners has been uncomplicated. As indicated, Prof London was on sabbatical in 2013 and Dr Chris Colvin managed the project on a day-to-day basis while Prof London was away. Prof London has taken back leadership of the project in 2014. Mr. Moses Mulumba has taken on PhD studies but has put in place mechanism to enable him to continue leading the Ugandan research whilst finishing his PhD.

The project is within budget for year 2.

For the Cape Town site, expenditure for year 2 was lower than planned for a number of key reasons. This is detailed in an annexure to the financial statement for UCT.

7.0 Project Milestones – in relation to proposed schedule

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

Table 2.0 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	In South Africa, services in the W Cape have declined support; we have initiated training through the CMHF. In Uganda, sites successfully chosen
Completion of first round of health committee training (SA)	Month 18	First round of training in Klipfontein sub-district completed by 24 months
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. Training successfully undertaken for VHTs and HUMCs in each district. PDCs were dissolved and now mostly serve as VHTs
Follow up meetings with the VCT's and PDC's together with the community (Uganda)	Month 36	On track for Month 36; Follow up will be done with HUMCs, VHTs and Health professionals

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 were made to other civil society forums in year 2
Holding CSO meetings (Uganda)	Month 6, 24, 36	Ongoing
CSO activist internships: exchange 2 per year SA&Uganda for 2 weeks	Month 12, 24, 30	Two exchanges completed in year 2; two planned for year 3
Dissemination of policy brief to key stakeholders in civil society and government (SA and Uganda)	Month 36	In SA, policy brief has been circulated to health committees; will be further distributed to policy stakeholders; On track for Month 36; In Uganda, 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	Given policy changes and a draft guideline produced by the SA Dept of Health, we have held off on engaging parliamentary structures until more clarity on the ground; will complete this in year 3, along with national colloquium.
Strategic lobby meetings with policy makers (Uganda)	By month 30	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 (SA)	By month 24	We have not been able to secure W Cape Health Department buy in yet but have included some managers in our Health Committee training; Will continue to work on this, perhaps in the W Cape if W Cape remains inhospitable.
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	W Cape provincial health department declined to support this; have one site from the City of Cape Town Health Department; Will document good practice elsewhere if prevented from intervening
Roll-out of the model to other sites and districts (SA)	By month 36	Unclear if roll out possible in SA given policy hiatus; On track in Uganda 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	A total of 12 students are directly connected to the project, including two PhDs and 10 Masters students.
Dissemination of pamphlet/s on health committees to Civil Society structures	By month 18	Pamphlet was produced and distributed. A complementing poster is under development.

Regional stakeholder meeting of health and civil society	By month 12	Regional stakeholder meeting of health and civil society (SA and Uganda) was held in month 13
2 nd regional meeting of health & civil society	By month 24	Planned to have larger meeting in Sept 2014 to combine regional meetings in year 2 and year 3 linked to the GHSR conference to take advantage of economies of scale; EQUINET convened a regional meeting in Jan 2014 so no need to have duplicated meetings.
3 rd regional meeting of health and civil society	By month 36	as above
LN participation in the 3 rd 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 3 rd 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. Spin-off case study project initiated

In general, most 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 and manual produced
Revised training programme and materials for health committees based on initial experiences and evaluation	Month 18	Piloting has been completed, revisions made, will be printed early in year 3; manual in use since mid 2013.
Web-based training module following feedback on curriculum	Month 18	Discontinued due to lack additional funding
Evaluation report on effectiveness of capacity building intervention for health committees (SA)	Month 36	On track for month 36: Two students active for their MPH theses
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, briefs are being developed from the discussion paper for dissemination in the next phase.
Policy brief on health committees as vehicles for community participation in realising the right to health	Month 18	Being distributed to key stakeholders; Will be presented to portfolio committee once clarity on national Department of Health processes.
Production of popular materials targeting policy makers (Uganda)	Months 12 and 30	On track for months 12 and 30, a policy brief draft has been developed and is getting ready for print and dissemination.
Training programme and materials for health workers on health committees as vehicles for community participation in realising the right to health	Month 12	Not accomplished in year 2 due to health services in W Cape reluctance to recognise health committees; However, we have facility staff participating in HC training and will work with them; fall back is to shift focus to E Cape where cooperation better. Current HC trainers to build curriculum for health workers
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 36
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	Only one site secured (a City of Cape Town site). Project ongoing.
Evaluation report on success of the pilot 'model' complaints resolution system (SA)	Month 24	As above. Only likely to be completed by month 30; Will add component to document best practice existing by month 36
Report on Field Assessment for local systems for health rights (Uganda)	Month 30	Drawing from the 1 st and 2 nd year findings, gaps in the local systems have been indentified and these will be taken back to the district authorities for further discussion. We intend to work with two HUMCs to address some some of the gaps and use this as a case study at the end of the project
Materials for an MPH module on globalization and health developed	Month 12	No additional funding secured for Canadian partner – will not be realised
Develop IT platform for web-based teaching	Month 12	No additional funding secured for Canadian partner – will not be realised

Postgraduate student research theses finalised (SA and Uganda)	By month 36	Of the 12 students, we anticipate 6 will have completed by 36 months.
Pamphlet/s explaining and promoting the role of H Comm's in health rights (SA)	Month 12	Pamphlet on health committees distributed to CMHF Pamphlet on Health Committee audit in plain English finalised and distributed
2 nd 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	Will be presented to regional meeting in September 2014
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

Outputs in year 2 are listed below. (Outputs previously listed for year 1 are not repeated here).

1. Papers:

- a. Stuttaford M, Kiewiets D, Nefdt W, Reynolds V, Rhodes G, Sigasana L, London L. (2014). Conceptualizing Implementation of the Right to Health: the Learning Network for Health and Human Rights, Western Cape, South Africa. In *Current Legal Issues: Law and Global Health*, Oxford University Press (in press)
- b. Müller A, Crawford-Browne S. *Challenging medical knowledge at the source – attempting critical teaching in the health sciences*. Agenda (in press).
- c. Müller A, Gahagan J. *Towards an inclusive people-centred health system: addressing sexual orientation and gender identity*. Under review with Health Policy and Planning.
- d. London L, Fick N, Himonga C, Stuttaford M. Social solidarity and the Right to Health: Essential elements for people-centred health systems. Under review with Health Policy and Planning.
- e. London L, Thomas J, Mulumba M, Mbombo N, Loewenson R. Can parliamentary action advance the right to health? Experiences from East and Southern Africa. Under review with Health Policy and Planning.

2. Reports:
 - a. Center for Health, Human Rights and Development. *Community Participation in Health systems governance: Experience with Health Unit Management Committee approach in Kiboga and Kyankwanzi districts. Discussion paper No. 2.* CEHURD, Kampala, 2013
 - b. Haricharan H. (2013). A National Rapid Appraisal of Health Committees in South Africa. Learning Network for Health and Human Rights; URL: <http://salearningnetwork.weebly.com/resources.html>
3. Policy inputs
 - a. Cape Metropolitan Health Forum and the Learning Network for Health and Human Rights. Submission to the Western Cape Government Health Department: Comments on the document Vision 2030. Unpublished report, 2012.
 - b. The Learning Network for Health and Human Rights and the Health Systems Trust. Submission to the National Department of Health: Comments on the draft Health Committees Guideline.
4. Training manuals
 - a. Gender and Human Rights manual for health professionals: CEHURD together with the Ministry of Health and WHO country office are working towards publishing the final version of a Gender and Human rights manual which will be used as a national document for training on human rights issues
 - b. Learning Network for Health and Human Rights. Training manual for health committees. Cape Town. 2013. With Facilitator's guide.
5. Popular outputs:
 - a. Pamphlet: What is a health committee?
 - b. Pamphlet: How are health committees functioning?
 - c. Poster: What is a health committee? (in process)
6. A series of banners on health rights: Part of a photovoice exhibition
7. Pamphlets on the right to health adapted for use in Uganda

10.0 Specific Dissemination Activities

1. Training workshops:
 - a. Photo-voice launch in October 2013 with about 170 participants; subsequently, the exhibition has toured through the townships where the photos were taken (Hanover Park, Athlone and Delft) and City Library and the University of the Western Cape. .
 - b. Workshop on Using a Health and Human Rights Toolkit to 39 participants from 22 civil society organisations in March 2013.
 - 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 Kyankwanzi 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. Haricharan H. (2013). Extending Participation: a collaborative research project to strengthen community participation. Paper presented at the International Congress for Qualitative Inquiry, Urbana-Champaign.
 - b. Boule T. (2013). Community mapping – igniting community action. Workshop presented at the Public Health Association of South Africa conference, 25 September 2013, Cape Town, South Africa.
 - c. Muller A. (2013). Discrimination of lesbian, gay, bisexual and transgendered people by health care workers: A call to action. Poster presented at the Public Health Association Conference, September 2013. Müller A. *Barriers to health care for lesbian, gay, bisexual and transgender South Africans* Poster presentation, 9th Public Health Association of South Africa Conference, Cape Town, South Africa.
 - d. London L. Universal health care and the right to health - no gains without community agency. Presentation to the American Public Health Association conference, Boston, Nov 2013.
 - e. Abstracts submitted to the GSHR Conference:
 - i. Haricharan HJ, London L, Stuttaford M. Improving primary health care through community participation in health.
 - ii. Fick N, Stuttaford M, Abrahams L, Rajap A, Cornelius A, London L. Using photo-voice as a participatory method to explore community perceptions of health
 - iii. London L, Fick N, Himonga C, Stuttaford M. Social solidarity and the Right to Health: Essential elements for people-centred health systems.
 - iv. London L, Thomas J, Mulumba M, Mbombo N, Loewenson R. Can parliamentary action advance the right to health? Experiences from East and Southern Africa.
 - v. Mulumba M, Hasuniar R, Nantaba J. Community participation in health system governance: Experience with the Health Unit Management Committee approach in Kiboga and Kyankwanzi districts.
3. The project has also made use of the GO4HEALTH project as a platform to share experiences and findings on community participation research as well as disseminate our pamphlets on the right to health. CEHURD was represented at various meetings and conferences involving discussions on formulating goals and governance for Health for the post 2015 MDGs Agenda namely;
- In May 2013, CEHURD was represented in Heidelberg, Germany during the GO4HEALTH conference with a consortium of academics to discuss key findings on community consultations for which one of the domains of inquiry was Community Participation in health.
 - In July 2013, CEHURD participated in a meeting in Washington DC through our collaborative work with the O’Neil Institute at the University of Georgetown. The meeting was discussing among others utilizing and undertaking consultations on the proposed Framework Convention on Global Health (FCGH) with CEHURD as part of the Steering Committee for the Joint Action and Learning Initiative (JALI).
 - In March 2014, CEHURD participated in the GO4HEALTH collaborators meeting which involved discussions on a possibility of developing indicators for

participation as a strategy for measuring performance on post 2015 Sustainable Development Goals.

- CEHURD as the Africa region collaborator on the GO4HEALTH project collaborated a national level meeting with the Community Working group on Health in Zimbabwe. This meeting was an opportunity to share best practices on utilizing community participation in developing the post 2015 MDGs Agenda.
- Presentations to the GO4HEALTH consortium meetings have included 1) The state of PWDs health rights in Uganda and effective strategy for post 2015 MDGs Agenda (Med Sengooba),; 2) The State of Maternal-Child health rights in Uganda and effective strategy for post 2015 MDGs Agenda (Prof. Ben Twinomugisha).

4. Other seminars, collaborations and academic activities

a. Fons Coomans:

- i. Colloquium – The Right to Food; panel including Monique Salomon, Coordinator of Tshintsha Amakhaya, an alliance of NGO’s working on land and social justice issues and Sheldon Magardie, Regional Director, Legal Resources Centre, Cape Town; hosted by the School of Public Health and Family Medicine, UCT, 20th March 2013
 - ii. Seminar – The Right to Benefit from Scientific Progress, participants responding Professor Anwar Mall, Health Sciences Faculty, UCT and Nathan Geffen, Treatment Action Campaign; hosted by the School of Public Health and Family Medicine, UCT, 19th March 2013
- b. LN Presentation to School of Public Health and Family Medicine Research Day, UCT, August 2013
 - c. LN Presentation at South African Human Rights Commission organised event to raise awareness about access to health care as a right, October 2013.
 - d. CEHURD attended the ICASA Conference which took place from 7-13th December as well as the IP Congress Cape Town. We engaged participants in side meetings to discuss critical emerging issues from our research. The IP Congress discussed how communities can also utilize IP to improve their health and the underlying determinants of health. A presentation was made on how communities can utilize and benefit from IP. (presentation by Primah Kwagala).
 - e. CEHURD was also represented at the meeting organized by the International Initiative on Maternal Mortality and Human rights (IIMMHR) during which we fronted the need and advantage for utilizing community participation in realizing maternal health rights. A recommendation was also made by participating organizations to utilize community participation and consultation with communities on maternal health strategies before informing national level.

11. Impact

We believe that the work of the two projects is contributing to elevating the importance of community participation in both countries’ health systems. This will be more formally tested the research unfolding in both settings but we point to a number of key developments to suggest that key policy makers are responding to the work of the project in both settings.

- a) Despite CEHURD being a key player in litigation against the Ministry of Health in Uganda with regard to violations of the right to health, it is also the case that CEHURD has been invited by the Ministry to provide input to its human resources strategies and materials for maternal health. The work on participation is finding early resonance with key decision-makers at different levels;

- b) Similarly, in South Africa, we can see growing interest from senior public servants in harnessing civil society inputs to the development of policy at national level, with some indication this is more widely shared across provinces. The LN has set up an advisory panel for its EU funded project and its most consistent participants are senior officials from the Department of Health concerned to find sustainable strategies for community participation.
- c) There is definitely regional interest in participation and health rights as seen by the EQUINET initiative, partly catalysed by the Uganda-South Africa work. This is also reflected in some of the discussions globally within the People's Health Movement.

There is also some evidence of increased agency at community level, with galvanisation of action that had not been on the agenda previously. For example, the Cape Metro Healthcare Forum in Cape Town has lodged an action with the Public Protector to take back ground lost to the health department when it withdrew support for community structures. Further, training with Health Committees has prompted requests to draw in broader issues of diversity to address racism, sexism and other forms of discrimination in their work, a signal of the growing capacity at local level to see themselves as vehicles for change rather than extensions of the services, which has been dominant to date.

However, all these indications need to be carefully tested for empirical evidence and this will be the focus of the last year of the project.

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 struggled to recruit students in the first two year of the project. We had anticipated a post-doc joining the team in 2013 to work on gender but her commitments prevented her from doing so. Similarly, a participant in the PHA in 2012 had indicated her intention to pursue a PhD with the LN in 2013 but her personal circumstances changed and so she withdrew. It was only late in year 2 that we have located an MPH student who will be examining the role of gender in the work of health committees in Cape Town. We plan to allocate a visiting intern in mid 2014 to look at gender within the LN as it pertains to the capacity and agency of women CSO participants.

As indicated in the first year report, the LN supported 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 MA in Social Anthropology thesis was completed in 2013 and raised important issues about safety, identity and lack of access to services for a particularly vulnerable group. Another related development is the work of a post-doc on the project examining access to health care for LGBT persons and this interfaces with the diversity work in engaging health committees.

13. 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.

Appendices:

Annex 1: Submission to the Department of Health: Draft Policy on Health Committees, 2013

Annex 2: Submission to the Western Cape Government Health Department: Comments on Vision 2020

Annex 3: Health System Governance - Community participation as a key strategy for realizing the right to health in Uganda: The case of Kiboga and Kyankwanzi districts

Annex 4: A rapid appraisal of Health Committees in South Africa.

Annex 5: Pamphlets on the Right to Health (Uganda)

Annex 6: Briefing document: Community Participation through Health Committees