

**Report to the Open Society of South Africa: Learning by doing and doing by learning: A civil society network to realise the right to health.
(OSF Grant # 02819; Project Investigator Leslie London)**

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**Report to the Open Society of South Africa: Learning by doing and doing by learning: A civil society network to realise the right to health.
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19th April 2011

Background

This is the final report on the OSF Grant # 02819 for the Learning Network for health and human rights (OSF) which is a collaboration between 6 civil society organisations¹ working in the health sector in the Western Cape, and researchers based at the Universities of Cape Town and Western Cape. This is the second grant to the Learning Network since 2008 and represents a progression building on the activities contained in the first grant (# 02616) and related work, part funded by the South Africa Netherlands Programme for Alternative Development between 2008 and 2010.

In brief, the project aims to examine the relationship between vulnerability, community agency and the use of human rights approaches to reduce health inequalities and realize the right to health, and, through a process of participatory action research, to draw lessons for how best the right to health can be operationalised. The work covered in this reporting period for this particular grant # 02819 relates to consolidation of earlier work begun under grant # 02616.

Rationale

To briefly recap, this project is premised on the understanding that, despite the presence of a constitution hailed as amongst the most progressive in the world, socio-economic inequalities have been increasing in South Africa and the realization of rights, particularly the right to health, remains extremely difficult. Evidence accumulated through work in the Southern African region points to the critical importance of social mobilization by NGOs and community-based organizations as essential to make rights real. When civil society organizations exert agency for poor and marginalized people, it appears that human rights can become instrumental to advancing health equity. This project therefore seeks to map out how it is that civil society agency plays this role by putting together a Learning Network of civil society groups around health to derive lessons for best practice in realizing the right to health.

The previous work under grant # 02819 confirmed the following:

In relation to the research questions:

- the complex nature of participation in health and suggested high degrees of suspicion amongst health officials towards claims of accountability; co-existence of high levels of rights awareness with limited levels understanding of health as a right in CSO's suggesting the importance of engaging CSO

¹ The CSOs are Women on Farms Project (WFP), The Women's Circle (TWC), Ikamva Labantu, Ikhaya Labantu, Epilepsy South Africa (W Cape branch) and the Metropolitan Health Care Forum. The University partners include the University of Cape Town (Health and Human Rights Programme in the School of Public Health and Family Medicine), University of the Western Cape (Nursing), Maastricht University (Centre for Human Rights) and Warwick University (Institute for Health).

leadership and members in a learning process; the need to unpack the tension between individual versus collective rights; difficulties relating to trust in the health services.

In relation to the research process:

- the difficulties of implementing an iterative spiral is complicated by the unpredictability of community-responsive work; novel methods of data collection offer new opportunities for participative research; increased engagement from organizations for their programmes; the value of internal and network-wide seminars has been tremendously valuable as a way to reflect on practice; for CSO activists, engaging in research has opened new opportunities for critical engagement.

In relation to building networks:

- International links are important for sharing and testing the LN experience

Objectives

The full objectives of the project as proposed are included in the box below. At the end of this report, we reflect on the progress in meeting these objectives and what has been learnt thus far.

This project will seek to answer this question by answering the following specific research objectives in an iterative process.

- (i) Understanding and practice of human rights by civil society groups:
 - a. How do civil society groups understand and utilize human rights in their work on health, at an organizational level and at the level of individual members?
 - b. How does this understanding influence members' expectations from, and interaction with the health services?
 - c. What strategies are useful in expanding the scope for human rights approaches amongst civil society groups?
- (ii) Understanding and practice of human rights by health care providers:
 - a. How do health care providers understand human rights and its applicability to their work?
 - b. How do health care providers understand what communities and community members can and should expect from the health system?
- (iii) Does bringing members of civil society groups and health care providers together to discuss and explore models for realizing rights to health generate opportunities for
 - a. Overcoming adversarial approaches to rights claims in the health sector?
 - b. Building trust between providers and community members
 - c. Building trust within the health services

1. Research Activities (April 2010 – March 2011)

(i) The understanding and practice of human rights by civil society groups

a. Knowledge, understanding and practice **questionnaire**

In the course of the year, the LN recruited an intern to conduct repeat questionnaires of LN participants' understanding and practice related to human rights and to compare differences in responses. Of the 40 baseline questionnaires, the intern was able to re-interview 20 participants. A draft report comparing baseline to follow ups is in process and gives some sense of changes in understanding and reported practice as a way to evaluate the work and training of the LN with CSO's. Preliminary findings are that individuals who have participated in the LN over the past three years appear more confident to assert rights, have a better understanding of rights, have increased their awareness of rights violations; express greater trust both in their own organization and in LN; and express higher levels of communal solidarity and positive attitudes about LN. There is also greater awareness that staff of health services neither understand nor respect patient rights, and of the need to educate health workers on patient rights and to set up systems to improve patient staff interactions. This evaluation concludes that "... although causal relationships cannot be determined on the basis of this study, there is some evidence that engagement in the Learning Network positively reinforced the principles of human rights within organizations and cultivated solidarity and a community of support between organizations." The report is still being finalized.

b. **Case studies.** Three case studies were selected from a pool of 26 case studies held by the LN for work to deepen the case studies:

Case 1: Community action to change the way a service was organized. Community members reported that a clinic serving their community had set up services such that any patients requiring HIV-services were redirected to a separate room with a different entrance and that this practice was made public. This led to much stigma and discrimination. The local health group intervened with the clinic staff to ensure that the service was changed so that there was no distinction made between patients needing HIV-related services and other services. A focus group with a 'natural group' in the community and 10 in-depth interviews was held and used as an opportunity to also look at social solidarity in the community. The data are still being analysed.

Case 2: A women gave birth in an ambulance after having earlier been turned away by health care providers from a Maternity Obstetric Unit twice whilst in labour. The case illustrates the mismatch between the service's policies and the effects on patients. One in-depth interview was conducted with the patient's husband and further interviews are planned with the woman who gave birth and with health care providers involved.

Case 3: Information emerged in the course of our training workshops about forced HIV testing of women attending for reproductive health services at

a facility. A field worker fluent in Xhosa interviewed two of the three women involved in these cases and will be doing a third in depth interview in the coming months. One of these case studies has been used as material in the toolkit on health rights and information on this issue has been passed on to the relevant authorities for further action. A local HIV NGO, the AIDS Legal Network, published its own report during this period, which confirmed reports from all over country of conditional/forced testing when women try to access sexual and reproductive health services. We are collaborating with the ALN now to plan development of further materials on women's rights in relation to HIV testing and to design a representative study to obtain more representative data on which to base lobbying action. This is ongoing.

c. The LN piloted the **prototype toolkit**

The idea of a Toolkit to assist with taking up health rights violations originated from the CSO's within the LN, particularly around the need to understand what constitute a violation of health rights and how to lodge a complaint. The LN has held 19 workshops with 161 participants from 9 different community-based organizations (both within and outside the LN) to pilot all four sections of the toolkit. This included work with deaf research assistants based at a project at UCT aiming to secure deaf persons' rights to Sign Language interpretation in health care. The deaf researchers will be using the toolkit on the right to health in their work and would be the first time a health rights toolkit is tested using sign language.

The finalized text is at the stage of DTP layout and the toolkit is presently scheduled for publication in May, with a planned launch in the second last week of May, at which the Chairperson of the Human Rights Commission has agreed to speak. Further, an article on the toolkit is planned for publication and dissemination strategies are in place for local distribution. The toolkit will also be the basis for ongoing collaboration with EQUINET partners in the Southern and East African region.

d. **Photo voice:** The groups from TWC have extended the Photovoice work by taking photos of what human rights mean to them. Eleven in-depth interviews were completed with LN participants based on over a 100 health and on human rights images captured by women members of TWC. The photos were mainly images of social determinants of health. Three of the participants collaboratively developed analysis of the results of photos related to health. Themes emerged related to substance abuse, healthy and unhealthy environments, food health risks and disability. The photos have been used by community members to prompt local action, and formed the basis for a presentation to the Public Health Association of South Africa conference in December 2010 by the community members and the LN Research Coordinator. .

e. The Women on Farms Project has begun to put together a new **health team in Rawsonville**

The Research Coordinator conducted a training workshop with the health team on the right to health, as well as two in depth interviews on the issue

of individual and collective rights and social solidarity with regard to health rights. While the intent was to track the development of health team, it appears that this initiative has not resulted in a sustainable structure with which to work.

f. Language as a component of the right to health

This study sought to explore barriers to access to health care posed by language mismatches between patients and providers. The international human rights framework is silent on the role of language in guaranteeing the right of access to health care, so this project seeks to explore this gap. Data from health care encounters involving Xhosa-speaking patients and signing deaf patients are being assembled. The two sets of data will be used to identify arguments to support language as a component of the right to health and the implication that interpreter services are a core government obligation visavis the right to health.

This research has been complemented by a number of other activities, including a seminar in October at which a UCT linguistics professor presented her research into violations of health rights experienced by patients as a result of the absence of Xhosa speaking staff or interpreters. A second seminar in April 2011 presented findings from the study with deaf patients illustrating how patients who reaches a service but who are not able to enjoy communicated in a language he or she understands, is subject to a violation of their right to access health care. This is being developed into a paper for publication; also, our Maastricht colleague will help in developing a submission at international level to the UN committee responsible for the Covenant dealing with the Right to Health (ICESCR) to argue for greater attention to matters of language in setting benchmarks for the right to health.

- g. One of the LN member CSO's, Epilepsy SA has undertaken research into **human rights and disability**. With LN support, 7 focus groups and two in-depth interviews were conducted to obtain a broader understanding of disabled people's awareness of human rights. The findings suggest poor knowledge about disability rights, and that respondents were unable to explain what a right is. This will be used for future patient education and advocacy by the organisation (creation of a toolkit on disability rights). The research will also be presented to the Public Health Association of South Africa conference in December 2011 and will be worked up as a publication for a South African social work journal.
- h. The LN has been doing ongoing work around **health committees**, exploring the extent to which they have the skills and resources for effective community participation. This has included three pieces of empirical work.

Firstly, one Masters student (Ms Young) completed her thesis on Health Committees (HC's) as a vehicle for community participation in advancing the right to health and graduated in June 2010. This was based on a mix of qualitative and quantitative research conducted with three facility

committees and staff. Report back meetings have been held with all HC's that participated, and with the Plenary of the Cape Metro Health Care Forum at which senior health officials from the Provincial and City Health Departments were present. The research has formed the basis for development of a pamphlet for health committees and communities, outlining the roles of HCs based on best practice from research. Some HC have adapted the text of pamphlet for their own use even before finalization. The findings of the study are being developed as two working papers aimed at journal publication: "Measuring community participation in health: What can we learn from South African Health Committees?" and "Community Health Committees as a vehicle for community participation in advancing the right to health."

Secondly, research has been conducted into the draft policy on community participation and health committees by a visiting student from the US, under the supervision of the LN. This research is currently being written up for publication and for feedback s to local stakeholders.

Thirdly, an audit of health committee capacity was completed in December involving 250 respondent questionnaires from 53 HC's, as well as 3 in-depth interviews (with non-functioning HC's). Although the data are still being finalized, the preliminary findings suggest serious deficits in the capacity of health committees to meet the objectives of the draft policy, principally related to lack of health service support and point to an urgent need for capacity building amongst HC's. The audit is also identifying qualitative data about barriers to HC functioning similar to that identified in the study (Ms Young's thesis) , including lack of support, no space to hold meeting, no resources, uncertain roles and functions and little support from facility managers.

The findings of all three studies will help to inform the Metro Health Care Forum initiative to consolidate its policy base in 2011.

- (ii) Exploring the **understanding** and practice **of human rights by health care providers**
 - a. The project by Ms Young described above has begun to engage health care providers in the clinics. Her study completed 16 interviews with health care providers about community participation. The key findings are that health care providers have some basic knowledge of right to health and what it means for patients but were critical about whether right to health can be realized in practice.
 - b. One of the case studies involves community action in a rural town to redress problems related to HIV stigma [see (i) b Case 1 above]. The project is currently interviewing, with permission of the Department of Health, the facility staff at the facility involved. One health care provider at the clinic has been interviewed and further interviews are planned. The triangulation with the community data will allow for further exploration of what rights mean in a contested context .

- (iii) Does bringing members of civil society groups and health care providers together to discuss and explore models for realizing rights to health generate opportunities for advancing health rights?
- a. **A ‘Public Health Ward round.’** This idea emerged from a Review and Reflect meeting at which the case involving failed obstetric care [see (i) b Case 2 above] was discussed. The LN propted to set up a forum for structured engagement over violations of health rights set up as a learning opportunity, and developed a proposal to hold a public health equivalent of a clinical ward round. The proposal has been sent to one of the Senior Managers in the Health Department to sound him out about the idea. Further, the PI and the Research Coordinator met with an obstetrician responsible for Midwife Obstetric Unit services in the districts and with Metro staff responsible for professional support services and quality assurance to brainstorm the idea. The plan is to pilot the activity at a sub-district level with the support of an enthusiastic director and will be pursued further in 2011.
 - b. The LN ran a seminar for the **Programme for Enhancement of Research Capacity at UCT (see below)** on the question of African knowledge paradigms and their relevance for conceptualization of the right to health. The seminar was attended by a sub-district manager from one of the Metropolitan areas and a number of his staff, as well as CSO members of the LN. He raised a number of questions about the operationalisation of concepts such as ‘ubuntu’ in practice for health service managers, challenges which will form part of the ongoing research agenda for the LN.
 - c. Contacts have been established with senior clinicians responsible for **obstetric care** to explore opportunities for improving the treatment pregnant women receive in the services. This is based on evidence identified in some of the cases collected by the LN to date.
 - d. SANGOCO Western Cape ran an **NGO week** in September 2010. The LN hosted a dialogue between Health Committees, civil society organizations and the Department of Health. This meeting is perhaps a start in bringing CSO’s and health care providers together to identify common solutions. There was open discussion with representatives from the health department related to barriers to community participation in health decisions. The Cape Metro Health Care Forum intends to use some of the information gathered during NGO week and during this dialogue with the DOH to take further action to advocate for improved community participation in health. The MHCF staged a protest on 20th October to highlight lack of progress on formalizing the Health Committee policy.
- (iv) **The African knowledge project** under UCT’s Programme for Enhancement of Research Capacity (**PERC**) awarded the LN a small grant to explore the contribution of African philosophy to the conceptualization of health rights as collective rather than individualist claims. The project has held two open seminars (March and September 2010), developed an annotated bibliography on the area of Ubuntu and the right to health, and participated in a PERC writer’s workshop in February 2011 and at a workshop on knowledge generation in May 2010 at which the project’s preliminary research findings

were presented. The outputs from the project will comprise a chapter for a forthcoming book as well as two papers, one exploring the concept of ubuntu as deepening our understanding of the right to health, and one exploring the horizontal application of rights in a health care context. The papers are "The Right to health in African Cultural context" – Professor Chuma Himonga; "Dialogue, co-learning and knowledge creation on the right to health: reflections from the Learning Network" – Dr Maria Stuttaford; "The meaning of the right to health in horizontal relationships and the regulating role of the government" – Professor Nomafrench Mbombo.

The discussion generated by this work under the PERC grant touched on many issues relating to universalism vs. cultural relativism and human rights. Following this up, a further seminar on culture and human right will be held in May 2011 to a broader audience.

- (v) The LN continued to host its monthly **internal discussion seminars**.
- On 20th April 2010, the LN hosted Prof Fons Coomans from Maastricht University talking to the questions of different approaches to identifying violations of the right to health;
 - An analysis of Health committee's capacity to effect participatory engagement in health decision making and the association the performance has in realizing the right to health was presented by Esther Nako, UWC, May 2010.
 - Professor Chuma Himonga presented her first draft of her PERC paper, then titled "Consolidating African philosophies into human rights law" in June 2010.
 - In July 2011, Professor Lucy Gilson led a discussion on the topic of trust and power in the health system and explored the ways in which one can use the notion of trust to strengthen health systems to improve access.
 - In August, a visiting intern from the US, Michael Ekema, presented the findings from his research on language as a right.
 - In September 2010, the LN hosted Glen Mpani from OSF to lead a discussion on Outcome Mapping as a method for the LN to evaluate its work. This was a process explored further but was used as introduction to Outcome Mapping to introduce LN participants to the approach.
 - In October 2010, the team held a meeting at which Ruth Nugent of Epilepsy SA presented a draft of her PHASA paper "Disability & human rights toolkit as a best practice methodological approach for realising human rights of people with disabilities."
 - In November, there was no formal seminar but rather a discussion of potential papers possible from the health committee audit, led by Hanne Haricharan
 - In January 2011, Chris Colvin led a seminar on culture and human rights for the research team
 - In April, Professor Fons Coomans presented with SOPHEM researchers Hanne Haricharan and Marion Heap a paper

exploring language as a component of the right to health (see earlier elaboration).

- Prof Leslie London also presented in April an internal seminar on the work of Amartya Sen and its relevance for right to health work.

(vi) **Capacity building**

Since inception, the LN has supported 8 postgraduate students, 3 at postgraduate diploma level (still ongoing), 3 at Masters level (all completed – 1 a Masters in Adult Education in 2009; 1 a Masters in Public Health in 2010 and 1 an MPH in 2011). The project is also supporting 2 PhD students (still ongoing). All are part-time students. The student theses have addressed different aspects of the LN's programme (Rights awareness; models for community participation; effectiveness of rights pamphlets; building organisational capacity; interventions with providers to support community participation). All but one of the students are female, 4 are black and the 2 PhD candidates are black women. One of the PhD candidates is also the director of a LN CSO member organisation.

Of the postgraduate students involved with the project, progress has been as follows:

- a. Ms Gabriela Glattstein-Young completed her thesis – community health committee's as a vehicle for participation in advancing the right to health and graduated with a distinction for her thesis in June 2010. She is currently focusing on writing two articles from the research findings.
- b. Ms Wendy Nefdt PhD thesis focuses on the role of social capital as a mechanism through which the LN member organizations increase their capacity to advance health, and the role of a human rights approach in facilitating this process. She has started data collection and is presently on a study visit to the Netherlands and attending a conference in the UK where she is presenting her preliminary findings. Her field research is progressing well.
- c. Another MPH student – Ms Morgan Strecker – has undertaken an evaluation of the LN set of Right to Health pamphlets. Her qualitative research study seeks to assess the coverage and effectiveness of the Learning Network (LN) pamphlets developed around the right to health among 6 civil society organizations actively involved in the LN, their members and their constituents. She interviewed 40 informants and documented the distribution of approximately 3000 pamphlets from the LN. The field work was completed by December 2010 and the thesis is currently under examination.
- d. Ms Ester Nako has had some changes to her circumstances, accepting a post in Johannesburg. She remains committed to a PhD at UCT but it remains to be seen how this will be feasible.

In addition, the project is hosting a number of visiting students/interns:

- e. Caitlin Purdue is an undergraduate student from the University of North Carolina working on a joint project which will conduct a policy analysis of the Health Committee policy for the MHCF. The report is presently being written up.
- f. Khai Tram is an undergraduate student from Stanford assisting with the follow up of the baseline questionnaires and with the audit of health committees. The final report is being written up.
- g. Michael Ekama and Brian Gilchrist are interns visiting on a programme through Mount Sinai University in New York for US minority students. They are assisting with the Health Committee audit and conducting a sub-project examining language barriers a violation of the right to health in health facilities.

Other capacity building activities included:

- h. Knowledge-making in Africa - Two Perspectives – 2 members of LN attended this seminar – 8 September 2010
- i. Making search engines work for you – Research Coordinator – 9 September 2010
- j. Writing a successful grant proposal – Research Coordinator – 14 September 2010
- k. Grant proposal workshop – Research Coordinator – 15 September 2010
- l. Dr Maria Stuttaford from the University of Warwick visited the project in September and ran a Writing workshop which enabled peer feedback on participants' papers. This is part of the academic production of knowledge being facilitated through the LN.
- m. Research Budget Management – Research Coordinator – 4 November 2010
- n. February 2011 - Dr Maria Stuttaford – second writing workshop – progress on papers, and to attend LN Strategic Planning
- o. 31st of March Advanced Nvivo training – 10 participants attended (3 members of the research team)
- p. Fons Coomans visit (4-7 April 2011) – to discuss and comment on various papers (Language and rights, Ubuntu and rights, contributed to PHM talk and plan for writing papers (violations and development of toolkit)

(vii) Conference submissions are detailed below.

- a. The Public Health Association of South Africa (PHASA) held its annual conference in East London in 29 November – 01 December 2010. At the conference, presentations were made of a number of LN research activities.
For an oral presentation (under the theme of social determinants of health) a presentation was made of “Using photo-voice as a participatory method to explore community perceptions of health” (Fick, Stuttaford, Susan Jantjies, Maureen Aasvoel, Leslie London). The discussion and interest from the floor was very animated and a number of important connections made with participants at the conference.
For poster presentations, two pieces of research were presented: (i) Disability and human rights toolkit as a best practice methodological approach for realising human rights of people with disabilities (Ruth

- Nugent, W Nefdt, Fick, Leslie London); (ii) Challenges to sustainable and meaningful community participation. Hanne Haricharan
- b. International Conference hosted by the Institute for Development Studies, Sussex: **Social protection for social justice** – The role of social capital for realizing the right to health and social justice – Wendy Nefdt is presenting in April 2011.
 - c. Conference on **Plural Legal Systems**
This is a conference to be held in September 2011. The LN submitted a concept note for a panel on “Community agency, power and social solidarity: Time for a rethink about how the right to health is conceptualised?” which has been accepted for presentation.

2. Organisational Activities

- a. Three meetings of the LN **Exco** during the period under review;
One meeting took place in March 2010 with SANGOCO and PHM to discuss partnerships and sharing of network lessons; One meeting of the Exco was held specifically in preparation for NGO week and for a coming regional meeting in October (see below) and a further Exco Meeting (Oct 26th) to set up the terms of reference for a Strategic Planning Review to use Outcome Mapping approaches, scheduled for early 2011, and also the terms of reference for appointing a part-time coordinator to replace the current temporary coordination function held by one of the researchers, leaving in 2011.
One of the issues debated in the Exco has been how to ensure CSO contributions are properly valued in LN academic outputs.
- b. Three **Review and Reflection** Meetings during the period under review -
The first, on 13 April 2010, was to consolidate our learnings as a network
A second Review and Reflect meeting was held on 29 June 2010, which included presentation on the photovoice project by the photographers and discussion and consolidation of lessons learnt. A further meeting was held on 16 November 2010 – Application/testing of the toolkit with LN members, well attended, mainly on part of health committee’s and representatives and constituency of WFP; Meetings were also held in November to practice presentations for PHASA in December
- c. Co-learning within the Network (**seminars/workshops**)
The Women on Farms Project hosted a workshop on Participatory Community Mapping as an Action Research method for other learning network member organizations on Friday 16 April 2010. This is an example of sharing of skills and information horizontally within the LN.

TWC held a women’s day event in August, attended by over 700 people, which saw LN right to health pamphlets distributed. The event had a focus on health – VCT and general health screenings were provided along with music and dancing.

Epilepsy South Africa hosted a workshop in September 2010 on epilepsy, disability and human rights for approximately 20 participants from the LN,

mainly Health Committees. This workshop provided information on epilepsy, the psycho social impacts of disability, and the rights of the disabled.

The LN also participated in a joint Civil Society seminar (organised by the Black Sash and others) on mobilising for fulfilment of human rights commitments: Seminar on understanding the International Covenant on Economic Social and Cultural Rights and the Millenium Development Goals – 15 September 2010. A LN representative attended this seminar which was about including a broader group of organisations interested in coming together as a collective to analyse, reflect on the MDGs and promote the ratification of the ICESCR and its Optional Protocol. This campaign is ongoing and the LN will remain involved. A LN CSO also participated in a PHM Right to Food campaign meeting in April 2011 as part of their interest in work around food security.

- d. **Training:** The LN Research Coordinator has assisted Ikamva Labantu with training on the right to health their Early Childhood Development and family support services staff. This was also used as an opportunity to test aspects of the toolkit on the right to health.

The Research Coordinator also worked with a group of deaf research assistants to pilot the full toolkit on the right to health, which involved training them in the Right to Health toolkit workshops with sign language translation

Epilepsy South Africa invited the LN to participate in training on human rights and the right to health specifically at their advocacy workshop attended by approximately 30 people.

e. **NGO Week presentations**

SANGOCO NGO week was held in September 2010. Three workshops were run by the LN. The first presented the LN as a case study for other NGO, drawing out lessons learned. The second was a capacity building session for Health Committees on Community Participation in Health and the role of Health Committees. This was in preparation for a Dialogue with health service managers the following day. All three events were relatively successful with good participation.

Key issues that emerged in the workshop on participation in health were:

- Lack of recognition of health committees
- Need for training and capacity building for health committees
- Need for resources to support the functioning of health committees
- Need for HC links with political structures
- Progress with community participation since the National Health Act

In the responses from department of health, the main obstacle identified was that they could not act on the issues raised until formal structures and legislation relating to community participation had been finalized

- f. **Other networking** - we continued to engage with other networks and organizations (e.g. the Network against Violence against Women; the AIDS Legal Network, who have recently brought out a report on coerced HIV testing; and with the People's Health Movement)

3. Funding

Funding secured:

- a. Additional funding was secured from the Joint Oxfam support programme for campaigns on health (JOSCH) specifically for development of the toolkit.
- b. A small additional grant (R50 000) from DVV was secured for future materials development.
- c. In December, we heard news that a proposal submitted to the National Research Foundation (NRF) in terms of a call for community engagement research was successful. This will run over three years from 2011 and supplements another existing NRF grant for 2010 to 2012
- d. A second NRF grant application for the LN was successful and secured between R 50 000 and R 100 000 per annum for three years going forward from 2010.
- e. A small grant was received from the Commonwealth Civil society grant programme to fund a Southern African regional meeting to develop the toolkit for right to health for regional application
- f. UCT awarded the LN a top up of R60 000 to support regional activities on health rights.
- g. Additional funding was secured from OXFAM and Fair Play for Africa in anticipation of the October regional meeting to bring more delegates to the meeting in Kampala.

Funding applications

- h. To OXFAM for further regional work
- i. Proposal to Dutch Embassy
- j. Concept note to IDRC
- k. UN Democracy Fund – application in December
- l. Oppenheimer Africa Project Award

4. Dissemination Activities

- a. Conference presentations are listed above. We have presented LN work at the Public Health Association conference (Dec 2010), the Institute for Development Studies International Conference on Social protection for social justice (April 2011) and will present at a Conference on Legal Pluralism scheduled for September 2011.
- b. Feedback on findings of the Health Committee research has been provided to participating Health Committees, to the Metro Health Care Forum and to senior health officials.
- c. A pamphlet on the role of Health Committees, aimed at community members and new Health Committee members (outlining the context and role of health committees) has been drafted, but cannot be finalized due to ongoing uncertainty regarding the status of the Health Committee policy in the Western Cape (supposedly finalized but yet to be signed off by the

MEC). Nonetheless, Health Committees have found the text so useful they are using the contents of the pamphlet themselves for dissemination purposes.

d. Regional Meeting - Uganda

The LN succeeded in raising a Commonwealth Foundation small grant to co-host with HEPS-Uganda a one-day regional meeting of civil society actors from organisations working on issues of the right to health in Uganda, South Africa, Kenya, Zimbabwe and Malawi. The meeting took place in Kampala on the 8th October 2010 and was an opportunity to follow-up the resolutions of past conferences of the Regional Network for Equity in Health in East and Southern Africa (EQUINET) on health rights, but also focused on the development of a training manual on health and human rights for regional implementation. The conference report is available at URL:

<http://www.equinet africa.org/bibl/docs/Hrights%20mtg%20rep%20Oct2010.pdf>).

Suggestions for the Way Forward included a proposal to extend the toolkit currently being developed by the LN for regional application; to explore human rights curricula for health workers; and to share best practice around mechanisms for community participation in health, such as health committees.

- e. Lastly, distribution of LN pamphlets has continued since the last report. Approximately 35 000 pamphlets have been disseminated, 150 sets of the pamphlets were distributed during TWC's women's day celebration on 9 August; 300 copies of the right to health pamphlet distributed to first year medical students; A reprinting of the six Right to Health pamphlets was completed (4500 copies of 6 RTH pamphlets reprinted – increased demand for pamphlets. All pamphlets were posted on school of public health and family medicine, health and human rights division website, and are now free for download with a Creative Commons Open Access copyright. (URL: <http://www.hhr.uct.ac.za/material/material.php>). Further, 2000 copies of the new pamphlet on how to complain about violations of health rights were printed, 100 copies distributed at the Review and Reflect meeting.
- f. Lastly, as indicated above, at the SANGOCO NGO week, three presentations were made to a local CSO audience: On lessons learned, on health committees, dialogue with health officials on community participation.

5. Outputs

In relation to what was planned in the project proposal, most of the project outputs have either been achieved or are clearly on track to achievement as indicated below.

Outputs in the project	
As originally proposed	Current progress
A finalized toolkit for use by community members and CSO leadership	Text for toolkit finalized – to be printed in May 2011; Launch scheduled for late May
A manual on Health and Human Rights for use by CSO leadership, aimed at crystallising network members' best practice experience, and serving to make this available within the network and to a wider audience	The Toolkit will serve as a manual, and can be adapted for wider use. Discussions have started with EQUINET partners to adapt toolkit for S and East African region.
Two policy briefs, one on women farm workers health; one on community participation on health	One policy brief on community participation in health; interns in 2011 will develop a further material for WFP on health and safety
Modules for in-service training for Health Care providers in the Metro	This has not been implemented because of a longer lead time needed to build health service buy in for the Ward Round concept.
Project Reports	Four reports were completed for the OSF
A CD of training materials on Health and Human Rights	The project has a closed Vula Site but has not had time to produce the training materials in a CD format. The focus on the toolkit has taken preference; however, this remains an objective of the LN in 2011.
An inventory of health committees in the W Cape Metro available to community organizations and members	Thea database of health committee contact details has been assembled and will be made available to community organizations and members after feedback on the audit is provided to the Metro Health Care Forum, scheduled for June 2011.
An audit report on training needs of health committees in the W Cape Metro	The audit report is presently being finalized; we anticipate it being available in June 2011.
Research reports on measuring community participation in health; on skills training needs of health committees; on the Rawsonville health team development	One MPH thesis completed; two research reports being finalized; 2 publications in process.
Training materials for use by PHM in its RTH campaign	The LN has developed a new pamphlet on dealing with violations of the right to health and the toolkit will be available for PHM advocacy in its lead up to the

	People's Health Assembly to be held in Cape Town in 2012.
Four or more conference presentations on the work of the LN	During the period of the OSF grant, there were 3 presentations at PHASA and one the IDS Conference. A panel with 6 presentations has been accepted for September 2011.
Five or more journal manuscripts submitted for publication	There are certainly 4 papers and one chapter in progress. None have been as yet submitted.
One Masters students graduated; 2 students accepted onto PhD programmes	1 Masters in adult education graduated in December 2009; 1 Masters in Public Health graduated June 2010; 1 Masters in Public Health to graduate in 2011; 1 PhD student registered and in process of data collection; 1 PhD student pre-registration;
An Outcome Mapping framework for the project, with appropriate tools for ongoing reflection and monitoring	The LN has held three meetings and have a draft planning and evaluation framework, finalized on 18/4/2011

6. **Other achievements** not specified in original proposal include:

- Hosting joint dialogue in 2010 with W Cape health department officials on Health Committee Policy;
- Partnership with HEPS Uganda to extend project to South and East Africa 2010+
- Secondary research projects on (a) Ubuntu and the right to health – reconceptualising human rights in an African philosophical frame (through UCT); (b) Language as a component of health care access (through NRF); (c) plural health seeking behavior in the rights framework (University of Warwick); (d) best practice on health rights for the Southern and East African region (Commonwealth Fund); (e) policy analysis of health committees (University of North Carolina)
- Partnership with SANGOCO on NGO week (2010); with PHM on health rights campaigns; with Black Sash and HEU on National Health Insurance advocacy
- Hosting interns from northern institutions for service learning: Mt Sinai School of Medicine and Yale University (US); York University (UK); collaboration with York (Canada) on postgraduate teaching
- Diversification of funding to include: Oxfam, DVV, NRF, Commonwealth Fund, University of Cape Town
- Database of health committee contact details for community action; 26 capacity building workshops or activities within the network; 3 Review and Reflect meetings

Capacity of member organisations

Research capacity of CSO member organisations was strengthened as follows: In 4 of the 6 LN member organisations, organisational leaders were able to study at UCT (3 for PGD in Adult Education and 1 for a PhD). Additionally, the LN facilitated sharing with the members of research methods through its internal seminars (see above) and through training opportunities hosted as part of regular Review and Reflect meetings.

This included training in community mapping; use of photovoice and application of research tools. Epilepsy South Africa adapted LN research instruments for their own research to identify training and advocacy needs of people with epilepsy. This research will be presented at the PHASA Conference in December 2010.

7. Reflection on Key Lessons

The research questions

- The issue of individual versus collective consciousness (and rights) remains critically important. The project will need to tease this out as it goes forward.
- Trust remains a major challenge, particularly (but not solely) between community structures and providers/managers. This will be the focus of the LN work over the next period.
- The project has begun to establish engagement with the health services in different ways. This reflects the progress of the LN in being able to engage outwardly, and less inward focus. This will form the basis for the next three year cycle.
- However, what has been much more difficult to accomplish has been engaging with the services to bring them into the same space as the CSOs. Building trust within the LN CSO's has taken three years. Building trust between the health services and the CSO's is more complex and takes far longer
- Confirming the key role of an active civil society in realizing health rights: Without strong and empowered civil society groups, the state is not held accountable, whether at national or local level; Moreover, focusing participation as a rights argument ensures that community voice is not displaced into political fora, but can act at the point at which public servants make decisions which affect people's rights
- We have teased out how collective action is vital to realizing health rights, particularly for socio-economic rights claims. The contribution of traditions and practices based on African philosophies could help to shape how the right to health is conceived and defined in international human rights law. We are working with partners in the region and internationally to see if we can provide guidance to human rights scholars and advocates to reframe rights away from individual claims towards approaches based on social solidarity and to locate such an analysis firmly in international human rights debates

The LN generated **new knowledge in the area of community participation**, critical for health rights. This is particularly based on the early findings from the Health Committee Audit, which indicate important preliminary findings:

- HC sustainability is a challenge for community participation. The nature of Health Committees is highly fluid, and many respondents have been members for less than 1 year.
- Most HC members serve as “assistants” to facility staff, much less frequently dealing with complaints, budgets, service delivery, governance, monitoring and evaluation. i.e. their function is rarely linked to governance, in contradistinction to stated policies. Furthermore, the vast majority of HC members are unaware of the draft policy framework.
- Participants from the CMHF were positive about the research but wanted to know how they can move forward from all of these “negative aspects” and

focus on what can be done to improve the situation of HCs. Members of the CMHF agree that there are insufficient resources to sustain the HC's and a lack of political will to support the HCs.

- The next step, after the audit is completed, is to look at strategic options for the way forward. The LN and the CMHF will continue to work together to empower HCs and devise a plan of action.

The research process

- For some of the team, who are steeped in the CSO culture, the experience of engaging in research formally with an academic prism has opened new vistas for the participants; new opportunities to exercise critical engagement, new insights. However, as pointed out, the learning is mutual, and is the key ingredient that keeps participants within the network.
- We have placed the issue of power within the research process under a rights analysis, surfacing what is hidden and openly engaging with inequalities in power between partners, so as to develop strategies to manage power imbalances and reflect that equality in our Network's practices. This has provided new insights into the way in which knowledge is generated and owned, with implications for how universities engage with communities. The resulting debates provide direction for best practice regarding service learning and socially engaged research. By acknowledging that CSO's provide unique information about people's lived experiences and how policy is being implemented daily, and through universities providing knowledge and access to intellectual resources that would otherwise not be available, a mutual partnership is better able to influence policy
- Within the above paradigm, the LN has also developed some experience and success with the process of co-learning and collaborative data gathering. Novel methods of data collection (e.g. use of photovoice; different forms of reflective practice) allow for higher degrees of participation and more meaningful co-learning

Building networks

- Reflection on our own practice (networking mainly between CSO's and University partners, we are only just beginning to see networking happening between NGO members of the LN. This will be tracked in one of the PhD studies.
- The new areas of knowledge production and reflecting on the place of community ownership of intellectual property generated through the LN's work is a novel and exciting area to challenge the LN. Relationships between the University partners and the CSO partners have been substantially remodeled in the three years of the LN existence.
- The LN is slowly succeeding in facilitating more CSO – CSO networking. For example, Epilepsy SA (ESA) has been working with The Women's Circle (TWC) around epilepsy education and how to marry ESA's disability rights with TWC's adult education approaches. Similar requests have been made by Women on Farms Project. The process of knowledge generation has also been a learning experience within the LN, highlighting the power relations between academic and non-academic partners. This has led the LN to seek successfully a research grant to study the process of knowledge creation and ownership within the LN. This is funded by the NRF and will unfold over 2011 to 2013

- The lessons learned have been distilled and the LN is now able to engage with other stakeholders and networks in a more substantive manner. This means that the LN can begin to undertake lobbying and policy advocacy in a way that it was not able to previously.
- Interesting, the Network against Violence against Women, a well established regional network, have approached the LN as they are keen to learn about the LN as a model. We will pursue this in 2011, but it does point to the importance of sharing best practice and the contribution the LN can make to building civil society more broadly
- The engagement with HEPS-Uganda and EQUINET has highlighted the vast amount of knowledge and expertise resident in the South and the benefits to be obtained from south-south networking. HEPS-Uganda has a number of on-the-ground projects from which the LN can learn, and vice versa. We plan to push this aspect of the LN's work as much as possible (and funding will allow).

Links to advocacy

In two clear examples, the LN research has contributed to LN member organisation advocacy work. The

- The Metro Community Health Care Forum workshopped the outcomes of the dialogue held during the SANGOCO NGO week facilitated by the LN and decided to picket the provincial legislature. In particular, the CMHF is opposed to the signing-off on the District Health Council Bill as they feel other things must be done before this can happen – in particular, the finalisation of the Health Committee Policy. LN research has provided them with evidence for such actions.
- A second example is from the Women on Farms Project who have been explicitly offering rights training to women farm workers. It is evident in WFP work that farm women understand the pamphlets and used them to make posters which illustrate their understandings of the Right to Health, which then they turned into placards for protest action, based on their posters and pamphlets.
- Another lesson has been the importance of wider partnerships as instrumental to achieving policy shifts. For example, the SANGO Coalition (SANGOCO) has created spaces for public debate on policy issues. The LN's participation in these activities brought evidence to a structured dialogue with service managers about health committee roles and functions. This also strengthened the LN's grasp of strategic interventions needed to advance health rights. It has also enabled the LN to influence the agenda of SANGOCO to the extent that human rights have emerged as a unifying theme within the work of SANGOCO in the health sector. These lessons learned have enabled the LN to engage with other stakeholders and networks more substantively. This means that the LN can undertake lobbying and policy advocacy in a way that it was not able to previously.

8. Income and Expenditure

The project has over-expended on salary as the Project coordinator's salary has to be paid from one university fund. The over-expenditure will be reversed by funds from one of the NRF research grants held by the project to support the Coordinator's time not covered by the OSF grant.

Other line item costs are more or less on track according to budget.

The total grant is R 41 469 in deficit and will be reversed as indicated above.

OSF Financial Report as at 31 March 2011

Item	Budget (ZAR)	Prev Expenditure (ZAR)	Current Expenditure (ZAR)	Total Expenditure (ZAR)	Balance (ZAR)
Salaries	167 000	170 618	40 443	211 061	-44 061
Research Implementation Fees	39 270	21 748	15 466	37 214	2 056
Material Costs	15 000		15 000	15 000	-
Travel	6 000	4 366	1 100	5 466	534
Levy 10%	22 727	17 046	5 682	22 728	-1
Total	249 997	213 777	77 691	291 469	-41 472

Funds received from OSF	250 000
Less expenditure	291 469
Deficit	-41 469