Community participation is a crucial asset for achieving human rights in public health, yet many health systems do not have policy in place to establish the required frameworks that enable functioning participation. In South Africa’s Western Cape Province, community health committees (HCs) were formally established through the National Health Act of 2003 but have not been fully realized due to delays and difficulties in implementation. A Policy Framework for Community Participation/Governance Structures for Health has been approved to outline the roles and duties of HCs, but is still in draft form. To predict the future strengths and weaknesses of this policy, a thorough study of the policy development process is needed. This proposal adds to the previously approved protocol, “Learning by doing and doing by learning: A civil society network to realise the right to health” (PI: Leslie London). Complementing the work of this project and its Learning Network, interviews with key informants and in depth research of community participation policy will provide greater understanding of the policy making process, further insight into the best practices necessary for interaction between providers and community members, and new models for realizing rights to health.

Table of Contents
Research Objective ........................................................................................................................................... 2
Background and motivation for the study ...................................................................................................... 3
1. Review of the literature ............................................................................................................................. 3
2. Participation in the context of South Africa ............................................................................................. 4
3. Policy relevance ......................................................................................................................................... 6
Project design .............................................................................................................................................. 6
1. Study setting ............................................................................................................................................. 6
2. Relevant experience and expertise ........................................................................................................... 7
3. Three Month Plan .................................................................................................................................... 8
Table 1: Objectives ....................................................................................................................................... 9
Methods ....................................................................................................................................................... 10
1. Population .............................................................................................................................................. 10
2. Data Collection ...................................................................................................................................... 11
3. Management and Staffing Plan ............................................................................................................. 12
Ethical considerations .................................................................................................................................. 103
Research Objective

The purpose of this project is to document and analyze community participation in health services. This project aims to study the process of the development and formation of South Africa’s Western Cape Draft Policy Framework for Community Participation/Governance Structures for Health in order to better understand the relationship between policy frameworks and realization of community participation in health. This study plans to highlight best practices to develop policy that advances the right to health using a rights-based community participation approach to advance health systems.

Successful community participation depends on proper implementation of effective policy, which remains incomplete and unrealized in much of South Africa. This proposed project furthers the policy goals outlined in the White Paper on Transformation of the Health System in South Africa and the Draft Policy Framework for Community Participation by developing resources for understanding the policy making process and ensuring community participation in health services through research to:

1. Interview ten to twelve key informants regarding the Policy on Health Committees, including examination of the:
   a. Process of the development and formation of the draft policy,
   b. The current status of the policy, and
   c. Predicted obstacles and facilitatory factors to implementation.
2. Educate those interested in improving community participation (public health professionals, the legal community, public health advocates, and others) to apply rights-based policy as an effective tool for meaningful community participation.
3. Collaborate across the Learning Network, UCT School of Public Health and Family Health and Human Rights program through Professor Leslie London, and University of North Carolina through Professor Benjamin Mason Meier.
4. Create a manuscript for publication based upon the analysis of this study.
Background and motivation for the study

1. Review of the literature

Greater community participation in health systems is an important aspect to any rights-based health policy. With increased public participation, individuals have more autonomy to assess their health needs and problems, collaborate with others to create solutions specifically tailored to their community and evaluate the success and continued adjustments to health care programs (Dujardin, 2004). This participation allows for a sustainable health policy that better addresses the local community and greater achievement of the right to health for all. Benefits to community participation include increased community awareness of health related programs and activities, wider dissemination of knowledge and health education and increased equity of health care provisions (Zakus and Lysack, 1998). If mechanisms for participation within the health system are created, community participation has the potential to reach these intended goals and have a positive impact on realization of rights to health.

Yet creating a policy that effectively implements valuable community participation is made difficult in addressing and defining the complex realities of the process of community participation (Askew and Khan, 1990). In order to create policy that truly realizes community participation and leads to greater achievement of the right to health, one must look at the way in which community participation is structured, functions and relates to other sectors of society (Mandan, 1987).

In defining the process by which representatives are elected, appointed or assigned to HCs, policy makers assume that HCs provide an accurate assessment of the community’s needs, resources and values in order to build partnerships within the health system and increased community participation (Jonas, 1978). However, this cannot be accomplished if minority and disadvantaged groups are not accurately represented or do not have substantial authority within the HCs. Politics and social structure may dominate community participation; if these issues are not explicitly addressed in policy creation, existing social structure of inequality will only be reinforced (Jonas, 1978). Thus, the operational aspects of community participation must be understood before rights-based health outcomes are achieved, as the selection of HC members—by direct election from the entire community, election from specified interest groups, or appointment from local government—is crucial to the future success of any HC (Jonas, 1978). In order for community leaders to be seen as legitimate spokespeople in the eyes of the community, the method of selection must be perceived as valid and just.

Beyond the selection process, determining who is a legitimate representative of the community is a difficult task. Community participation requires individuals to possess sufficient health knowledge, as well as willingness to donate time and energy to these projects (Zakus and Lysack, 1998). The nature of participation creates a series of
opportunity costs that many community members cannot afford, including lost pay, travel costs, and training difficulties (Zakus and Lysack, 1998). Rather than true representatives, people who can afford to participate in the HC are often part of the elite class and may not be seen as legitimate spokespersons for the community at large. Without meaningful participation from minority or impoverished groups, community participation cannot adequately achieve its intended benefits (Zakus and Lysack, 1998). Even when minority groups or other groups generally left out of the participation process do find ways to participate, the political and social environment may not create an environment where they feel they are adequately represented. Therefore, policy makers must carefully study of who is included in the community and who could potentially be excluded through community participation policy.

In implementing this policy, goals, expectations and methods of participations must be clearly established and defined to ensure positive links between the local government and HCs. Significant community input should be used when creating the infrastructure and organizing bodies, as these organizational structures must be mutually accepted to sustain positive working relationships (Lysack, 1996). In order to avoid implementation problems, careful and specifically defined objectives and member powers and responsibilities must be defined in a transparent and interactive way within the community (Lysack, 1996). Meaningful participation can only be achieved if the process is transparent and seen as effective and legitimate representation of the community’s needs.

Where the creation of HCs alone will not ensure the benefits of community participation, a transparent, just and carefully defined policy must establish a process in which each committee members’ specific roles and responsibilities are clearly defined. More importantly, each committee member must be perceived as valid representatives of the community and must appropriately address the community’s concerns and values. Community participation is vital to addressing the human right to health, and it is crucial that policy addresses the process in which these HCs are established and maintained.

2. Participation in the context of South Africa

Over the past ten years, several southern African governments have worked to create executive and legislative measures to include community participation in health systems. Recognizing community participation as an important aspect in realizing the right to health, formal structures for participation were designed to promote community involvement and improve health for all. These community participation structures were identified as health center committees (Boulle et al, 2008).

In the aftermath of the Apartheid regime, the new democratic government worked to reform the inefficient and unequal health system and create a unified District Health System based on the values of decentralization, participation and equity (Levendal et
In 1997, these objectives and principles were explicitly stated in the White Paper on Transformation of the Health System in South Africa (White Paper) (Department of Health, 1997). The White Paper emphasized South Africa’s commitment to community participation, stating as one of its goals “to foster community participation across the health sector,” and established mechanisms to improve communication between the community and health services (Department of Health, 1997). However, the extent to which the White Paper’s goals would be achieved and contribute to promoting community participation remained unclear (McIntyre and Gilson, 2002).

Community Health Committees (HCs) became the formal structure for community health participation under the National Health Act of 2003 (Department of Health, 2004). The legislation required that every health facility be linked with a HC and have community-elected representatives, including a health facility manager and a local ward councilor (Department of Health, 2004). Although the National Health Act sought to define HC roles and powers under provincial legislation, the National Act is not fully developed with regard to HCs and has not been implemented in most of the nine provinces (Paradath and Friedman, 2008). In the Western Cape, a policy framework for community participation has not been fully established, despite a commitment for community participation in the Provincial Health Plan of 1995 (Ministry of Health and Social Services, 1995). Although a policy framework for community participation has been written, it remains in draft form and thus has not been implemented (CMHF, 2009). After the National Health Act of 2003 was implemented, policy makers began outlining the specific frameworks for community participation, with the roles and responsibilities of HCs described and defined in the Policy Framework for Community Participation/Governance Structures for Health. The ability of this Policy Framework to provide much needed mechanisms for meaningful community participation has not been studied, and it is unclear how effective it will be once implemented.

Through the creation of HCs, it is clear that South Africa has acknowledged the importance of participation in the Health Care system, but this commitment has not reached so far as to create tangible policy results at the provincial level. In fact, a 2003 survey found that HCs were established in only three out of five Primary Health Care facilities in the country (Reagon et al, 2004). Recent studies bear similar discouraging findings, concluding that many HCs are ineffective, poorly functioning or that the HCs members felt their opinions were neither valued nor considered within the health service system (NNMU, 2006).

The reasons for this policy failure in facilitating effective community participation needs to be studied. Studies found that community participation was significantly hindered when participation in decision-making was not fully supported by governance structures and where public participation was absent from the first stages of implementation (Baez and Baron, 2006). Other studies note that the scholarly literature has not fully described the complex factors that facilitate and impede
community participation, including power relations within communities, bureaucrats and the health services. If these factors are not addressed in a comprehensive approach to community participation, meaningful participation through South African HCs will not be realized (Paradath and Friedman, 2008).

This proposal complements an extends Professor London’s larger project, “Learning by doing and doing by learning: A civil society network to realise the right to health,” which seeks to address the high levels of health inequality in South Africa by understanding the complex relationship between community participation and rights-based health system reforms. The project seeks to improve the interactions between health care providers and community members by developing training materials on human rights, best practices for community engagement in health facilities, and new models for realizing rights to health. By identifying needs and monitoring outcomes of community and health worker training, this project plans to develop best practices for organizational leadership, document training materials and increased functioning of HCs.

3. Policy relevance

Previous research, case studies and observations strongly suggest that community participation is a key factor in advancing the right to health. Yet evidence also suggests that community participation is largely absent from many health systems; even in systems where a form of community participation is established, considerable problems in implementation impede the functioning of participatory mechanisms and and the realization of health equity (Brownlea, 1987). Further research is needed to understand how participation through South African HCs can be implemented in practice. The proposed research will help clarify the relationship between community participation and the right to health by exploring this in the context of the Western Cape HCs and the Draft Policy Framework for Community Participation/Governance Structures for Health. This study intends to describe the process of development and implementation of the community participation policy framework and to predict the future problems and successes of the policy in achieving true community participation. The conclusions from this study seek to guide future development and implementation of policy on Western Cape Health Committees, as well as other policy mechanisms for participation nationally and internationally. The study findings will also contribute to a growing body of literature attempting to understand the relationship between participation and the right to health.

Project design

1. Study setting
The study will take place within communities possessing community health facilities and operational HCs in the Cape Metropolitan area of South Africa’s Western Cape Province.

Currently, the Cape Metro Health Forum (CMHF) constitutes a single health district with 8 sub-district health fora and 86 clinic committees; the Draft Policy Framework for Community Participation/Governance Structures for Health seeks to coordinate and formalize these community participation structures within the District Health System (DHS) in the Western Cape. By focusing on partnerships with other stakeholders, this Draft Policy seeks to enforce the quality of care at all levels of the health system and to establish mechanisms to improve public accountability and promote dialogue between the public and all relevant stakeholders.

The CMHF executive consists of 1 representative from each of the 8 sub-districts in the Cape Metro, and 1 representative each from the management of City Health and the Metro DHS. The executive coordinates the effectiveness of the sub-district health fora, create strategies for optimal community participation structures and evaluate the effectiveness of the health committees and hospital boards across all 8 sub-districts.

Each sub-district health fora consists of 1 representative from each health committee within the sub-district, 1 representative from each district hospital board, 2 managers from the sub-district health management team, and representatives from relevant civil society organizations. Each sub-district is responsible for coordinating the effectiveness of the CHC committees and hospital boards within the district, implement sub-district strategies for optimal community participation structures and evaluate their effectiveness.

In accordance with the Draft Policy Framework for Community Participation/Governance Structures for Health, each community health committee (CHC) must include one or more local councilor, one or more members of the community served by the health facility and the head of the facility. Three to eight members are to be elected by patients and communities, as well as the head of the facility served by the committee and a local ward councilor. The main role of the CHCs is to take steps to ensure that the needs, concerns and complaints of the patients and the community are properly addressed, as well as to foster community support for the programs of the facility.

2. Relevant experience and expertise

This project builds on the Learning Network’s ground-breaking work in studying the practice of human rights of health care providers and how the interaction between providers and community members can generate new models for realizing rights to health. Combined with the expertise of Leslie London of the University of Cape Town, Benjamin Mason Meier of the University of North Carolina at Chapel Hill, and various public health and legal professionals, this project is uniquely positioned to add
to the scholarly literature, to develop policy resources concerning community participation and to educate organizations in applying this work.

3. Three Month Plan

The project will identify all policy related to community participation in the health system in the Western Cape Province, and through a combination of online research and interviews with key informants known to the researchers, examine legal community participation initiatives throughout the nation and the policy implications derived from them.

The research team will explore, through analysis of the collected information, the degree to which health policy has been implemented for community participation, how effective these initiatives have been, and future implications of drafted health policy frameworks. This will allow examination of how various policy approaches have addressed challenges to community participation and what problems and obstacles to implementation various informants predict in the future. This study of the process of policy making and challenges in community participation will add to the existing knowledge and assist to inform policymakers.

This project is proposed for a three-month period, beginning June 3, 2010, with major project activities and deliverables carried out in the five overlapping objective presented in Table 1 and described below: