

PART A: PROTOCOL

1.0 INTRODUCTION

1.1 PROBLEM IDENTIFICATION

Since the Alma Alta declaration on Primary Health Care (PHC), several governments have taken legislative and executive measures to include community participation in the delivery of health services. There is evidence to suggest that community participation can assist the progressive realization of the right to health; nevertheless, many authors agree that that the form of community participation envisioned by the Declaration is largely absent from health systems (Lawn et al., 2008; Rohde et al., 2008; Rosato et al., 2008; Walley et al., 2008).

PHC presented the guiding principles for health system transformation in South Africa which aimed to address the vast health inequities created during apartheid (Department of Health, 1997). Community Health Committees (HCs) were established as formal structures for participation in health and were anticipated, in part, to improve health equity through community partnerships with local health facilities (Boulle et al., 2008). Even so, variations in access and utilization of health services in South Africa remain patterned by income rather than need to maintain pervasive discrepancies in health status (Gilson & McIntyre, 2007). Preliminary data collected as part of a larger study on the right to health (SANPAD project: 07/35, 2008) highlights that although some HCs thrive, numerous others feel their inputs are neither valued nor considered in the planning and provision of health services. While some studies suggest that participation can progress the right to health, there remains a paucity of evidence linking participation to the right to health and existing data underscores a serious deficit in the implementation of community participation.

1.2 LITERATURE REVIEW

To avoid duplication, this section has been moved to Part B

1.3 JUSTIFICATION

Case studies, observations and empirical evidence suggest that community participation can advance the right to health. However, the corpus of writing linking participation to the right to health is still in its infancy and there remains uncertainty as to why some Health Committees flounder while others flourish. Further research is needed to understand the link between participation and the right to health and to explicate how participation through South African HCs can be implemented in practice. The research proposed herewith will assist to clarify the relationship between participation and the right to health by exploring this in the context of Western Cape HCs. In addition, this study will be the first in South Africa to elucidate best practice for meaningful participation through Health Committees. It is intended that the findings of this study will be used to inform future development and implementation of policy on Western Cape Health Committees, as well as forms of participation nationally and internationally. It is also intended that the study findings will contribute to a growing body of literature hoping to understand the relationship between participation and the right to health.

2.0 RESEARCH AIMS AND OBJECTIVES

2.1 AIMS

1. To clarify the relationship between the progressive realization of the right to health and community participation.
2. To draw lessons on best practice for community participation in health through Community Health Committees (HCs) in the Western Cape.

2.2. OBJECTIVES

1. To describe the nature and extent of community participation in health as it is perceived by members of HCs and health service providers at corresponding health facilities in three different Western Cape communities.
2. To compare/contrast perceived levels of participation across the three communities.
3. To identify and describe the factors impeding and facilitating meaningful community participation through Western Cape HCs.
4. To investigate if and how HC activities are associated with changes in the accessibility, acceptability, availability and quality of health services.

3.0 OPERATIONAL DEFINITIONS

HUMAN RIGHTS Consists of internationally recognized standards and norms that are legally protected by human rights law. Human rights are universal, indivisible, interdependent and interrelated. Human rights can be applied for the protection of groups or individuals and oblige states to respect, protect and fulfill these rights (WHO, 2002).

RIGHT TO HEALTH The right to health does not mean the right to be healthy or that low-income countries must adopt expensive health care; however, it does oblige governments to devise a plan of action leading to the timely achievement of this right (WHO, 2002). The right to health consists of the right of *access* to health care and the right to its underlying determinants, including adequate sanitation, nutrition, education, housing, healthy occupational and environmental conditions as well as access to health-related education and information (General Comment No.14, CESCR, 2000).

COMMUNITY In the context of the present study, community refers to individuals living in a defined geographic area who are serviced by the same health facility and who are represented by a specific Community Health Committee (Western Cape Department of Health, 2007).

PARTICIPATION The definition of participation put forth by EQUINET (2000) at a Regional meeting on public participation in health systems is the most appropriate for the present study. At this meeting, EQUINET defined participation as “involving genuine and voluntary partnerships between

different stakeholders from communities, health services and other sectors based on shared involvement in, contribution to, ownership of, control over, responsibility for and benefit from agreed values, goals, plans, resources and actions around health” (EQUINET/TARSC, 2000). This definition is understood to entail participation in the identification of health priorities, planning and implementation of strategies to address health needs as well as in the monitoring and evaluation of outcomes.

COMMUNITY PARTICIPATION The definition of community participation provided by Rifkin and colleagues (1988) is most appropriate for the present study involving health committees where participation takes place around a shared need, as each Committee is intended to represent those living in the geographic catchment area of the facility (Western Cape Department of Health, 2007). Community participation is understood as: “a social process whereby specific groups with shared needs living in a defined geographic area actively pursue identification of their needs, take decisions and establish mechanisms to meet those needs” (Rifkin, Muller & Bichmann, 1988, p. 933). Rifkin and colleague’s definition is also relevant because it recognizes that community participation is not an “all or nothing” affair but that varying levels of participation exist in different aspects of health delivery, as demonstrated in preliminary data.

4.0 METHODS

4.1 POPULATION AND SAMPLING

4.1.1 Population

The study population consists of three main categories of potential respondents relating to Community HCs in the Western Cape, namely: key informants, HC members from the community and service providers at corresponding health facilities.

- **Key Informants:** These are individuals who are considered to possess substantial knowledge of and experience with Western Cape HCs.
- **HC members from the community:** These are individuals who live in the facility catchment area and who have been chosen in some way to sit on the HC as ‘community representatives’.
- **Health Service Providers:** For this study, these individuals are defined as the clinic staff responsible for providing medical services and staff responsible for the operation and/or management of health facilities where HCs are operational or were previously operational. Service providers include: facility managers, nurses, doctors, pharmacists, social workers, occupational therapists and physiotherapists (where relevant).

4.1.2 Study setting

The study will take place within communities possessing community health facilities and operational (or previously operational) HCs in the Cape Metropolitan area of South Africa’s Western Cape Province. The South African health system has undergone major restructuring from 1994 upon transition to a democratic government. The health system that exists today is

modeled on a District Health System, wherein administrative and geographic areas containing all relevant health care activities are clearly demarcated to contain a well-defined population (Tarimo, 1991). Districts constitute the hub of management and implementation while effective referral systems occur through cooperation with other health networks (Department of Health, 1997).

The Cape Metropole (or “Metro”) constitutes a single health district with seventy-two HCs operating across eight sub-districts as of February 2009 (Cape Metropolitan Health Forums [CMHF], 2009). The National Health Act (Department of Health, 2004) states that every health facility should be linked to a HC which is comprised of community-elected representatives, the facility manager and the local ward councilor. The Act left the articulation of HC roles and powers under the guidance of Provincial legislation which remains at different stages of development across South Africa’s nine provinces (Paradath & Friedman, 2008). The number of HCs within a specific sub-district is variable as facilities are unevenly distributed across sub-districts and not all health facilities are associated with an operational HC.

4.1.3 Sampling

Sampling will be performed using a *multistage stratified purposive sampling method*.

- 1) **Key Informants:** Key informants were purposively selected from amongst the Cape Metro Health Forum (CMHF) Executive and from Metro District Health Service (MDHS) officials based on their involvement in a larger study on the right to health (SANPAD project: 07/35) and on their level of experience with the HCs.
- 2) **HCs:** Three HCs were purposively selected based on information from key informants, using the following criteria: (1) a community possessing a “strong” HC -

holds regular meetings which are well attended, takes regular action in the community or facility; (2) a community possessing a “moderate” HC – may hold regular meetings but are poorly attended, takes minimal action in the community and facility; and (3) a community possessing a “weak” HC – fails to hold regular meetings, no action evident, struggling to function or non-operational (has ceased to hold regular monthly meetings). (*Caveat*: While this is the anticipated criteria of the three committees ultimately selected for the study, the researcher acknowledges that these distinctions may not be so clear-cut)

- 3) **HC members from the community:** No sampling. Given the relatively small size of HCs (3 to 10 members), all community members within each of the three selected HCs will be invited to complete the quantitative questionnaire and to participate in an in-depth interview.
- 4) **Health Service Providers:** To minimize the burden on health services, service providers will be purposively selected (with the assistance of facility managers) for in-depth interviews on the basis of a combination of factors: long service at the facility (over 5 years), having greater knowledge of or contact with the community HC, representing the range of occupational backgrounds at the clinic (i.e. pharmacists and social workers might be included at larger clinics). Service providers who are interviewed will also be asked to complete a questionnaire.

4.1.4 Sample

- Key Informants: 2 individuals
- 3 communities in the Cape Metropolitan area:
 - The X **community**: the X HC has been selected as a purported “strong” HC and corresponds to the X Day Hospital.

- The **Y community**: the Y HC has been selected as a purported “moderate” HC and corresponds to the Y Clinic.
- The **Z community**: the Z HC has been selected as a purported “weak” HC and corresponds to the Z Clinic.

Within each of these three communities, I will include:

- All community members on the HC: Approximately 3-8 members per committee
- A purposive sample of roughly 5 service providers (inclusive of the facility manager) will be asked to participate in the study.

Exclusion criteria:

- Youth requiring parental consent will be excluded from participating in the study (youth are not presently members of HCs nor are they health service providers).
- Sex and gender are not exclusion criteria

4.2 STUDY APPROACH: MULTIPLE METHODS

The mixing of methods can augment both the quality and scope of findings that may be reached using one method alone (Greene & Caracelli, 1997) and is increasingly common in health research (Sale & Brazil, 2004). The present study will use a multiple methods approach that combines quantitative questionnaires, direct-observation, in-depth interviews and documentation. A review by Levers and colleagues (2007) found that scientific literature on participation largely failed to capture the contextual nuances of factors facilitating and impeding participation and recommended that qualitative strategies be employed for such investigations. Accordingly, the questionnaire will enable the quantification of perceptions on

community participation in health from a given community while multiple sources of qualitative data will provide a more holistic and nuanced understanding of the type of participation that is actually taking place. In this manner, qualitative findings can assist the triangulation of quantitative results and facilitate an understanding of inconsistencies. Multiple sources of qualitative data will provide a deeper understanding of the barriers to and facilitators of participation through HCs and of the relationship between participation and the right to health. In addition, interesting findings from document analysis or observational data can uncover important threads of information for further exploration through in-depth interviews while multiple data sources will assist the triangulation of qualitative findings.

4.3 DATA COLLECTION

4.3.1 Key informant interviews

Key informants were interviewed in order to guide the selection of the three HCs for the study (listed above). Key informants also facilitated access to the selected HCs and the corresponding health facilities. In-depth interviews with key informants were semi-structured to enable a more free-flowing dialogue. A topic guide was used to ensure that certain topics were covered.

4.3.2 Pilot phase

A draft questionnaire will be piloted with a group consisting of three community members, two health committee members and three health service providers in a Cape Metropolitan community other than the three chosen for the main study. This pilot phase will assess the *validity* of the ranking matrix, identify ambiguities in the questionnaire and evaluate the

duration of time required for questionnaire completion. The piloting session will also test project information, feed-back/reporting and consent forms for clarity and comprehension. As a result of piloting, research instruments may be amended or adapted to improve intelligibility and validity.

4.3.3 Questionnaire

Within the three communities, a tool for the measurement of community participation in health (developed by Rifkin et al., 1988) will be applied in the form of a questionnaire in order to measure degrees of participation in health-related processes as perceived by HC members and service providers at corresponding facilities. Questionnaires will be interviewer-administered.

Drawn from the works of Agudelo (1983) and an analysis of over 100 case studies, Rifkin and colleagues (1988) identified five factors influencing community participation which could be incorporated into a framework for the assessment of participation processes in health programs. These factors are: leadership, organization, needs assessment, resource mobilization and management (Rifkin et al., 1988). For each factor, Rifkin and colleagues (1988) created a continuum consisting of five ranks where each rank represents a certain degree of participation in the health care program or setting being assessed. A mark is then placed at the rank which best describes the health care program or setting and a figure resembling a pentagram can be made by linking the marks assigned for each of the factors (see Figure 1 below). Since narrow participation is represented by lower scores on the continuum (health professionals take leadership roles, plan and implement without lay participation in decision-making), connecting a series of lower ranks together would result in a small or “tight” pentagram. Conversely, broader participation is represented by higher

scores (community takes leadership position to plan, implement and assess, using professionals as a resource), which will be connected into a larger pentagram.

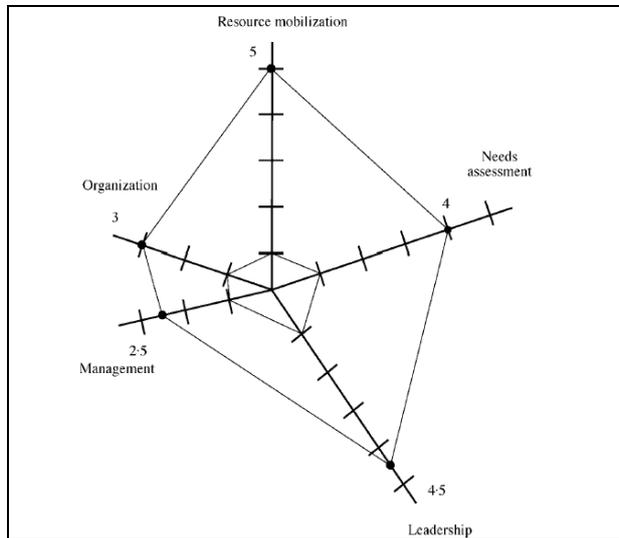


Fig.1. Example of a participation pentagram (Eyre & Gauld, 2003).

Rifkin and colleagues (1988) suggested that this measurement tool could be used to compare levels of participation in the *same* programme at *different* points in time (thus assessing changes over time), levels of participation as perceived by *different* participants in the *same* programme or to compare levels of participation across *different* programmes at one point in time. This study will use the measurement tool to compare levels of participation across the three different HC-facility pairs at one point in time.

Rifkin and colleagues (1988) did not provide guidelines regarding what methods to use for data collection and various methodological approaches have been used when adopting their framework. Types of data previously used with this framework include participant-observation, in-depth interviews, questionnaires or a combination of the three (Bichmann, 1987 in Rifkin et al., 1988; Matheson, 1990; Bjaras, Haglund & Rifkin, 1991; Eyre & Gauld,

2003); however, the original article (Rifkin et al., 1988) applied the tool as a series of in-depth interviews.

Due to time constraints, this study will apply the measurement tool in the form of a questionnaire rather than a series of in-depth interviews. The questionnaire was generated using a list of questions supplied in the original article (Rifkin et al., 1988) which was intended to assist evaluators to adapt the tool for different contexts. As illustrated by Bichmann when piloting the measurement tool in Nepal (in Rifkin et al., 1988), a matrix has been created by the researcher that describes the conditions necessary for a particular rank under each of the five factors (see ranking matrix in Part C, supplement A). A series of questions relating to each of the five factors will be asked in the questionnaire and the responses to these questions will be matched to descriptions in the matrix. The rank corresponding to this description then becomes the level of community participation in the factor, as it is perceived by a respondent (i.e. a description matching a rank of 3 under leadership means that the respondent perceives community participation in leadership to be moderate). Thus, the completion of the questionnaire by one study participant will give rise to a rank for each factor.

4.3.4 Direct observation

If granted access, direct observation will take place at HC meetings and any meetings taking place between members of the HC and health facility staff. It is anticipated that observations made on these occasions will enable data triangulation and may facilitate a deeper understanding of the information provided by respondents during in-depth interviews (and/or focus groups). In particular, observations providing insight into the relationship between HCs and health facilities, the factors facilitating or impeding community participation through HCs and the relationship between HC activities and the right to health will be sought.

4.3.5 In-depth interviews

Interviews lasting 1 – 1.5 hours will take place at a location chosen by the participant and will be tape recorded or noted in detail. Interviews will be semi-structured in order to enable a more free-flowing dialogue but a topic-guide will be used in order to ensure that key topics/questions are covered. All recorded interviews will be transcribed verbatim and those conducted in Afrikaans will be translated into English. As data collection and analysis will take place concurrently, topic guides can be adapted to explore emerging themes related to the study objectives.

4.3.6 Documentation

Policy documents, reports from the MCHF executive in addition to reports and minutes of meetings held by individual HCs and the MCHF executive will be used to supplement and triangulate other data sources. Documentation will be obtained from key informants and HCs involved in the main study.

4.3.7 Site preparation (health services)

Prior to the initiation of data collection at a facility, the researcher will organize a meeting for health service providers in order to explain project information, and time commitments. In light of limited space and human resources, the researcher will be extremely flexible with respect to interview time and locations. Where possible, the interviewer will book interview space outside of the facility and during times when staff are not working. When it is necessary to conduct interviews within the facility, the interviewer will take initiative to book space well ahead of scheduled interviews. Health service providers that have participated in a personal capacity will be involved further in feedback and reporting of research findings.

5.0 ANALYSIS

5.1 QUESTIONNAIRES

Due to the very small sample sizes within respondent subgroups and the fact that rank data is likely to be skewed, data will be analyzed to establish median ranks and the inter-quartile ranges (IQR) for each HC-facility pair. Median values will offer an indication of central tendency while the IQR will provide an indication of the amount of dispersion within each HC-facility pair. The median ranks provided by each HC-facility pair will be plotted on each axis of the pentagram to generate overlapping visual representations. For each HC-facility pair, it will be possible from the plots to visualize the overall perceived level of participation in health and to make comparisons across different communities. The Kruskal-Wallis test will be employed to determine if median scores provided for each factor (leadership, organization, etc.) differ significantly across communities. However, as some of the sample sizes used are necessarily small (most HCs are comprised of less than 10 members), the power of any statistical test employed will be very low and is unlikely to detect a statistically significant difference. Consequently, the emphasis will be on the visual presentation of the data rather than statistical significance.

All quantitative analysis will be performed using STATA 10® statistical software.

5.2 QUALITATIVE DATA

A ‘theoretical’ thematic analysis approach, driven primarily by the original research questions posed, will be the main analytical approach employed (Clarke & Braun, 2006). The researcher (GGY) will initially code data to themes defined by the study objectives. As

analysis progresses, the data will also be coded inductively based on themes that emerge from the data but which are relevant to the main research questions and objectives (“theory-driven” coding). Codes will then be sorted into related concepts and “families”, consisting of “parent” (main theme) and “child” (sub-themes) before being refined into the final themes included in the report (Clarke & Braun, 2006). Analysis will involve moving backwards and forwards between the data set as a whole, coded data that is being analyzed and analysis of data that has just been collected. Constant comparison between themes will occur throughout the analysis process to ensure that relationships between various concepts are fully explored and to highlight inter-relationships between the ideas, beliefs or perceptions of different groups of respondents.

All qualitative data will be managed with the data management software, NVivo 8[®]. Accordingly, a coding scheme will be established in Nvivo in five stages: (1) a ‘skeleton’ scheme created from study objectives will serve as a starting point for analysis; (2) after the first “x” number of transcripts has been analysed, a preliminary scheme will be generated by incorporating themes that emerge from the dataset into the starting skeleton; (3) major themes and their interpretation will be presented at a feedback meeting with HC representatives who’s comments will be used to shape further analysis and interpretation; (4) throughout the analysis of the remaining transcripts, the scheme will be modified through the addition of a few further emerging themes and the linking of related themes into coding families; before (5) the scheme is condensed by eliminating redundant codes and establishing relationships between free codes and coding families.

6.0 VALIDITY AND RELIABILITY

6.1 QUALITATIVE DATA: RIGOUR

Lincoln and Guba (1985) identify four principles that should be met to enhance the accuracy or “trustworthiness” of findings in qualitative studies. These criteria are credibility, dependability, conformability and transferability. The researcher will employ methods that take these principles into consideration during the analysis and write-up phases of the study. These techniques will be discussed briefly below.

6.1.1 Credibility

Credible interpretations are those which make sense to research participants and are consistent with the data (Lincoln & Guba, 1985). Credibility will be enhanced by posing open-ended questions, actively searching for responses that contradict initial hypotheses, testing alternate explanations and trying to account for inconsistencies in explanations provided. Emerging themes and interpretations will be triangulated using data from different sources in order to improve the credibility of the analysis.

6.1.2 Dependability

Dependability of the results is gauged by the extent to which the study findings and *process* can be replicated by other researchers (Lincoln & Guba, 1985). Dependability will be enhanced by comparing transcripts coded by the researcher with a few transcripts that have been independently coded by project supervisors. In addition, sufficient documentation will be provided on the data collection and analysis process such that replication is theoretically possible.

6.1.3 Confirmability

Confirmability relates to the researchers acknowledgment of his/her centrality to the decisions made in the research process (Lincoln & Guba, 1985). This means that regardless of the researcher's standpoint, external researchers should be able to substantiate the findings given the data used and a transparent account of the analysis process. Confirmability in this study will be enhanced by the researcher leaving an "audit trail" of notes and memos (will be done within Nvivo 8) of thought processes and decision-making during the analysis and write-up phases.

6.1.4. Transferability

Transferability is essentially known as external validity in quantitative research and is the extent to which the lessons learned from the study can applied to a similar context (Lincoln & Guba, 1985). Transferability will be enhanced in this study be describing enough of the context, participant characteristics, interactions with the researcher and the environment in which data was collected so that other researchers hoping to apply the learnings to another location can judge transferability with greater accuracy.

6.2 QUANTITATIVE DATA:

6.2.1 Validity

The validity of quantitative findings is largely dependent upon the validity of the underlying matrix used to assign individual ranks as well as the questions in the questionnaire itself. The questionnaire and ranking matrix are based on similar instruments applied by Bichmann (Rifkin et al., 1988) for his study of community health workers and community health

councils in Nepal, Bjaras (1991) in his study of a community intervention program in Sweeden and by Eyre and Gauld (2003) in their study of rural community Health Trusts in New Zealand. Since previous studies have successfully used similar instruments to assess the construct of community participation in health, it is believed that they possess face validity in the form of consensual validity.

To check for content validity, individuals involved in the pilot phase will be asked to comment on the descriptions of various ranks in the matrix and clarity of questions in the questionnaire. In addition, the questionnaire will be reverse-translated between English and Afrikaans to ensure a high-quality translation.

In the absence of a gold standard, the “validity” of ranks assigned by the researcher (GGY) will be assessed by inter-rater reliability. A second, more experienced researcher will take a simple random sample (using a random numbers table) of 10% of the questionnaires on which to conduct the ranking exercise. Cohen’s kappa will then be calculated to determine the level of agreement between these two assessors (after removing the amount of agreement due to chance).

6.2.2 Reliability

Reliability of the questionnaire will primarily be determined by the way questions are worded, the clarity of questions posed and whether the participants understand the questions being asked. Reliability may also be influenced by the participant’s level of knowledge with regards to HCs in their community as well as the administration of questionnaires. Comprehension by English second-language respondents will be enhanced through the availability of questionnaires in the first language of study participants and the presence of a

translator. In addition, the questionnaire will be adapted following the pilot session to improve the intelligibility of questions.

Unlike service providers who may have varied interaction with Health Committees, members of the same Committee are expected to have similar experiences and are therefore expected to give somewhat congruent responses in the questionnaire. Accordingly, the reliability of the questionnaire will be partially assessed using Fleiss' Kappa which will measure the amount of agreement amongst members of the same HC.

7.0 EXPECTED IMPACT ON HEALTH SERVICES

Space requirements at each facility:

- Use of a meeting room for a once-off 15-20 minute introduction to project / presentation of project information.
- Use of an office for in-depth interviews lasting 1 hour (5 in-depth interviews per facility) and completion of questionnaire (20 mins)
- Report-back meetings to be held at a central location in community- not at health facility

Equipment requirements at each facility: None

Time Requirements from staff at each facility:

- 15-20 minutes for introduction to project meeting
- 1-1.5 hrs for combined completion of questionnaire (20min) and in-depth interview (1hr)

8.0 ETHICAL CONSIDERATIONS:

8.1 RISKS TO PARTICIPANTS

The study purpose, aims and methodology will be explained thoroughly to participants in a language of their choosing and will have to opportunity to ask questions. Participants will be informed that they may decide to no longer participate in the study at any time and that such withdrawal will not affect the health care of themselves or their families. It will be emphasized to participants that all transcripts will be anonymized and all information collected will be strictly confidential. Participants might have elevated hopes regarding study outcomes; however, it will be stressed by the researcher that improvements to the health system and to levels of participation within their community are not guaranteed outcomes of the study.

In order to prevent any unintended occupational or social detriment to study participants, all transcripts will be anonymized at the point of transcription using a standardized procedure, all questionnaire data collected will be kept confidential, and all raw data (transcripts, field notes, questionnaires) will be stored in a locked cabinet.

Participants may request to receive a copy of the transcript to check. A group meeting will be held nearing the end of the write-up phase so that the primary investigator can report-back to participants regarding the research findings and so that participants can provide feedback. Once the report is complete, participants may request to receive a copy.

All participants will be given the name and contact information of the research supervisor, the primary investigator and the secretary of the ethics committee should a participant have further questions or feel that he/she has not been treated well within the study.

8.2 BENEFITS TO PARTICIPANTS

Individuals will not receive financial or material reward as a direct result of their participation in the study. However, it is intended that the findings of this study will be used to inform the future development and implementation of policy on Western Cape Health Committees. Since the results will be fed-back to participating HCs and health facilities, the findings may be used to initiate greater cooperation and information-sharing between communities and the health services. Service providers and communities would benefit from a shared understanding of HC objectives and a sense of mutual respect that may result from such exchanges.

In addition, this study will have generated a measurement tool for community participation in health that has been piloted and used in the context of HCs in the Western Cape. The larger project on the right to health (SANPAD Project: 07/35) may use this instrument to audit progress in the levels of participation experienced by communities with operational HCs in the Western Cape. The findings from such auditing processes will be used to inform strategies to alter the level of community participation in health that is able to occur through Community HCs.

9.0 ANTICIPATED GAINS IN KNOWLEDGE

- The study findings will assist to build the body of literature attempting to clarify the relationship between participation and the right to health.
- This study will also be the first in South Africa to provide lessons on best practice for community participation through HCs. Lessons learned can illustrate how community

participation in health might best be implemented in South Africa and have the potential to inform provincial and national policy guidelines.

10.0 WRITE – UP AND DISSEMINATION

10.1 VOICE

Voice is a critical concept in qualitative research that will be considered by the investigator during the write-up phase of the study. Voice means that qualitative research aims to give a public voice to the findings by using participant’s own words (Ulin *et al.*, 2005). The researcher will use quotes and brief phrases from participants in written reports and presentations (while maintaining anonymity) in order to “empower” research participants while communicating important contextual information (such as emotion, detail and nuance).

10.2 DISSEMINATION

It is anticipated that the findings of this study will be of use to several different stakeholders, all of whom will be considered in the dissemination process. Report-back meetings will be held with all research participants nearing the end of the write-up phase to share research findings and also to obtain feed-back. A report-back meeting will be scheduled for the health facility and the HC in each of the three communities involved. Final copies of the report will be posted to managers of the health facilities as well as any participants at facilities who request it. A policy brief outlining the key study findings and policy recommendations will be sent to the relevant health authorities and will be made available to other stakeholders.

Findings will be presented at the Cape Metro Health Forum (CMHF) plenary as the information will likely become useful for future engagement with the health authorities.

The preliminary research findings will be presented at the annual EQUINET (Equity in Health in Southern Africa) conference in Uganda (September 2009) and the PHASA (Public Health Association of South Africa) conference in Durban (December 2009). Finally, an article detailing the study and its findings will be written for publication in a peer-reviewed journal in order to further disseminate the information learned with individuals concerned with community participation, health and human rights.

11.0 CHANGES TO THE PROTOCOL

The pilot study revealed that low literacy levels combined the complexity of the questionnaire and low levels of knowledge about local HCs created an obstacle to obtaining valid and reliable measurements from community respondents. The protocol was subsequently changed to involve only HC members and service providers in completing the questionnaire and these changes are reflected in the above protocol. While the exclusion of community members from the study is recognized as a limitation to this study, time limitations did not permit the development, piloting and application of a separate questionnaire for community respondents. Uncertainty around community perceptions can be partially satisfied by a study conducted by fourth year medical students investigating community knowledge, awareness and understanding of one HC in a Cape Metro community (Alfred, De Klerk, Mabaso, Singh & Xiphu, 2009). However, further investigation is needed in the area of community perceptions of community participation through HCs.

12.0 BUDGET

ITEM	COST (ZAR)
Transport <ul style="list-style-type: none"> ▪ Transport for interviewer (based rate of R2.96/km for 4 months) 	5 000
Research Infrastructure <ul style="list-style-type: none"> ▪ Transcription ▪ Translation ▪ Nvivo® qualitative research software ▪ Audio recorder 	16 000
Supplies and stationary <ul style="list-style-type: none"> ▪ Photocopying and printing ▪ Refreshments for participants ▪ Flip-charts ▪ Stationary 	1 000
Telephone Scheduling interviews and meetings with facility managers, report-back meetings R50.00/month x 4 months	200
Dissemination	300
Grand Total	22 500

13.0 SOURCES OF FUNDING

Financial and Contractual Information

Is the study being sponsored or funded?	<u>Yes</u>	No
If yes Is the study sponsored/funded by a Pharmaceutical Company?	Yes	<u>No</u>
<p>Who is the sponsor/funder of the study?</p> <p style="text-align: center;">SANPAD</p> <p>(South Africa Netherlands research Programme on Alternatives in Development)</p>		
<p>What is the total budget / sponsorship for the study?</p> <p style="text-align: center;">Approximately R25, 000</p> <p>Conference Funding? (Travel, subsistence?)</p> <p>EQUINET & THE PUBLIC HEALTH DEPARTMENT</p>		
Are there any restrictions or conditions attached to publication and/or presentation of the study results?	Yes	<u>No</u>
Does the contract specifically recognize the independence of the researchers involved?	<u>Yes</u>	No
Will additional costs be incurred by the hospital/clinic?	Yes	<u>No</u>

14.0 TIMELINES

General Overview

Activity/Month	2008			2009												2010		
	O	N	D	J	F	M	A	M	J	J	A	S	O	N	D	J	F	M
Proposal write-up and revision			x	x	x													
Literature			x	x	x													
Review																		
Ethical approval (UCT HEC)						x												
Approval (Province)									x	x								
Pilot study/ Training						x	x	x										
Key Informant Interviews							x	x										
Selection of Communities and negotiation of access								x										
Field Work (questionnaires, interviews, observation)									x	x	x	x						
Analysis, Feedback, revision of field tools							x	x	x	x	x	x						
Write-up											x	x	x	x	x	x		
Ethics Review												x						
Course work	x	x		x	x	x	x	x	x	x	x	x	x	x	x			
Submission of Thesis																	x	
Feedback & Dissemination															x		x	x

Data Collection / Field work / Feed-back & Dissemination

Activity/Month	2009								2010			
	June	Jul	Aug	Sept	Oct	Nov	Dec	Jan	Feb	Mar	Apr	
With Health Committees:	x	x	x	x								
With Health Facilities		x	x	x								
Feedback to research sites									x	x		
Dissemination of findings:												
<ul style="list-style-type: none"> Conferences Province Journal Publications 				x			x			x	x	
										x	x	

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UCT ETHICS PG 1

UCT ETHICS PG 2

PROVINCIAL APPROVAL

Dear Gabriela,

Thank you for your request. Permission is hereby granted for you to conduct the research as set out in your protocol at Bluedowns as Macassar Clinics.

Contact People: Eastern Sub District:

Dr P Nkurunziza (Sub District Manager)
Tel: (021) 850-4315 / Cell: 084 800 0644

Ms T Mgqweto (Programme Manager)
Tel: (021) 850-4312 / Cell: 084 222 1487

Please note the following:

1. Any client information obtained must be kept confidential.
2. Access to the clinics must be arranged with the relevant Managers such that normal activities are not disrupted.
3. A copy of the final report must be sent to City Health Head Office within 3 months of its completion and feedback must also be given to the clinics involved.
4. Your project has been given an ID number (10143). Please use this in any future correspondence with us.

We would value any research recommendations which would help to improve our services.

Thank you for your co-operation and contact me if you require further information or assistance.

Yours sincerely

Hélène Visser

Dr G H Visser
Manager: Specialised Health

cc Dr P Nkurunziza
Ms T Mgqweto

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PART B: LITERATURE REVIEW

1.2 LITERATURE REVIEW

1.2.1 REVIEW OBJECTIVES

- To determine the background and origins of community participation in health.
- To describe existing knowledge on community participation in health generally.
- To describe community participation and community governance structures in Southern Africa.
- To describe existing knowledge on Community Health Committees in South Africa.
- To determine what has been written about community participation and human rights.

1.2.2 SEARCH STRATEGY

Search terms: Community participation, health, human rights, right to health, Alma-Ata, Primary Health Care, South Africa, Community Health Committees,

Search Sources: Search engines, the UCT library catalogue, government databases, UN and WHO online catalogues, online databases of relevant regional non-governmental institutions and networks (i.e. Health Systems Trust, Regional Network on Equity in Health in East and Southern Africa)

Search engines: PubMed, Science Direct, Google Scholar

Inclusion criteria: English language books, published articles from peer-reviewed journals, published or unpublished reports, hearings, conference

presentations and post-graduate dissertations which contribute to achieving the review objectives.

Exclusion criteria: Articles from non-peer-reviewed journals and any piece of writing that was not written in English or did not contribute to achieving the review objectives.

1.2.3 QUALITY CRITERIA

- Articles from journals possessing a high impact factor in the social sciences or health sciences (i.e. Social Science and Medicine, Lancet, New England Journal of Medicine, Health Policy and Planning, Health Promotion International)
- Studies conducting a primary analysis of original data were evaluated on the basis of methodological rigour. For qualitative research, this included a level of reflexivity, multiple coding and some degree of data triangulation. For quantitative research, this included validity and reliability of research instruments, sampling methods likely to yield a representative sample of the population of interest and the use of blinding, where possible. For reviews, the search strategy, potential sources of bias and limitations should have been described and discussed in detail.

1.2.4 SUMMARY & INTERPRETATION OF THE LITERATURE

I. THE PRIMARY HEALTH CARE MOVEMENT

For many, the Alma-Ata declaration on Primary Health Care (PHC) represented a revolutionary change in thinking on health systems and development, underpinned by key principles such as equity, social justice and community participation (Vuori, 1986; Lawn, Rohde, Rifkin, Were, Paul & Chopra, 2008). The Declaration promoted the concept of health as an outcome of social determinants, thus supporting the notion of intersectoral collaboration for the provision of a comprehensive menu of programmes and services. It provided the guidelines for health-sector reform that would enable low- and middle-income countries to meet the health needs of vulnerable and underserved groups. In addition, the Declaration highlighted the responsibility of governments for the health of their people while advocating for the right and duty of people to plan and implement their own health care as a prerequisite for equity in health (World Health Organisation [WHO], 1978).

Yet over 30 years since the writing of Alma-Ata, health sector reform has still not adequately addressed issues of equity, access, coverage and quality in health services (Lehmann & Matwa, 2008). In some countries, these aspects have worsened. While opponents use this as an indication that PHC is a failed experiment, others argue that PHC as envisioned by Alma-Ata is an experiment that, in many cases, never took place (Werner & Sanders, 1997; Laverack & Wallerstein, 2001). The approach faced active resistance from authoritarian governments, elites, medical professionals (Werner & Sanders, 1997), and those within the public health sector itself (Walsh & Warren, 1979). The open-ended language of Alma Alta became its “Achilles heel”, leaving the Declaration vulnerable to interpretation by oppressive regimes (Navarro, 1984). Other world events impeded the successful implementation of a comprehensive PHC approach, including an oil crisis and the subsequent global recession

which diminished resources for expenditure on health, the introduction of structural adjustment programmes by development banks and high-priority health issues requiring vertical programmes (Chan, 2008).

Academics pioneering the literature on participation and PHC maintain that the principles of Alma-Ata are still relevant today as the same health issues faced by policy-makers at Alma-Ata persist and have been joined by new challenges (Lawn et al., 2008; Rohde, Cousens, Chopra, Tangcharoensathien, Black, Bhutta & Lawn, 2008). These academics argue that experiences documented over the past 30 years can serve to clarify the importance of Alma-Ata and demonstrate how its components can best be put to use in different settings. For example, Rohde and colleagues (2008) present several illustrative cases where low-income countries have achieved impressive outcomes by progressively building comprehensive health systems to high coverage. Yet even in situations where considerable progress has been made, there is a general consensus that community participation is the one key principle of Alma-Ata that is most often neglected (Lawn et al., 2008; Rohde et al., 2008; Rosato, Laverack, Howard Grabman, Tripathy, Nair et al., 2008; Walley, Lawn, Tinker, de Francisco, Chopra, Rudan et al., 2008).

II. PARTICIPATION: ITS BENEFITS AND LIMITATIONS

While cited as being “at the heart” of the PHC approach (Ahmed, 1978), the literature describes numerous examples where a true commitment to community participation in health is absent in terms of the vision projected by Alma-Ata. Many reasons have been offered for this, including cultural factors (Foster, 1987; Stone, 1992), power relationships (Prichard, 1986; Nichter, 1986; Brownlea, 1987), lack of political will (Tatar, 1996; Werner & Sanders,

1997; David & Zakus, 1998), conceptual and operational problems (Navarro, 1984; Ulgade, 1985; Mandan, 1987). Due to the frequent debasement and manipulation of community participation as a means to legitimize public health policies that have been planned and implemented from the top-down, many authors approach the concept with reservation (Brownlea, 1987; Mandan, 1987; Rifkin, Muller & Bichmann, 1988; Stone, 1992; Tatar, 1996; Werner & Sanders, 1997).

Other limitations of community participation in health have been highlighted over the years. For instance, it is often urban-born and educated elites who take-on key leadership roles in participative structures in low- and middle-income countries (Askew & Khan, 1990; Reidy & Kitching, 1986). Therefore authors question whether structures intended for participation are truly representative of communities, are free from vested interests and whether they sufficiently highlight the health needs of vulnerable groups (Mandan, 1987; Brownlea, 1987; Woelk, 1992). Conversely, for participative structures that appear to adequately represent their communities, authors highlight the fallacy of assuming intra-community homogeneity. It may not be accurate to assume that all individuals from the same community view improvements in health as a priority, believe that health improvements can be achieved in similar ways or are prepared to co-operate towards the goal of better health (Foster, 1982; Mandan, 1987; Stone, 1986;). Furthermore, structures for community participation face additional challenges when not equipped with the resources to effectively participate (Mandan, 1987) or when such structures are not taken seriously by bureaucrats and health professionals (Lowenson, Rusike & Zulu, 2004).

Some authors have gone further to critique the discourse of participatory development as a whole, stating that practitioners of community participation have not sufficiently considered the criticisms of ‘participants’ and have fell-short of conducting more rigorous investigations

into the frequent failure of participatory approaches to result in its anticipated outcomes (Cooke & Kothari, 2001). These authors argue that genuine reflexivity in the field of participatory development requires an acknowledgement that participation may be ‘tyrannical’ in the sense that it has the potential to facilitate and perpetuate the illegitimate or unjust exercise of power (Cooke & Kothari, 2001).

In spite of these complexities, limitations and drawbacks, theoretical arguments supporting community participation in health are compelling. Some of the dominant arguments include: lowered costs for service delivery through voluntary community efforts and mobilization of resources from outside the health sector (Brownlea, 1987; Martin, 1983; Stone, 1992; Dujardin, 1994; Craig & Mayo, 1995), thereby increasing the *availability* of health services; greater accountability and bureaucratic responsiveness (Brownlea, 1987; Dujardin, 1994; Potts, 2008), thereby making health services more *accessible*; superior *quality* of care through more equitable client-provider relationships leading to improved feedback mechanisms and services that are more socially and culturally *acceptable* (Nichter, 1984; Vuori, 1986); increased consciousness and sense of responsibility for health by community members accompanied by gains in power from acquiring new skills and securing control over resources (Oakley, 1989; Stone, 1992; Craig & Mayo, 1995), all of which are intended to improve the effectiveness and sustainability of health interventions, programs and services.

Beyond theory, case studies, observations and empirical evidence indicate that community participation does have positive impacts on health and health systems. National programmes utilizing community participation in China, Cuba, Tanzania, Sri Lanka and Venezuela served as some of the first examples of how community involvement improves the success of health initiatives and had a major impact on the individuals who ultimately gave rise to Alma-Ata (Mandan, 1987; Werner & Sanders, 1997; Lawn et al., 2008; Rosato et al., 2008). Since then,

cases demonstrating successful community participation initiatives have emerged around the world. Community involvement in the planning of diarrhea control programmes in Mozambique and in the planning and provision of services in the San Ramon district of Costa Rica contributed to substantial reductions of infant mortality rates around the late 1980s (Werner & Sanders, 1997). Structures for participation in Tanzania, India, the Puno region of Peru and North Belfast have improved accountability of health services, thereby enhancing coverage, access, quality and effectiveness of services (Reid & Kasale, 2000 cited in Loewenson, 2000; Potts, 2008). A meta-analysis by Rosato and colleagues (2008) presented evidence from published and ongoing trials, indicating that interventions involving community mobilization can result in substantial reductions in morbidity and mortality of infants, mothers and children. On a regional level, studies in Southern Africa indicate that dialogue between communities and health services are required for improved treatment compliance and for preventative measures to be effective (Gilson, Kilima & Tanner, 1994; Loewenson, 2000). Additionally, investigations by Loewenson and colleagues (2004) into Zimbabwean Health Centre Committees (HCCs) revealed an association between these participatory structures and improved health outcomes in severely under-resourced settings. Despite the fact that HCCs were poorly trained, poorly resourced and received weak recognition by health services, the research by Loewenson and colleagues (2004) revealed that these Committees helped to increase drug availability at clinics, provided health information to the community, improved the quality of care by building important components of clinic infrastructure for patients and secured links between health workers and the community to promote access. These findings underscore the significance of participation in health and suggest that community participation can have the effect of making health services more accountable, acceptable, accessible, available and of greater quality, even in resource-poor settings.

III. PARTICIPATION IN THE CONTEXT OF SOUTH AFRICA

Over the past decade, several governments in Southern Africa have taken executive and legislative measures to include community participation in the delivery of health services. Formal structures for community participation in health were anticipated to promote community involvement in service delivery and the improvement of community health. While largely serving similar functions, such structures have been identified in this region as health center committees, neighbourhood, village or community health committees (Boulle, Makhamandela, Goremucheche, & Loewenson, 2008).

In South Africa, Primary Health Care presented the guiding principles for health system transformation focusing on the vast health inequities inherited from apartheid. The new democratic government aimed to convert the inefficient and deeply fragmented health system into a comprehensive, unified one modeled on a District Health System and based on the underlying tenets of decentralization, participation and equity (Levendal, Lapinsky & Mametja, 1997). The White Paper on Transformation of the Health System in South Africa (Department of Health, 1997) emphasized the national Department of Health's commitment to community involvement, stating as one of its goals "to foster community participation across the health sector". Towards the achievement this aim, the White Paper set-out to involve communities in the planning and provision of health services, to establish mechanisms for improved dialogue and feedback between communities and service providers, and to encourage communities to take greater responsibility for their own health (Department of Health, 1997). Furthermore, the White Paper acknowledged the essentiality of "active participation and involvement of all sectors of South African society" in order to achieve health goals set at various levels, as well as the specific importance of women,

children, vulnerable and under-served groups in participatory processes (Department of Health, 1997).

Formal structures for participation in health took the shape of community health committees (HCs) in South Africa, which were established under the National Health Act of 2003 (Department of Health, 2004). The legislation required that each health facility be linked to a community HC, comprised of community-elected representatives, the health facility manager and a local ward councilor (Department of Health, 2004). The Act left the demarcation of HC roles and powers under the guidance of Provincial legislation; however, this legislation remains at varying stages of development across South Africa's nine provinces and is yet to materialize in most (Paradath & Friedman, 2008). The Western Cape Provincial Health Plan of 1995 articulated a commitment to community participation in the planning of local health services through the establishment of Community HCs (Ministry of Health and Social Services, 1995). Yet, a policy framework for Community governance structures for health remains in draft form in the Western Cape Province (Cape Metropolitan Health Forum [CMHF], 2009) and it is unclear whether this framework can provide the basis for meaningful participation.

The creation of HCs in South Africa indicated a degree of acknowledgement for participation as an important principle of the Primary Health Care approach, to which national and provincial Departments of Health signalled commitment through policy documents. In spite of this theoretical commitment, a 2003 survey concluded that community HCs existed in only three out of five Primary Health Care facilities in the country (Reagon, Irlam & Levin, 2003). These findings are consistent with more recent studies highlighting the fact that many HCs in the country are functioning poorly or ineffectively, if at all (Nelson Mandela Bay Metropolitan University [NMMU], 2006; Boulle et al., 2008; Paradath & Freidman, 2008). In

addition, preliminary data collected in the Western Cape as part of a larger project on the right to health (SANPAD project: 07/35, 2008), indicated that numerous Committee members felt their inputs were neither valued nor considered in the planning or provision of health services.

In attempting to account for the failure of community governance structures to facilitate participation in East and Southern Africa, two literature reviews (Baez & Baron, 2002; Levers, Magweva & Mpofu, 2007) and one original research study (Paradath & Freidman, 2008) have investigated the barriers and facilitators to the *effective functioning* of community governance structures. The literature reviews were conducted with considerable methodological rigour, well describing the purpose and methodologies. Baez and Baron (2002) included South Africa in their review and concluded that community participation had the greatest impact when supported by functional governance structures that promote participation in decision-making. These authors noted that such instances were few in number but that efforts to promote genuine participation could be improved if regional success stories were collected into a single advocacy document. The review by Levers and colleagues (2007) chose six African nations, excluding South Africa, for their investigation. This review indicated that public participation in health was most absent at the stage of implementation, that scientific literature has failed to capture the contextual nuances of factors facilitating and impeding participation and that qualitative strategies should be employed to investigate research gaps, specifically power relations amongst communities, bureaucrats and the health services. The investigation by Paradath and Friedman (2008) was the first original research study to include HCs from all nine of South Africa's provinces. However, due to the large geographic scope of this study, only facility managers were included in a survey on community HCs while the viewpoints of HC members themselves were assessed through three focus groups held in the Provinces of KwaZulu Natal, Eastern Cape and the Free State.

The inability of these investigators to include HC members in their survey and the inclusion of Committee members from just three of South Africa's nine Provinces is likely to have influenced their results. All three studies suggest that the inclusion of participation in policy is not enough to ensure meaningful participation; still, no published studies to date have attempted to elucidate best practice for meaningful participation through South African HCs (Paradath & Friedman, 2008).

IV. THE RIGHT TO HEALTH

The right to the highest attainable standard of health (known as “the right to health”) was first described in the WHO Constitution (1946), has been concretized in international human rights law through the Bill of Rights (Universal Declaration of Human Rights [UDHR], 1948; International Covenant on Economic, Social and Cultural Rights [ICESCR], 1966; International Covenant on Civil and Political Rights [ICCPR], 1966) and was reiterated by the Declaration of Alma-Ata (WHO, 1978). The attainment of every right involves entitlements (“claims”) and responsibilities (“duties”). Human rights are principally focused on the relationship between groups/individuals (“claim-holders”) and the state (“duty-bearer”), such that governments have an obligation to *respect, protect, promote* and *fulfill* the rights of its people (Mann, Gruskin, Grodin & Annas, 1999). As with all human rights, the right to health is inter-related with and indivisible from civil and political rights (i.e. life, freedom, expression) as well as other social, cultural and economic rights (i.e. education, housing, culture) (Mann et al., 1999). Accordingly, the WHO's definition for the right to health aptly extends beyond the right to be healthy to include the underlying social determinants of health such as adequate nutrition, sanitation, education, participation and access to health-related information (WHO, 1946).

The right to the highest attainable standard of health is outlined in Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESR) which has been ratified by 160 States as of January 2010 (UN Treaty Collection). Although the decision to ratify an international human rights treaty is voluntary, ratification commits a country to comply with the treaty's provisions and its general comments. The principle of *progressive realization* recognizes that certain rights (such as the right to health) cannot be fully operationalized overnight; however, a State Party must show deliberate and concrete actions that demonstrate commitment to its obligations under the treaty (WHO, 2002).

General comment (GC) 14 was written in 2000 to provide elaboration on the right to the highest attainable standard of health and to provide guidance for State Parties to progressively realize this right (UN Committee on Economic, Social and Cultural Rights [CESCR], 2000). The Comment defines the nature and content of the right to health and clarifies the specific and general obligations of State Parties. In particular, GC 14 lists specific "core" measures which must be undertaken by *all* State Parties, regardless of resource capacity, and specifies the need for specific progress indicators and benchmarks. The General Comment also establishes four criteria by which the progressive realization of the right to health can be monitored, including availability, accessibility, acceptability and quality. In this manner, GC 14 reaffirms international commitment to the realization of the right to health and enables the HRC to draw clear distinctions between State *inability* and State *unwillingness* (WHO, 2002).

In South Africa, the right to health is provided for in three sections of the constitution: Section 27 provides for the right of access to health services, social security, sufficient food and water; section 28(1)c provides children with the right to basic nutrition, shelter, social services and health care services; and section 35(2)e provides detained persons with the right

to medical treatment at state expense. While South Africa has not yet ratified the ICSECR, section 39(1) of the Constitution requires courts, tribunals and forums to consider international law when interpreting the Bill of Rights (Republic of South Africa, 1996). Indeed, several major cases in the Constitutional Court have borrowed from international human rights laws for interpretation (*RSA v. Grootboom*, 2000; *Minister of Health v. T.A.C.*, 2002), underscoring the relevance of international human rights standards and norms in the South African context.

V. PARTICIPATION AND THE RIGHT TO HEALTH

Recent international developments in this area have emphasized the importance of participation for the realisation of the right to the highest attainable standard of health (Potts, 2009). In the preamble of this monograph, Paul Hunt, former UN Special Rapporteur on the Right to The Highest Attainable Standard of Health, formally recognizes participation as a human right and an integral component of the right to health (Hunt, 2009). Importantly, Hunt also acknowledges the dearth of research exploring the interface between participation and the right to health.

Participation has been explicitly mentioned within international human rights documents, including general comment 25 of Article 25 of the ICCPR (CCPR, 1996) and CEDAW general recommendation no.23 (CEDAW, 1997). However, these references are predominantly related to participation in democratic decision-making in a non-health related context. In addition, Potts illustrates through case law that the present legal interpretation of participation in these documents is not ideally suited to claims for community involvement in health (2005). Potts (2005) asserts that since state parties are entitled to determine the

‘modalities’ of participation, community participation in health may be striped to its narrowest form, existing only as consultation rather than effective involvement in planning and implementation processes.

Closer inspection of the health and development literature reveals that much of the language around participation in WHO documentation resembles that of human rights documents and vice versa. For instance, the Declaration of Alma-Ata strongly reaffirmed that “health is a fundamental human right” (Alma- Ata, 1978, para 1), stating that “people have a right and a duty to participate individually and collectively in the planning and implementation of their health care” (Alma- Ata, 1978, para 4). In addition, human rights academics emphasize the role of Alma-Ata in outlining the conditions necessary for states to realize the right to health and its influence on GC 14 (Dujardin, 1994; Backman, Hunt, Khosla, Jaramillo-Strouss, Fikre, Rumble et al., 2008). GC 14 on the right to health (Article 12) has particular relevance for participation as it advocates for “... participation of the population in all health-related decision-making at the community, national and international levels” as critical for the realization of the right to health (GC No.14, para 11). The General Comment instructs states to develop and adopt a national public health strategy and plan of action through *participatory* processes as a minimum core obligation (GC No.14, para 43(f)). Furthermore, GC 14 establishes four criteria that can be used to evaluate the right to health, namely availability, accessibility, acceptability and quality.

As discussed in previous sections, the interdependency of human rights means that the realization of the right to health is contingent upon the attainment of other human rights, such as participation. Case studies, observations and empirical evidence have demonstrated that community participation is associated with improvements in quality, access, availability and acceptability (refer to section 1.2). However, clear linkages between participation and the

right to health are not well developed in the literature. While some authors have hinted at the significance of participation for the realization of the right to health (London, 1997; Lister, 1998; Wilder, Fischer & Brunner, 2002; Backman et al., 2008), virtually none (aside from Potts, 2005 & 2009) have attempted to concretize this relationship.

1.2.5 JUSTIFICATION FOR FURTHER RESEARCH

Findings presented by South African studies and preliminary data collection underscore a serious deficit in the implementation of community participation within a health system requiring transformation to begin addressing issues of equity. In spite of the apparent significance of participation for the operationalization of the right to the highest attainable standard of health, the corpus of writing linking participation to the right to health is still in its infancy. Furthermore, the purported benefits of participation are approached with reservation by many who highlight the frequent manipulation and debasement of its principles. Thus, research is needed to clarify the link between participation and the right to health and to elucidate best practice for meaningful participation through South African Health Committees. The proposed research will make contributions locally to the development of Health Committees, to the international body of literature on participation in health and, more importantly, to the body of literature on participation and the right to health.

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**PART C: JOURNAL
MANUSCRIPT
(SOCIAL SCIENCE & MEDICINE)**

Community Health Committees as a vehicle for community participation in advancing the right to health

Word count: 7,949

Key words: community participation; health; human rights; South Africa; Community Health Committee; Mixed-method

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Abstract

The principles of Primary Health Care guided health system transformation in South Africa where community health committees represent formal structures for participation in health. While there is evidence to suggest that participation can assist the progressive realization of the right to health, this link is not well established in the literature and Southern African studies underscore a deficit in the implementation of meaningful community participation.

The present study used mixed methods to explore the relationship between participation and the right to health and to draw lessons on best practice for community participation from three health committees in South Africa's Western Cape Province. Best practices identified include: facility managers willing to shift the balance of power, intersectoral activity, intra-committee apprenticeships, an association between Committee action and visible change, as well as the use of media and written sources of information. Evidence provided by this study supports an important interrelationship between participation and the right to health that is highly influenced by elements of power. Study findings demonstrate that even in resource-constrained settings, structures for community participation were able to advance the right to health but that this was constrained by the degree of power held at various levels of decision-making. Lessons learned here contribute to a growing body of theoretical literature hoping to understand the link between participation and the right to health, and can inform national and international policy development and implementation for participation in the right to health through health committees.

Introduction

Since the Alma Ata declaration on Primary Health Care (PHC), which advocated the right and duty of people to plan and implement their own health care, several governments have taken legislative and executive measures to include community participation in health service delivery. Yet, 30 years since the writing of Alma Ata, health sector reform has still not adequately addressed issues of equity, access, coverage and quality in health services (Lehmann & Matwa, 2008). In some countries, these aspects have worsened. While opponents use this as an indication that PHC is a failed experiment, others argue that PHC as envisioned by Alma Ata is an experiment that, in many cases, never took place (Laverack & Wallerstein, 2001; Walley, Lawn, Tinker, de Francisco, Chopra, Rudan et al., 2008). Moreover, several authors contend that community participation is one key principle of PHC that is most often neglected (Lawn, Rohde, Rifkin, Were, Paul & Chopra, 2008; Rosato, Laverack, Howard Grabman, Tripathy, Nair et al., 2008).

South Africa is no exception. In the new democracy, PHC presented the guiding principles for post-apartheid health system transformation and established the basis for adopting a District Health System model (Department of Health, 1997). Formal structures for participation in health took the shape of Community Health Committees (HCs) which were anticipated, in part, to address health inequities through community partnerships with local health facilities. South African studies have, however, highlighted the fact that many HCs are functioning poorly or ineffectively, if at all (NMMU, 2006; Boule, Makhamandela, Goremucheche, & Loewenson, 2008; Paradath & Friedman, 2008). Furthermore, preliminary data collected as part of a larger project on the right to health found that while some HCs appear to thrive, numerous others feel that their inputs are neither valued nor considered in

the planning and provision of health services (SANGOCO, 2009). These findings underscore a serious deficit in the implementation of meaningful community participation.

Several explanations have been offered for the failure of meaningful community participation to prosper in most health systems. Hypothesized barriers to participation include cultural factors (Stone, 1992), power relationships (Brownlea, 1987), lack of political will (David & Zakus, 1998), lack of sufficient community representation (Mandan, 1987; Woelk, 1992) and disagreement concerning the conceptualization of the terms “community” and “participation” (Jewkes & Murcott, 1998). Two previous literature reviews (Baez & Baron, 2002; Levers, Magweva & Mpofu, 2007) and one original research study (Paradath & Friedman, 2008) have investigated barriers and facilitators to the *effective functioning* of community governance structures in East and Southern Africa. These studies report that the inclusion of participation in policy is insufficient to ensure meaningful participation and that political commitment and support at the district level is critical for the successful functioning of these structures. Still, no published studies to date have attempted to elucidate best practice for meaningful participation through HCs (Paradath & Friedman, 2008).

Despite evidence to suggest that community participation can assist the progressive realization of the right to health (Gilson, Kilima & Tanner, 1994; Lowenson, 2004; Rosato et al., 2008), clear linkages between participation and the right to health are sparse in the literature. While some authors have hinted at the significance of participation for the realization of the right to health (London, 1997; Wildern, Fischer & Brunner, 2002; Backman, Hunt, Khosla, Jaramillo-Strouss, Fikre, Rumble et al., 2008), virtually none (aside from Helen Potts, 2009) have attempted to concretize this relationship.

Given the dearth of research investigating the relationship between participation and the right to health and uncertainty regarding how participation might be operationalised through South African HCs, the aims of this paper are: (1) to describe the nature and extent of community participation through HCs; (2) to draw lessons on best practice for community participation in health through HCs in the Western Cape; and (3) to explore the relationship between community participation and the right to health. This paper applies a pentagram model (Rifkin, Muller & Bichmann, 1988) to measure the degree of community participation in health, using quantitative methods. Through qualitative methods, the factors facilitating or impeding meaningful participation across HC-facility pairs are explored before examining how community participation through HCs is associated with changes in the realization of the right to health at local facilities.

Conceptual framework

Community participation is here taken to mean: “a social process whereby specific groups with shared needs living in a defined geographic area actively pursue identification of their needs, take decisions and establish mechanisms to meet those needs” (Rifkin et al., 1988, p. 933). Rifkin and colleague’s definition is appropriate for this study involving community HCs which are geographically bounded and where participation takes place around shared need.

The role of power in relation to community participation can be understood through the work of Rifkin (1986), who contends that participation requires a shift in power. Since the inclusion of people who have traditionally been excluded from the decision-making arena

requires that those who once held a monopoly over decision-making relinquish some of their power, tensions arise when the traditional decision-maker is unwilling to do so.

The right to the highest attainable standard of health consists of the right of *access* to health care and the right to its underlying determinants (CESCR, 2000). Of special relevance to community participation is General comment (GC) 14 which elaborates on the ICESCR's (International Covenant on the Economic, Social and Cultural Rights) provisions on the right to health. GC 14 (Article 12) advocates for "... participation of the population in all health-related decision-making at the community, national and international levels" as critical for the realization of the right to health. The General Comment also establishes four criteria by which the progressive realization of the right to health can be evaluated, namely acceptability, accessibility, availability and quality (Table.1). These criteria are used in this study to evaluate how community participation through HCs contributes to the progressive realization of the right to health.

TABLE 1 HERE

Methodology

Study setting

Fieldwork was conducted between May and August 2009 in the Cape Metropolitan Area of South Africa's Western Cape Province. The Cape Metropole (or "Metro") constitutes a single health district with seventy-two HCs operating across eight sub-districts. The National Health Act (Department of Health, 2004) states that every health facility should be linked to a HC which is comprised of community-elected representatives, the facility manager and the local

ward councilor. However, the Act left the articulation of HC roles and powers to the discretion of Provincial legislation which is yet to materialize in the Western Cape.

Ethics

Ethical approval was gained from the Human Ethics Committee at the University of Cape Town (REC REF: 091/2009). Informed consent was obtained from all participants. Research instruments were available in the preferred language of participants and interviews took place at a location of the participant's choosing. Data was anonymised at the point of capture. A report-back meeting was held with all relevant stakeholders and final copies of the report were sent to participants upon request.

Study Sample

Two key informants from the Metro District Health Services and the executive of the Metro HCs (CMHF) provided information for the purposive selection of three HCs based on the following criteria: (1) a "strong" HC - holds regular meetings which are well attended, takes regular action in the community or facility; (2) a "moderate" HC – may hold regular meetings but poorly attended, minimal action in the community and facility (3) a "weak" HC – fails to hold regular meetings, no action evident, struggling to function or non-operational.

All HC members were invited to complete the quantitative questionnaire and participate in an in-depth interview. A 100% response rate was achieved for 'strong' and 'moderate' HCs, but in the 'weak' HC only three former HC members out of six could be located (Table.2). To minimize the burden on health services, four to six service providers per facility were purposively selected for in-depth interviews. Criteria for selection of service providers included: long service at the facility (at least 10 years), having greater knowledge of or

contact with the HC and being representative of the range of occupational backgrounds at the clinic (i.e. pharmacists and social workers were included at larger clinics). Service providers who were interviewed also completed a questionnaire.

Access to HCs was gained through the CMHF executive committee. All three HCs chosen represent communities characterised by high levels of poverty and unemployment, with clinics providing services to both formal and informal settlements. The HCs within these communities are predominantly English and Afrikaans-speaking.

TABLE 2 HERE

Measuring participation

Drawn from the analysis of over 100 case studies, Rifkin and colleagues (1988) identified five factors influencing community participation which could be incorporated into a framework for the assessment of participation processes in health programs: leadership, organization, needs assessment, resource mobilization and management. Narrow participation is characterized by health professionals taking leadership roles, planning and implementing without lay participation in decision-making. Broader participation is characterized by the community taking positions to plan, implement and assess, using professionals as a resource (Rifkin et al., 1988).

Rifkin and colleagues (1988) proposed a pentagram model be used to visually plot measures of participation (Fig.1). The plot could then also serve to compare levels of participation within the *same* program at different points in time, or levels of participation as perceived by different role players or assessors at the same point in time. In the present study, this model

has been employed as a tool to compare levels of participation across three different communities.

FIG. 1 HERE

Methods

This study made use of multiple methods, augmenting both the quality and scope of findings that can be reached using one method alone (Greene & Caracelli, 1997). Qualitative methods functioned to answer separate but related objectives and served as a foundation for understanding and triangulating quantitative results. The merger of findings from multiple data sources during the analysis was guided by the study's conceptual framework.

Data collection and analyses

The measurement framework derived by Rifkin and colleagues (1988) was applied as an interviewer-administered questionnaire. Based on questions supplied in the original, a series of questions were developed under each of the five factors asking respondents to rate the level of community participation *as it occurs via the HC*. The combination of responses obtained under a given factor from a single respondent constituted a subjective description of the extent of participation for that factor. This description was then matched on a matrix of indicators and levels of participation (supplementary file A) in order to obtain an individual rank for that factor. STATA 10® statistical software was used to calculate median ranks and inter-quartile ranges for each HC-facility pair (Table.3). Using the median ranks, three overlapping pentagram were derived (Fig.2). The Kruskal-Wallis test was employed to determine if ranks differed significantly between HC-facility pairs. In addition, responses to individual questions from the questionnaire were analysed to supplement rank information.

Research instruments were piloted with three community members, two HC members and two health service providers within a Cape Metro community. Low literacy levels combined with the complexity of the questionnaire and low levels of awareness about local HCs did not allow the valid and reliable measurement of participation amongst community residents.

Qualitative data consisted of in-depth interviews, policy documents, meeting minutes from individual HCs and the MCHF executive, as well as observational fieldnotes from interviews and meetings held with and between respondent groups. Qualitative data were entered into NVivo© version 8. Data were analysed thematically, initially coding to themes defined by study objectives. As analysis progressed, data was also coded inductively based on emerging themes. Thus, a constant comparison/thematic approach guided analysis as an iterative process of collection and analysis ensued, with data segments from different respondent groups and communities continuously being compared back to one another.

Validity and Reliability

Previous application of instruments similar to the ranking matrix and questionnaire used in this study (Rifkin et al., 1988; Bjaras, 1991; Eyre & Gauld, 2003) suggests consensual validity. To assess content validity, the questionnaire was reverse-translated between English and Afrikaans and checked for clarity during piloting. In the absence of a gold standard, the ranks assigned by the investigator were checked for inter-rater reliability against the ranks assigned by a second researcher for 10% of the questionnaires. Cohen's Kappa was found to be 0.70, reflecting a good level of agreement after accounting for agreement due to chance (Landis & Koch, 1977). Inter-rater reliability amongst members from the same HC was

calculated using Fleiss' Kappa to lie between 0.41 and 0.46, a level of intra-Committee reliability considered to be moderate (Landis & Koch, 1977).

To improve the trustworthiness of qualitative findings, four principles were incorporated into the analysis and write-up of qualitative data, namely credibility, dependability, confirmability and transferability (Lincoln & Guba, 1985). In particular, credibility was enhanced by attempting to triangulate findings using data from multiple respondents and sources, while dependability was enhanced by having an experienced qualitative researcher (MS) independently highlight major themes from two of the transcripts. The themes identified closely matched those found by the principle investigator.

Results

Quantitative analysis

Although the differences in ranks were not statistically significant, community participation in health was perceived to be widest in the community with a 'strong' HC and was perceived similarly for purportedly 'moderate' and 'weak' HCs (Fig.2, Table.3).

FIG.2 HERE

Across all three communities, participation in HC leadership was ranked between 3 (moderate) and 4 (open). While almost all respondents agreed that the HC was made up of community-elected representatives, there was a shared perception that the community only partially supported HC activities when they knew about them (25/29 =86%) and that the

community at large had very little awareness of HC roles and functions (21/29 =72%). Facility managers and ward councillors were reported as “sometimes” and “never” in attendance of ‘moderate’ and ‘weak’ HC meeting but were reported as “always” or “often” in attendance of ‘strong’ HC meetings.

In all three communities, respondents ranked participation in HC organisation the highest of all five factors (Fig.2, Table.3) suggesting that HC organisation was community-driven. Indeed, the majority of respondents felt that HCs were mostly “owned” by members of the community (21/29 = 72%).

Participation in needs assessment was ranked lowest in the community with a ‘moderate’ HC. Most respondents from this HC-facility pair believed that community health needs were determined entirely by health professionals (8/9 = 89%).

Irrespective of community, participation was consistently ranked the lowest in resource mobilisation out of all five factors (Fig.2, Table.3). This was primarily due to an overwhelming consensus that few resources for health come from the community (27/29 = 93%) and that the HC has little to no control over how funds are allocated to programs and services in the community (20/29 = 69%).

Participation in the management of health programmes and services was ranked highest for ‘strong’ and ‘moderate’ HCs. In these communities, the HC’s impact on the way that health services were provided was perceived to be “large” or “great” (12/21 = 57%). In contrast, the weak HC’s impact was perceived to be “moderate” (5/7 = 71 %) or limited (2/7 = 29%)

TABLE 3 HERE

Qualitative analysis

Inhibitors and Facilitators of community participation

Power and (dis)trust

Power played an important role in the relationship between HCs and service providers in all three communities. Members of ‘moderate’ and ‘weak’ HCs indicated that they had limited power and respect from service providers. Members of these HCs revealed feeling fearful of “causing trouble” or being “treated differently” by facility staff if they spoke out:

HC8: “I can communicate with my community, most of the time, but sometimes you, in the facility man, you’re so scared to talk to the sister or ask, ‘what?’”

At the facility with a ‘strong’ HC, the manager intervened considerably to “streamline” operations so that contact with the Committee operated entirely through the manager. As previous HC meetings often resulted in “personal attacks” on service providers who were disliked by the community, this approach was intended to avoid hostility between facility staff and the community. However, the ‘strong’ HC held a degree of influence in the community and at the facility which appeared to be related to the presence of Committee members who were local political councillors or who were affiliated with numerous community organisations, and to the facility manager’s close ties with the Committee. The HC’s influence combined with the exclusion of service providers from discussions with the Committee seemed to generate a level of distrust towards the HC and sustained feelings of

threat amongst service providers. One service provider highlighted this tension, stating that facility staff would “dread” when the HC became involved in issues at the health facility:

SP10: “Especially when it’s election times... there *were* of the health committee members that were councilors, and the threat is always ‘I’ll go to the councilor.’ And the councilor phones the staff and says ‘I demand that that person be seen,’ and that caused a lot of friction amongst the staff and the health committee because, are they the watchdogs?”

Lack of legitimacy and limited progress

One of the greatest barriers to community participation through HCs emerged as the absence of a formal mandate, defining the powers and functions of HCs and providing guidance to Committees and willing facility managers. Members of the ‘strong’ HC conveyed satisfaction with the Committee’s progress; still, the absence of clear guidelines may be restricting more meaningful participation. The manager at this facility expressed uncertainty on how far to involve the Committee in facility operations, but foresaw the Committee’s function as potentially developing to include a level of decision-making on behalf of the community:

FM1: “We need to know our boundaries; we need to know where we should be involved and not involved, where it comes to community participation... I think that is the missing part for me, because that’s not being spelled out...”

The absence of clear guidelines also meant that HCs had no immediate control over what they could and could not accomplish, leaving Committees dependent on facility staff to make progress in the community. For the ‘weak’ HC, the sequence of events leading to the

Committee's collapse began with the failure of staff to attend HC meetings. Without staff involvement, the HC was unable to move forward on issues that had been placed on their agenda and participation from the community slowly declined until meetings became non-existent.

Limited progress also appeared to underlie the problem of membership on the 'moderate' HC. The scarce membership of this Committee was interpreted by most service providers as a general disinterest in health from the community. However, one service provider at this facility suggested that community members would be more willing to participate if the HC was associated with visible change:

SP7: "...If we start small, maybe with the suggestion boxes... and then we say 'okay, these people are addressing the suggestion box complaints.' And when people start seeing, 'okay somebody is listening, somebody does care.' And from that I think you'll start getting people to say 'there somebody listened to me, let me get involved.'"

This finding was reiterated by 'weak' and 'moderate' HC members who indicated that a lack of progress resulted in decreased motivation to remain on the Committee. Some members described their experience within the HC as an ongoing "fight" to push issues forward while others described the process as, "just – meetings and everybody go home, meetings and everybody go home." Where members felt they had achieved few tangible outcomes, they became frustrated and wanted to leave the Committee. One member who resigned shortly after data collection commented:

HC7: “sometimes you, you get the feeling that you’re wasting your time, you want to go, but if you love your community, if you want to make things better, you’ve got to keep on.”

Unclear roles and functions

Another consequence of not having of a clear mandate for HCs was a lack of consensus on what the roles and functions of HCs are and *should* be. Service providers generally felt that HCs were not sufficiently visible in the clinic and were too complaints-focused, rather than assisting the facility on a day-to-day basis with rude and unruly patients. In contrast, all HC members viewed their function as being primarily patient-focused and considered raising complaints on behalf of the community to be a major part of their role. Beyond this, however, Committee members held a surprisingly narrow vision for their HCs which largely omitted any form of involvement in the planning, implementation or evaluation of health programmes and services at the community level.

Facility managers as gatekeepers

In all three communities, service providers overwhelmingly reported having very little knowledge of and contact with their respective HCs, rendering facility managers as the sole point of contact between the HC and the facility. In the absence of legitimate and clearly defined powers, the extent of community participation that was possible through the HC was further concentrated on the availability and the will of the manager. These factors established facility managers as powerful gatekeepers (potential barriers and enablers) to the level of community participation taking place through the HC.

In the ‘moderate’ HC, the manager was reported to show little respect for Committee members, sometimes shouting at them in the facility. Although the HC requested involvement when issues were raised via the ‘compliments and complaints’ system, the manager decided to deal with these matters personally. When the Committee raised issues on behalf of the community, members said that the manager would “defend” facility staff by providing explanations for why incidents occurred, even if these explanations were unsatisfactory from the Committee’s viewpoint. One member said that she heard what other HCs were doing at their district meetings but explained that they could not do the same since, “they don’t let us in there, so what can we do?”

In contrast, the facility manager of the ‘strong’ HC demonstrated a high level of respect for members of the community and an interest in utilizing the Committee to improve service delivery. The manager maintained an ‘open door’ policy with the HC, allowing members to come and speak with him about matters arising in the facility and Committee members reported that matters raised with the manager often resulted in action. The manager kept the HC abreast of facility operations, from their budget and renovations to key challenges being faced, and engaged the HC in discussions around these subjects. Furthermore, a public meeting held jointly by the manager and the HC enabled the prioritization of community concerns, such as long waiting times and inefficient filing systems.

The presence and support of the facility manager also appeared to play a role in shaping the fate of the ‘weak’ HC. Several of the service providers and former HC members reported that the manager’s relatively recent arrival, in combination with her heavy burden of activities, contributed to her inability to provide greater support to the HC and to the Committee’s ultimate failure.

Representing the community

There were important differences in membership across the three HCs. Members of the ‘strong’ HC tended to hold a certain level of ‘expertise’, often having experience in the fields of community health, development or municipal politics. Unlike the other two Committees, whose members joined within the past 4 years, the ‘strong’ HC had a mixture of very long-term members (over 10 years experience) and newer members (less than a year on the HC). Newer members to this Committee indicated an eagerness to learn from more experienced members and offered this as part of their explanation for agreeing to join the Committee:

HC12: “It is nice to be on the board and then I can also *learn* from the board, because it’s the first time in my life that I’m on a day hospital board, so I’m learning a lot now, on the moment.”

Despite this variation, the three HCs also shared some characteristics. In particular, all three Committees struggled to obtain sufficient representation from certain groups in the facility catchment area. Informal settlements housing mobile communities and foreign populations were vastly under-represented on the Committees. While most HC members did not consider this to be an important barrier to community participation, several service providers viewed this under-representation as a critical shortcoming.

Participation and the progressive realization of the right to health

Albeit most evident for the ‘strong’ HC, all three HCs have, to some degree, succeeded in influencing the acceptability, accessibility, availability or quality of health care goods and services at their respective facilities.

Acceptability

The 'strong' HC helped to reduce excessively long waiting periods and improve staff attitudes. For instance, HC members would often ask patients how long they had been waiting and responded to unusually long wait times by investigating further and subsequently informing the facility manager. Members of this Committee also played a 'watchdog' function, often sitting in the clinic amongst patients to ensure that members of the community were treated respectfully by service providers. Problems experienced by the HC were subsequently reported to the manager who took corrective action. One HC member narrated an encounter she experienced at the facility which exemplifies this 'watchdog' role:

HC11: "There was a little guy... he asked the nurse a question that he's not going to work tomorrow, he wants a certificate because he want to see properly to his child... then she said to him 'jy hoef nie met my kom praat nie' [don't think you can talk to me]. You know, she was actually rude to him and that, and the facility manager was now gone, so I went for her, so I said 'this is not the way you speak to your patients, he's only asking for a certificate, tell him to sit down and wait for his certificate'."

Despite their limited power to deal with patient's complaints, the 'moderate' HC took up certain issues with the facility manager. Nurses once conducted the patients' initial assessments in an open area of the facility, which Committee members argued did not respect patient privacy. In another instance, HC members noticed that sick and elderly patients were having to find their own folders at reception. For both cases, as a result of HC objections, the manager intervened to rectify the scenario.

Accessibility

Key informants and several interview respondents concurred that the ‘strong’ HC was instrumental in ensuring that the day clinic was transformed into a 24-hour facility. As the nearest emergency medical services were previously out of reach for those without a vehicle or financial means to secure transportation, the establishment of this facility dramatically increased the physical accessibility of emergency services for many in the community, including vulnerable and disadvantaged groups.

Members of the ‘strong’ HC also provided information to patients with respect to clinic services, operating procedures and often notified patients of staff shortages so that patients were aware when they would have to wait longer than usual. The Committee further enhanced the accessibility of services at this facility by assisting chronic and elderly patients to find their way to the new pharmacy location and by supplying the pharmacy with a microphone so that patients could hear when their prescriptions were ready. Outside the facility, the HC created pamphlets and utilized a free local newspaper to distribute important health information and highlight changes taking place at the facility.

Availability

Members of the ‘weak’ HC lobbied health officials and local government structures to provide more staff for their clinic which often relied on a single nurse to render services to several areas. Although no concrete changes were made as a result of HC activities, members continued to apply pressure.

HC3: “We knock on the door all the times for staff, you know... they are aware there is a need for staff at our community clinic.”

HC16: “Sometimes 9 o’clock the, the office is closed, they can’t help any more because there’s only one sister... you see what I mean, this is not right [whispering], you have to have 2 or 3 people there, and that is the poor service, really. This is poor because I have to call it, I have to talk to the council, in Ward (number) council meeting, *really*.”

The ‘moderate’ HC ensured the availability of safe and potable water and adequate sanitation in the community by working closely with the environmental health officer. HC members often reported to the inspector when water was believed to be unsafe, having the potential to escalate into community-wide epidemics, or when living conditions in certain areas were believed to be unsanitary.

Quality

Qualitative data did not indicate ways in which HCs affected the medical and scientific quality of goods and services at corresponding facilities, however there were a few examples where HC activities improved the general quality of goods at the facility. The ‘strong’ HC sourced funds outside the Department of Health for renovations and extensions made to the facility and regularly ensured that toilet facilities in the clinic were functional and hygienic. The ‘moderate’ HC assisted in preserving the quality at their clinic by informing the manager when gang-affiliated security guards were responsible for missing equipment, while the ‘weak’ HC has made pleas to their community members to assist in watching over the facility in order to prevent further break-ins and theft.

Discussion

Research participants described a strained relationship between the HC and service providers, characterised by limited communication and areas of contested power. Shortcomings in the ability of Community HCs to serve as vehicles for meaningful community participation were most strongly related to the absence of a formal mandate equipping HCs with clear objectives and the authority to achieve them. The lack of clearly defined powers and functions for HCs appeared to reinforce other barriers, including the limited progress experienced by HCs, varied views on HC roles and functions and the position of the facility manager as a powerful gatekeeper. HC member expertise operated as both an inhibitor and facilitator of community participation, with the under-representation of vulnerable and marginalised groups hindering wider participation while expertise granted a degree of influence at the facility and in the community. In spite of the aforementioned barriers, HCs managed to advance the right to health by improving the acceptability, accessibility, availability and quality of health care goods and services; however, improvements in these four areas occurred unevenly across the three communities.

Findings from the questionnaire suggest that the ‘strong’ HC had generally higher levels of participation in health than the other two. Small, non-significant differences in the perceived levels of participation across communities may be attributed to the small sample size of sub-groups being compared. Irrespective of HC strength, participation was thought to be highest for the HC’s organisation but most deficient in resource mobilisation, suggesting the need for greater HC involvement in community-level decisions regarding resource allocation.

Although none of the three HCs included in this study demonstrated characteristics of wide community participation, lessons on best practice for community participation in health can

be extracted from these HCs, and include: a facility manager who is willing to share power with the HC and who helps tip the balance of power from health professionals towards the community; a form of apprenticeship between more and less experienced Committee members; intersectoral activity through the regular interaction of HCs with local politicians and environmental health officers; mechanisms for HCs to be involved in the lodging and resolution of patient-based complaints at health facilities; the extensive use of the media and written sources of information by HCs which has the opportunity to increase Committee visibility in the clinic and in the community, to disseminate important health-related information, to inform the community of HC activities and to broaden participation.

The evidence presented in this paper reinforces the concept that while formal organization can promote participation in health, structures alone do not ensure meaningful community participation (Levers et al., 2007). Failure to account for the shift in power which community participation necessitates (Rifkin, 1986) has allowed the dilution of participation through HCs. Delays in Provincial action to outline HC powers and functions may be understood as a covert approach to subvert policy implementation (Gilson & Erasmus, 2008), allowing health professionals to withhold decision-making power from communities. In the present context where HCs are highly dependent upon facility managers, a respectful and supportive manager can create an enabling environment where the HC can thrive, whereas power struggles between the manager and the Committee will operate to the detriment of participation. Findings suggest that an absence of visible change reinforces perceptions that HCs are powerless and discourages participation. In this manner, the restricted powers and progress of HCs undermines community participation by diminishing the very basis for participation to maintain a vicious cycle of disengagement.

Despite regular elections, incomplete representation of service users on the HC remains a barrier to participation through these community governance structures. Experiences from the field underscore the difficulty with which willing volunteers are found for participatory processes (Zakus & Lysak, 1998) and the seemingly contradictory finding that poor and disadvantaged groups are often the first to discount themselves from these processes (Baum, Bush, Modra, Murray, Cox, Alexander et al., 2000). In effect, a greater effort must be made to broaden participation in Community HCs; however, professional challenges to representativeness may also be a defensive mechanism to retain control over decision-making processes (Martin, 2006) and should not be used to prevent the extension of participation.

HC functions envisaged by Committee members were surprisingly narrow and do not equate with community participation as intended by Alma-Ata or with definitions of 'wide' community participation under the Rifkin framework. Most members felt that the HC should operate as a source of health information for the community and as a body for advancing complaints. Yet, these findings are not surprising in light of Mosse's work (2001), suggesting that local needs and priorities are often shaped by local perceptions of administrative realities. As a result, what is ultimately requested is that which is believed to be most easily delivered.

Study findings illustrate that while the right to health could be advanced through incomplete or moderate levels of participation, the purported 'strongest' HC had the greatest impact on the four criteria indicative of the progressive realization of this right. Most progress was made towards increased acceptability and accessibility of health services compared to availability and quality. This is likely due to the restricted means available to HCs for the advancement of community-based concerns. While changes in the acceptability of services were directly related to changes that could be affected at the local level, issues of availability

and quality were linked to systemic problems in the broader health system, a decision-making arena to which HCs did not have ready access. These findings underscore the significance of power in the relationship between participation and the right to health, indicating that the ability of these community governance structures to drive the progressive realization of the right to health remains constrained by the degree of power held at various levels of decision-making.

While evidence provided in this study illustrates how participation can advance the right to health, human rights literature suggests that a rights-based approach can reciprocally advance community participation. The human rights community is beginning to afford greater recognition to participation as a human right and an integral component of the right to health (Potts, 2009). The interdependency of human rights means that governmental failure to promote or fulfill the right to participation can hinder progress towards the realization of the right to health. As case studies from Southern Africa demonstrate, community mobilization around human rights entitlements can strengthen community engagement (London, 2007). While the scope of participation must still be clarified and negotiated with communities, greater awareness of the entitlements afforded by human rights law can establish a rights-based approach as a “powerful tool” for HCs to advance their right to participation. Furthermore, visible achievements made using a rights-approach can reverse the cycle of disengagement by providing evidence that HCs are powerful which increases membership motivation and thereby strengthens participation.

The study had some limitations. First, the study could not include community respondents as initially intended due to time constraints and the complexity of applying the Rifkin tool to this stakeholder group. Data from community respondents would have served to strengthen

triangulation of main study findings and allowed for a more robust interpretation. Second, the absence of a 'gold standard' against which to validate responses to the questionnaire is an important limitation to its interpretation as the 'true' level of participation in health for a given community cannot be known with certainty. Third, non-random sampling methods limit the generalisability of findings. Nevertheless, several study results are in-line with findings from regional investigations of community participation in health, reinforcing arguments for their external validity.

Indeed, the results of this study are broadly in accordance with a growing body of research in East and Southern Africa which attempts to account for the failure of community governance structures to facilitate participation. A recent survey across all nine South African provinces indicated the restriction of HC activities to problem solving (84%) and the limited involvement of HCs in resource mobilization (93% of managers reported no HC involvement in finances) (Paradath & Friedman, 2008). In addition, other studies in this region have identified ambiguity with regards to roles and responsibilities as one of the major factors inhibiting progress through community governance structures (Lowenson, 2004; Boulle et al., 2008).

Conclusions

While this study is valuable in adding confirmatory evidence of factors facilitating or impeding the effective functioning of HCs, it goes further to examine these factors in light of a conceptual framework for community participation to illuminate lessons on best practice for participation in health through South African HCs. Best practices identified include: facility managers willing to shift the balance of power, intersectoral activity with ward councilors

and environmental health officers, intra-Committee apprenticeships, an association between the HC and visible results, as well as the use of media and written sources of information.

In addition, this study provides evidence supporting an important interrelationship between participation and the right to health that is heavily influenced by elements of power. Study findings illustrate that where structures for participation are supported and allowed greater influence, they are able to make more concrete progress towards the realization of the right to health; however, progress made through HC activities was largely restricted to issues that could be influenced at the community-level. In this manner, advances in the right to health through participation are constrained by the degree of power held at various levels of decision-making. Future research investigating the relationship between participation and the right to health, must therefore consider elements of power and trust as critically influencing the nature and extent of this relationship. Moreover, while the purpose of participation must be clarified and negotiated with communities, this study highlights how a rights-based approach can mutually reinforce efforts to advance community participation.

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Table 1Description of four criteria by which to evaluate the right to health^a

Criterion	Description
Acceptability	Health facilities, goods and services are respectful of medical ethics and culturally appropriate, sensitive to gender and life-cycle requirements, as well as designed to respect confidentiality and improve the health status of those concerned.
Accessibility	Health facilities, goods and services are accessible to everyone without discrimination, within the jurisdiction of the State party. Four overlapping dimensions to this criterion include: Non-discrimination, physical accessibility, economic accessibility; information accessibility.
Availability	Functioning public health and health-care facilities. Goods, services, and programmes for health have to be available in sufficient quantity.
Quality	Health facilities, goods and services are scientifically and medically appropriate.

^aAdapted from General Comment No.14 (2000) and WHO (2002).**Table2**

Overview of study sample

<i>HC / facility</i>	Questionnaire & In-depth Interview		Key Informant Interviews	
	<i>Service providers</i>	<i>HC members</i>	<i>MDHS</i>	<i>CMHF</i>
<i>Strong</i>	6	7		
<i>Moderate</i>	5	4		
<i>Weak</i>	4	3		
<i>Totals</i>	15	14	1	1

Abbreviation key: MDHS = Metro District Health Services; CMHF = Cape Metro Health Forums

Table 3

Median (IQR) rankings for the five indicators of community participation by community

	Strong	Moderate	Weak	P-value ^a	All Communities
Number (n)	13	9	7		29
Leadership	3.75 (2 – 4)	3 (3 – 3)	3.5 (2 – 3.5)	0.24	3 (2.25 – 3.75)
Organisation	5 (4 – 5)	4.25 (3.5 – 5)	4 (4 – 5)	0.55	4 (4 – 5)
Needs Assessment	3.5 (3 – 3.5)	2.5 (2 – 3)	3 (1.5 – 5)	0.13	3 (2 – 3.5)
Resource Mobilisation	1 (1 – 2.25)	1 (1 – 2)	1.5 (1 – 2.5)	0.44	1 (1 – 2.25)
Management	4 (2.75 – 4)	4 (3.5 – 4)	3 (2 – 3.5)	0.11	3.5 (3 – 4)

^aKruskall-Wallis test for equality of medians

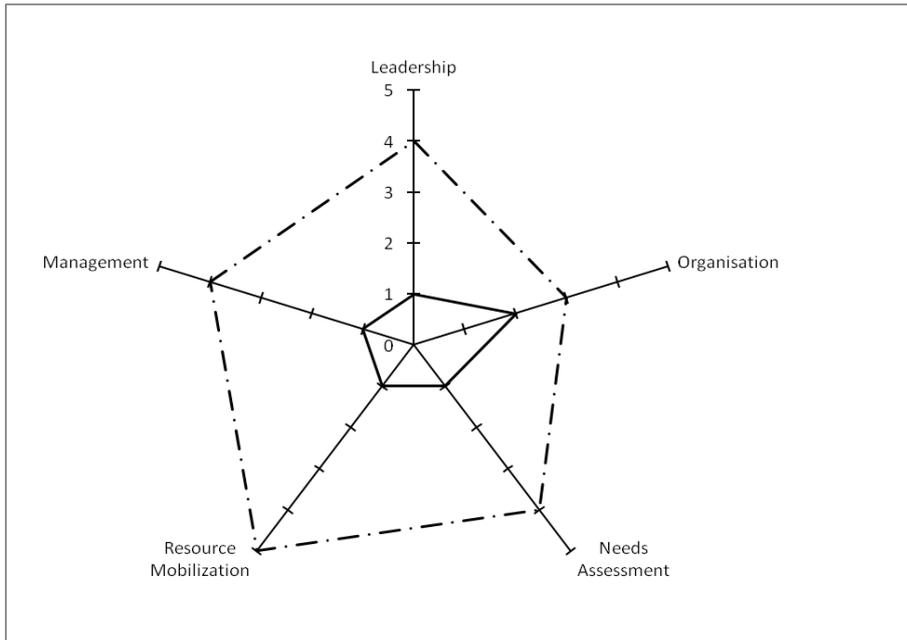


Fig.1. Example pentagram.

Narrow participation: — Wide participation: - . -

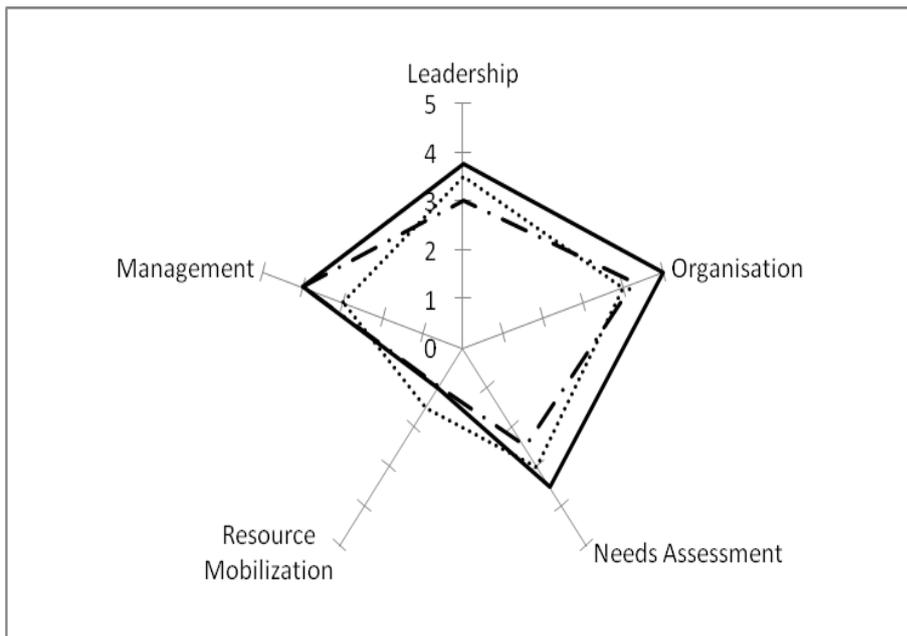


Fig.2. Pentagram models depicting perspectives on community participation in health within three HC-facility pairs.

Strong HC: — Moderate HC: - . - Weak HC:

SUPPLEMENT A

Table I
Ranking scale for process indicators of community participation ^a

INDICATOR	RANKS				
	1 = Narrow	2 = Restricted	3 = Moderate	4 = Open	5 = Wide
Leadership	One-sided (i.e. autocratic chairperson on HC driving decisions; health staff assume leadership), or HC leadership undemocratically selected.	HC members elected from community; HC tries to represent the interests of MOST people in the community; FM & SPs rarely attend HC meetings.	Community may not understand or acknowledge HC roles and functions; FM & SP sometimes involved in HC activities/meetings.	HC is active and their work is generally acknowledged by the community; HC acknowledges lack of input/representation from marginalized section(s) of community; FM, SP & WC often involved in HC activities/meetings.	HC fully represents a variety of interests in community and highlights issues for marginalized section(s) of community; community mostly aware of HC roles and activities; FM, SP & WC always involved in HC activities /meetings.
Organisation	HC structure externally imposed by health professionals/government authorities; HC structure unresponsive to change; limited community ownership.	HC structure externally imposed but some aspects have changed over time within certain restrictions.	HC structure externally imposed but some components have changed over time in response to community needs.	HC structure has completely changed over time to suit community needs; no restrictions to the change.	HC structure fully determined by community; HC is owned by the community; HC structure changes often or as needed.
Resource Mobilization & Allocation	External funding for clinic & HC only (government funds); HC has no control over how money is spent on health in community.	Small amount of resources raised by community; HC still has no control over allocation decisions.	Moderate fund-raising by community; HC plays a small role in allocation decisions.	Moderate fund-raising by community; HC involvement in most allocation decisions.	Considerable fund-raising by community; HC is a partner in all allocation decisions.
Management	Health professionals decide <i>how</i> services are provided; HC has no input regarding quality of care.	Health professionals decide how services are provided; HC entitled to provide suggestions /comments but often have little to no impact.	Mechanisms/structures in place for HC to communicate recommendations / complaints; these are considered and sometimes have effect.	Mechanisms/structures for HC to communicate recommendations / complaints; these are given considerable weight; HC members may have a supervisory role.	HC members and clinics act as partners to jointly manage service provision.
Needs Assessment	Needs assessment performed with a medical, professional viewpoint by individuals outside the community; Health programmes & services are externally dictated.	Most services provided in community are externally determined with consideration for local SP opinion; minimal consideration for community viewpoint.	Mechanisms/structures in place for HC to indicate community needs and gaps in health services rendered.	HC and facility jointly determine services/programmes provided in community based on externally conducted needs-assessments and community recommendations.	HC and facility jointly determine services / programmes provided in community based on locally generated needs assessment.

Abbreviation key: FM = facility manager; SP = service provider; WC = ward councillor

^a Adapted from Rifkin *et al* (1988) and Eyre and Gauld (2003).

SUPPLEMENT B

Since the study was chiefly initiated as an attempt to provide solutions to a local problem (poorly functioning and weakly effective HCs), there would appear to be a gap in the submission if it excluded local policy recommendations arising from the study findings. However, as the manuscript for an international Social Science & Medicine readership required greater emphasis on theoretical aspects of the study, most of the recommendations which were intended for local use did not quite fit into the manuscript. While these recommendations would not be expected to be included as a supplement for submission to Social Science & Medicine, they have been included following the manuscript as they relate directly to the study findings.

POLICY RECOMMENDATIONS

Based on the study findings, the following recommendations are made:

- 1. Revise and adopt a comprehensive provincial policy framework for Western Cape Health Committees (HCs) using a participatory process.**

The study has demonstrated how a lack of consensus and clarity on HC roles and functions operates as a major obstacle to community participation in health. Although a policy framework for Western Cape Health Committees has been created, it has remained in draft form for almost two years, lacks the clarity and detail necessary to remedy the barriers inhibiting meaningful participation through HCs, and has omitted key points which would enable HCs to play a greater role in the progressive realisation of the right to health. First, at the community-level, the framework lists HC functions which include: the provision of governance relating to service provision within the facility/facilities; taking steps to ensure

that the needs, concerns and complaints of patients and the community are properly addressed by facility management; as well as monitoring the performance, effectiveness and efficiency of the facility/facilities. However, the framework does not acknowledge the shift in power necessary for greater HC involvement in facility operations and the power struggles which are expected to arise in response to this attempted shift. The framework must therefore be explicit in outlining mechanisms for Committee involvement in facility governance, the lodging and resolutions of patient-based complaints and the monitoring of facility performance. Second, the draft framework states that it has been developed using the spirit and intention of community participation as outlined in the Alma-Ata declaration and the White Paper. If this is indeed the case, the framework should extend HC authority to include involvement in regular community needs assessments and the subsequent involvement in programme planning and resource-allocation decisions at the community-level. Third, the study illustrated the importance of intersectoral collaboration with local councillors and environmental health officers, as well as the under-representation of certain community groups on the HCs. Accordingly, the framework should consider ways to reinforce involvement from these role players. Fourth, the framework fails to outline mechanisms for HC involvement in decision-making and problem-solving at the health systems level. As demonstrated in the study, this is a major obstacle to HC advancement of the right to health, specifically in relation to the quality and availability of goods and services at health facilities. It is therefore recommended that a detailed plan for involvement in decision-making and problem-solving at the health systems level through the Cape Metro Health Forum executive committee be prioritised for inclusion in the policy framework.

Finally, the processes leading to the creation of the draft framework is not entirely clear. Preliminary data from a sub-study being conducted with Western Cape HCs (HC skills audit) suggests that many Committee members are unaware of the existence of a policy framework,

while those who do indicate awareness are unsure of what the framework entails. For HCs to be truly participative and for the framework to be embraced and implemented at the community-level, it is recommended that the policy be revised in partnership with Committee members themselves. For this to happen, framework development and implementation must occur through a genuine participatory process. Potts (2009) suggests a series of steps to ensure that participatory processes are fair and transparent and these steps are recommended for the development of a Provincial policy relating to HCs in the Western Cape. In particular, rules governing how discussions take place and how final decisions are made must be jointly determined before discussions ensue; the process must be guided by a neutral facilitator; everyone must have an equal opportunity to place items of importance on the agenda; and everyone must have the same information with which to engage in policy discussions.

2. Implementation of the policy framework: Establish mechanisms for the regular monitoring and evaluation of community participation.

As discussed in the study, the human rights community recognizes participation as a human right and obliges all states at all stages of development to ensure a minimum level of participation in health-related sectors. Monitoring and accountability is therefore emphasized in order to ensure that States take measures to facilitate meaningful participation. In addition, the draft policy framework identifies monitoring of facility performance to be a core function of community HCs and the monitoring of community HC performance to be a core function of sub-district Health Fora. In light of the complexity of the Rifkin framework, the usage of other indicators for the monitoring and evaluation of participation in health is recommended, such as the one recently developed by Potts (2009). The joint application of this measurement tool by the health services and sub-district Health Forums / community HCs is recommended

to monitor changes in the level of participation over time, to evaluate if and how different voices have been included in the process and to evaluate how final decisions are made. In addition, it is recommended that national human rights institutions, such as the South African Human Rights Commission, become involved by assisting to develop guidelines for participation and by responding to concerns around participatory processes at the provincial and national levels.

3. Develop and implement training and capacity building for HC members.

The adoption of a policy framework outlining the role and authority of HCs is likely to reduce their dependence on facility managers and establish Committees as vehicles with greater potential for meaningful and effective participation, *only* if it changes the existing balance of power. Policy which establishes the foundation for community participation through HCs must therefore be coupled with strategies to propel and sustain the power shift necessary for a widening of participation, such as training and capacity-building in human rights and in areas of decision-making where Committees have not traditionally had access. For example, the study found participation to be especially low in resource mobilisation, such that training should be offered which strengthens the capacity of HCs to participate in this decision-making arena. Other areas of HC authority outlined within the policy framework (e.g. monitoring and evaluation of facility performance, providing governance with respect to facility service provision) must also be supported by appropriate training and capacity-building.

The study also suggested the potential for a rights-based approach to advance participation in areas where it is currently deficient. Capacity-building workshops should be designed to

sufficiently ground HC members in human rights theory and application in order for HCs to be able to utilize a rights-based approach in their daily operations.

4. Create a learning network for HCs

Study findings highlight the utility of apprenticeships between more and less experienced HC members. While it is not always possible to retain members on the Committee for long periods of time, capacity-building strategies should include the formation of a learning network for HCs wherein weaker Committees are able to learn from stronger ones. This network should be supported (financially and logistically) by the health services.

5. Promote the involvement of vulnerable and marginalised groups in the HCs.

The study revealed that members of vulnerable and marginalised groups residing in the facility catchment area were vastly under-represented in HC leadership. Steps should be taken to widen participation by attracting members of these groups. Part of this effort could include a requirement in the provincial policy framework for HCs to have representatives from all locations in the facility catchment area.

Evidence from other studies indicate how fair and equal representation is influenced by the physical and economic costs of participation (Lysack & Zakus, 1998; Potts, 2009). Efforts to widen participation in South African HCs must therefore include an honest consideration of the costs of participation. It is recommended that the department of health consider the costs associated with participation through HCs (i.e. lost wages while attending training workshops

or meetings, costs of child care, transportation) and balance these costs through the provision of a monthly stipend.

6. Promote partnership between health facilities and HCs through participatory workshops and Participation, Research and Action (PRA) workshops.

While the existence of a provincial policy outlining the purpose and powers of HCs is likely to reduce committee dependency on facility managers, the majority of HC activity will remain at the level of community health facilities. Meaningful participation through HCs therefore remains predicated upon a relationship of mutual respect and understanding between Committees and facilities. Consequently, areas of contested power between health professionals and Committees may remain a barrier to participation, even in the presence of a progressive and participatory policy framework. In this manner, health professionals may still play an important role in enabling the power shift necessary for meaningful participation to occur.

In a study by Boule and colleagues (2008), participatory workshops with service providers increased their understanding of HCs and equipped providers with methods to give more effective support to HCs. A three-day PRA workshop was subsequently held with service providers and HC members that increased mutual understandings of HC strengths and limitations, of HC roles and responsibilities, and which aimed to increased participation in the long-run. It is therefore recommended that participatory workshops and PRA approaches be used as a starting point to foster mutual respect and understanding between facilities and HCs with an aim to buttress the power shift necessary for more meaningful participation.

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References should be given in the following form:

Adkins, L. (2002). *Revisions: Gender and sexuality in late modernity*. Buckingham: Open University Press.

Macintyre, S., & Ellaway, A. (2000). Ecological approaches: Rediscovering the role of the physical and social environment. In L. F. Berkman, & I. Kawachi (Eds.), *Social epidemiology* (pp. 332-348). New York: Oxford University Press.

Glenton, C. (2003). Chronic back pain sufferers-striving for the sick role. *Social Science & Medicine*, 57, 2243-2252.

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PART D: ANNEXES

APPENDIX A

PROJECT INFORMATION

Study Title: Community Health Committees as a vehicle for participation in advancing the right to health

You have been asked to participate in a research study that is being conducted as part of a Masters degree in Public Health and also as part of a larger project on the right to health in South Africa. Before you agree to participate, I would like you to understand why this research is being done, what I hope to achieve from it and what I will be asking of you as a participant.

Why is this research being done?

In the new South Africa, changes to the health system have focused on unfair differences in health remaining from apartheid. Community health committees (HCs) were formally established by South African law in 2003 as structures for participation in health. HCs were hoped to address the unfair differences in health through partnerships with health facilities. However, South African studies have highlighted the fact that many HCs are not operating as well as they could or should be.

As a result, Health Committees are a part of South Africa's plans to change the health system and lessen unfair differences in health but research suggests that the Committees still need a way to engage meaningfully with the health services. To make these Committees effective, so that their participation is beneficial to community health and responsive to community needs, research must be done to find out what kind of relationships currently exist between Health Committees and the facilities and why some aspects of community participation are not taking place.

What do I hope to achieve from this study?

- To learn about the current levels of participation in health from the view point of different people in the community and at the facility.
- To learn about the relationships between Health Committees and health facilities
- To learn about the factors influencing this relationship.
- To learn why some aspects of community participation are not taking place.
- To learn how community participation is linked to accessibility, acceptability, availability and quality of health services.

What research methods will be used?

- 1. A questionnaire** About the level of participation in health that takes place through the Health Committee
- 2. Interviews** To get more detailed information about participation in health in your community
- 3. Observations** Of activities in the community, at Health Committee meetings and at meetings between HC members and service providers at health facilities.

What is expected of you as a participant?

You may be asked to participate in one or more of the above activities.

Anticipated time commitments?

Questionnaires: 5-pages in length, take approximately **20 minutes** to complete

In-depth Interviews: Last approximately **1 hour**

What are the benefits of participation?

You will not receive money or material rewards by participating in the study. However, we anticipate that the findings from this study will provide information that can be used to improve the relationship between communities and the health services. Please note: the improvement of South Africa's health system and the improvement of community participation in health are **not** guaranteed outcomes of this study.

What are the harms/risks to you by participating?

There are no anticipated risks to you as a participant. The information collected from you will not be shared with anyone outside of the research team (it is confidential information). You should note that in all reports/publications, your name will not be used nor will information be linked to you personally (you shall remain anonymous).

Consent to Participate:

The **Consent Form** will further explain your rights and responsibilities in the research process and emphasis a few important points. Please read the form and if you are willing to participate, we will ask to sign that you agree to participate.

Contacts:

Gabriela S. Glattstein-Young
(Researcher - Masters Student, UCT)

Tel: 083 896 6929
Email: ynggab001@uct.ac.za

Professor Leslie London
(Supervisor – UCT)

Tel: 021 406 6524
Email: leslie.london@uct.ac.za

Questions or concerns for the University of Cape Town Research Ethics Committee
Lameez Emjedi

Tel: 021 406 6492

PROJEK INFORMASIE

Studie title: Gemeenskaps Gesondheidskomitees as strategie om deelname in die promosie van die reg tot gesondheid te bevorder

Jy is gevra om deel te neem in 'n navorsingstudie wat deel uitmaak van 'n Meesters graad in Publieke Gesondheid en ook deel is van 'n groter projek wat kyk na die reg tot gesondheid in Suid Afrika. Voordat jy instem om deel te neem aan die studie, wil ek graag verduidelik hoekom ons hierdie navorsing doen, wat ons graag daarmee wil bereik en wat dit sal behels van jou as deelnemer (participant).

Wat is die doel van hierdie navorsing?

In die nuwe Suid Afrika het veranderinge in die gesondheidssektor nog altyd gefokus op onregverdigte verskille in gesondheidsdienste wat gegrond was op apartheid. Gemeenskaps gesondheidskomitees (GKs = Health Committees) was voor voorsiening gemaak in die Suid Afrikaanse wetgewing in 2003 as strukture om die publiek se deelname in gesondheid te bevorder. Daar was gehoop dat GKs die onregverdigte verskille in gesondheidsorg sou aanspreek deur verhoudinge te bou tussen gemeenskappe en gesondheidsfasiliteite en sodoende die geleentheid te skep vir groter gemeenskaps betrokkenheid in die bevordering van gesondheid, en dus seker te maak dat gemeenskappe se gesondheids behoeftes nagekom word. Suid Afrikaanse studies het egter gevind dat baie GKs nie so goed funksioneer as wat hulle kan of moet nie.

Ter opsomming, GKs is deel van Suid Afrika se plan om die gesondheidssektor te verbeter en onregverdigte verskille in gesondheidsorg te verbeter, maar navorsing het bewys dat die GKs nie betekenisvol met die gesondheidssektor kommunikeer nie en dus nie effektief is nie. Om GKs meer effektief te maak sodat hulle deelname positiewe gevolge vir die gemeenskappe en hulle behoeftes het, is dit nodig om uit te vind watter tipe verhoudinge die GKs en gesondheidsfasiliteite op die oomblik het en hoekom die tipe verhoudinge bestaan.

Wat is ons doel met die studie?

- om te leer van die huidige vlak van deelname in gesondheid van die verskillend betrokke groepe in die gemeenskap;
- om uit te vind oor die verhoudings tussen die GKs en gesondheidsfasiliteite;
- om meer te leer oor die faktore wat hierdie verhoudings beïnvloed; en
- om te leer en uitvind waarom sekere aspekte van die gemeenskap se deelname nie plaasvind nie.
- om te leer hoe die gemeenskap se deelname met betrokke tot toereikbaarheid, aanvaarbaarheid, beskikbaarheid, en die kwaliteit van die gesondheids diens.

Watter navorsingsmetodes gaan gebruik word?

1. **'n Vraelys** wat handel oor die deelname in gesondheidsorg deur die gesondheid komiteer
2. **Onderhoude** om meer besondere informasie te kry oor deelname in gesondheid in jou gemeenskap
3. **Waarnemings (observations)** van aktiwiteite in die gemeenskap, bywoning van GK vergaderings asook vergaderings tussen GK lede en diensteverskaffers (service providers) by gesondheidsfasiliteite.

Wat sal jou verwag word as deelnemer?

Jy mag gevra word om ons te help in een of meer van die bogenoemde aktiwiteite.

Hoeveel tyd sal in beslag geneem word?

Vraelyste: 5 bladsye lank en neem ongeveer **20 minute** om te voltooi
Onderhoude: neem ongeveer **1 uur**.

Wat is die voordele van deelname?

Jy sal geen geldelike of materieële voordele ontvang deur aan die studie deel te neem nie. Ons verwag egter dat die bevindinge van die studie gebruik sal word om die verhoudinge tussen gemeenskappe en gesondheidsdienste verskaffers te verbeter. Let asseblief op: dat die verbetering van die Suid Afrikaanse gesondheidsorg dienste en/ of verbetering van gemeenskaps deelname in gesondheid nie versekerde gevolge van die studie is nie.

Wat is die risikos verbonde aan jou deelname aan die studie?

Daar is geen verwagte risikos verbonde aan jou deelname aan die studie nie. Die informasie wat van jou verkry word sal nie met enigiemand buite die navorsingspan gedeel word nie (dit word as konfidentiële informasie beskou). Jou naam sal in geen verslae of publikasies gebruik word nie en jou bydrae sal ook nie aan jou persoonlik gekoppel kan word nie (jy sal anoniem bly).

Toestemming (consent) om deel te neem:

Die **toestemmings vorm** sal verdere informasie bevat ten opsigte van jou regte en verpligtinge in die navorsingsproses en ander belangrike informasie. Lees asseblief die vorm noukeurig deur en indien jy bereid is om deel te neem aan die studie, sal ons jou vra om die vorm te onderteken.

Kontakte:

Gabriela S. Glatstein-Young
(Navorsers – Meestersgraad student, UCT)

Tel: 083 896 6929
Email: ynggab001@uct.ac.za

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University of Cape Town Ethics Komitee
Lameez Emjedi

Tel: 021 406 6492

APPENDIX B

CONSENT FORM

Study Title: Community Health Committees as a vehicle for participation in advancing the right to health

Hello, my name is Gabriela Glattstein-Young and I am a Masters student in Public Health at the University of Cape Town. I am doing a study to learn more about community participation in health and the right to health in the Western Cape. You should have already seen a copy of the information sheet and I would like to ask you to participate in this study.

You should know that if you do not wish to participate, you do not have to. You can withdraw from this study at any time during the process (either during the interviews, discussions or at any other time in duration of the research). If you withdraw, the health care of you or your family will not be compromised in any way.

If you do agree to participate, I may invite you to take part in some of the following:

- 1. A questionnaire – taking ~ 20 minutes to complete**
- 2. An interview – lasting about 1 hour**

Interviews and questionnaires can be conducted in your first language upon your request.

Any information collected for this study will be kept **confidential**. This means that only I and members of the research team will have access to questionnaires, tapes from recorded interviews and to the notes made from these tapes. The information collected from you will not be shared with anyone other than the research team without your permission.

What you say in questionnaires and in the interview will be kept **anonymous**. This means that in report/s, no individual names will be included nor will anything you say be linked to you personally in any way.

You will not be paid for your participation in the research. There are no anticipated risks to you as a result of the research. However, if you feel the need for support following the interview, I can give you a list of service providers that you can contact.

Please note that you should only agree to participate if you feel that you have a good understanding of the study and your role as a participant in this study. This means that you should take the time read the information sheet carefully and ask me any questions that you have.

Contact for additional information:

Gabriela S. Glattstein-Young (Masters Student in Public Health and researcher)

Tel: 083 396 6929

Email: ynggab001@uct.ac.za

Please complete the following if applicable to you

Declaration:

I, _____ (name)
have read the information sheet and/or it has been explained to me. I understand what the study is about and what is expected of me as a participant. I agree to take part in the research.

(Please x the boxes that apply to you)

I agree for notes of the meetings to be taken

Yes	No
-----	----

I agree for the interview to be tape-recorded

Yes	No
-----	----

Participant: _____
(Name and Surname) (Signature)

Researcher: _____
(Signature)

Date: _____

TOESTEMMINGSVORM

Studie Titel: Gemeenskaps Gesondheids Komitees as strategie om deelname in die promosie van die reg tot gesondheid te bevorder

Goeiedag, my naam is Gabriela Glattstein-Young en ek is 'n Meestersgraad student in Publieke Gesondheid van die Universiteit van Kaapstad. Ek doen 'n studie om meer te leer oor gemeenskaps deelname in gesondheid en die reg tot gesondheid in die Wes-Kaap. Jy het al 'n kopie van die projek informasie vorm gesien en ek wil jou nooi om deel te neem aan hierdie studie.

Dis belangrik dat jy weet dat as jy nie hoef deel te neem aan die studie nie. Jy kan enigetyd onttrek van die studie gedurende die proses (maw gedurende die onderhoude, besprekings of gedurende die loop van die navorsing). Indien jy wil onttrek van die studie, sal die gesondheidsorg van jou of jou familie in geen manier geaffekteer word nie.

Indien jy besluit om deel te neem, mag ek jou vra om deel te neem in van die volgende:

1. 'n Vraelys wat 20 minute sal neem om te voltooi
2. 'n Onderhoud van ongeveer 1 uur lank

Onderhoude en die vraelys kan, op aanvraag, in jou huistaal onderneem word.

Enige en alle informasie wat gedurende hierdie studie bymekaar gemaak word sal **konfidensieel** gehou word. Dit beteken dat slegs ek en my navorsingspan toegang sal hê tot die vraelyste, opnames van die onderhoude en enige notas wat gemaak word van die opnames. Die informasie wat van jou verkry word sal nie met enigiemand behalwe die navorsingspan gedeel word sonder jou toestemming nie.

Al jou antwoorde van die vraelyste en onderhoude sal **anoniem** gehou word. Dit beteken dat geen name in die verslae genoem sal word nie, en die informasie sal geensins aan jou gekoppel kan word nie.

Jy sal nie betaal word vir jou deelname in die navorsing nie. Daar is geen verwagte risikos vir jou as gevolg van deelname in die navorsing nie. As jy voel dat jy enige hulp nodig het na die onderhoud of fokus groep besprekings, kan ek vir jou 'n lys van mense gee met wie jy in kontak kan kom, wat jou sal kan help.

Let asseblief op dat jy slegs moet instem om deel te neem aan die studie as jy voel dat jy die studie en ook jou rol as respondent verstaan. Neem asseblief die tyd om die informasie vorm deeglik deur te lees en voel vry om my enige vrae te vra.

Kontak besonderhede vir adisionele informasie:

Gabriela S. Glattstein-Young

(Meestersgraad student in Publieke Gesondheid en navorser)

Tel: 083 396 6929

Email: ynggab001@uct.ac.za

Vul asseblief die volgende in indien dit van toepassing is op jou

Verklaring:

Ek, _____ (naam)

Het die projek informasie vorm gelees en/of dit is aan my verduidelik. Ek verstaan waaroor die studie gaan en wat van my as respondent verwag word. Ek stem in om deel te neem aan die navorsing.

(Maak asseblief 'n kruisie (x) in die blokkies wat op jou van toepassing is)

Notas mag van die vergaderings met my geneem word.

Ja	Nee
----	-----

Ek stem in dat my onderhoud opgeneem mag word op band.

Ja	Nee
----	-----

Respondent: _____
(Naam en van)

(Handtekening)

Navorsers: _____
(Handtekening)

Datum: _____

APPENDIX C

FEEDBACK AND REPORTING:

You may request to receive a copy of the transcript to check-over. A meeting will be held during the write-up phase of the study so that I can report-back to you on the findings and you can provide feedback. Once the report is complete, you may request to receive a copy.

I would like to receive a **copy of the transcript** to check it

I would like to **attend the report-back meeting**

I would like to **receive a copy of the completed report**

If you have ticked any of the boxes above, please provide your contact details below so that we can contact you to arrange feedback:

Name: _____

Cell No: _____

Work No: _____

Email: _____

If you do not have an email address and have requested a copy of the transcript or a copy of the completed report, please provide:

Mailing Address: _____

PLEASE NOTE: The personal information that you have provided will not be used for anything other than for purpose(s) you have selected above. By providing this information, your confidentiality and anonymity within the study will not be compromised.

TERUGVOERING EN VERSLAE:

Jy mag 'n kopie van die transkripsie van jou onderhoud aanvra om deur te lees en te sien of jou antwoorde korrek weergegee is. Ek is bereid om 'n afspraak met jou reël gedurende die finale fase van die studie sodat ek die verslag van die studie met jou kan bespreek en jy kommentaar daarop kan lewer. Sodra die verslag voltooi is, kan jy ook 'n kopie aanvra.

Ek sal graag 'n **kopie van die transkripsie van my onderhoud** wil hê om deur te lees

Ek sal graag 'n **verslaggewende vergadering** wil bywoon

Ek wil graag 'n kopie van die **voltooide verslag** ontvang

Indien jy enige van die bogenoemde wil ontvang, vul asseblief jou kontak besonderhede in sodat ons jou kan kontak:

Naam: _____

Selfoon nommer: _____

Werks telefoonnommer: _____

Email: _____

Indien jy nie 'n e-mail adres het nie, en graag 'n kopie van die transkripsie of die voltooide verslag wil ontvang, voorsien asseblief jou posadres:

Posadres: _____

LET ASB OP: Die persoonlike informasie wat jy aan ons toevertrou het sal nie vir enigiets anders gebruik word as waartoe jy hierbo ingestem het nie. Jou antwoorde in die studie sal steeds anoniem gehou word en nie geaffekteer word deur die verskaffing van jou kontak besonderhede nie.

APPENDIX D

QUESTIONNAIRE: Community Participation in Health

BACKGROUND

Thank you for agreeing to take part in this study.

We want to find out how you view community participation in health in your community.

This 5-page questionnaire will take about 20 minutes to finish.

Please do not write your name anywhere on this questionnaire.

Your answers will be kept anonymous- meaning that no one will know that it was you who completed this questionnaire.

DEMOGRAPHICS

Community where you live / work / operate?

(You may circle more than one, if applicable)

Are you:

- a. Member of a Community Health Committee (HC)
- b. Member of the community
- c. Staff at the Community Health Facility

NUMBER OF YEARS you have been:

- a. A member of this **HC**? _____ **Position:**

- b. A member of this **community**? _____
- c. Working at this **health facility**? _____ **Position:**

GENDER: _____

AGE: _____

FIRST LANGUAGE: _____

For each of the following questions, please circle or “X” the response that you most agree with:

LEADERSHIP

1. The clinic in my community has a Health Committee (HC)

Agree	Disagree	Don't know
-------	----------	------------

2. People from the community were **elected** onto the Health Committee.

Agree	Disagree	Don't know
-------	----------	------------

3. The Health Committee represents the **diversity** of people in my community.

Agree	Disagree	Don't know
-------	----------	------------

4. Health Committee leadership has **changed over time** to reflect what my community **wanted or needed**.

Agree	Disagree	Don't know
-------	----------	------------

5. Health Committee leadership is **mostly staff** from the Clinic.

Agree	Disagree	Don't know
-------	----------	------------

6. Most Health Committee decisions are made by **ONE person**.

Agree	Disagree	Don't know
-------	----------	------------

7. **Decisions** made by the Health Committee reflect what **most people** in my community want.

Agree	Disagree	Don't know
-------	----------	------------

8. The Health Committee **works together** with the local Clinic:

Always	Often	Sometimes	Rarely	Never	Don't know
--------	-------	-----------	--------	-------	------------

9. The **Facility Manager** attends Health Committee meetings:

Always	Often	Sometimes	Rarely	Never	Don't know
--------	-------	-----------	--------	-------	------------

10. **Other Clinic Staff** attend Health Committee meetings:

Always	Often	Sometimes	Rarely	Never	Don't know
--------	-------	-----------	--------	-------	------------

11. Ward councilors attend Health Committee meetings:

Always	Often	Sometimes	Rarely	Never	Don't know
--------	-------	-----------	--------	-------	------------

12. My community is aware of the Health Committee's roles and functions.

Mostly	Partly	Rarely	Never	Don't know
--------	--------	--------	-------	------------

13. My community supports Health Committee activities when they know about them.

Mostly	Partly	Rarely	Never	Don't know
--------	--------	--------	-------	------------

14. The Health Committee does NOT have representation from marginalized groups in my community (women, children, the poor, refugees).

Agree	Disagree	Don't know
-------	----------	------------

15. The Health Committee highlights health issues for marginalized groups in my community (women, children, the poor, refugees).

Agree	Disagree	Don't know
-------	----------	------------

ORGANISATION

16. The community did NOT choose the Health Committee's structure.

Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know
----------------	-------	----------	-------------------	------------

17. The structure of the Health Committee was created in response to community needs.

Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know
----------------	-------	----------	-------------------	------------

18. The Health Committee is mostly owned by the community.

Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know
----------------	-------	----------	-------------------	------------

19. The Health Committee has changed over time in response to community needs.

Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know
----------------	-------	----------	-------------------	------------

RESOURCE MOBILIZATION AND ALLOCATION

20. Resources for the **Clinic** come from the community (i.e. by user fees, fund raising, donations, etc.)

All	Most	A moderate amount	Some	None	Don't know
-----	------	-------------------	------	------	------------

21. Resources for the **Health Committee** come from my community.

All	Most	A moderate amount	Some	None	Don't know
-----	------	-------------------	------	------	------------

22. The **Health Committee** has **NO** say over how money is spent on health in the community.

Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know
----------------	-------	----------	-------------------	------------

23. The Health Committee is involved in **budget-allocation decisions** for health services/programmes in the community.

Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know
----------------	-------	----------	-------------------	------------

24. Members of the Health Committee are compensated for their time.

Agree	Disagree	Don't know
-------	----------	------------

MANAGEMENT OF HEALTH SERVICES

25. Do Health professionals make all the decisions about how services are provided with **NO input from the Health Committee**?

Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know
----------------	-------	----------	-------------------	------------

26. The Health Committee has **NO supervisory role** at the clinic.

Strongly Agree	Agree	Disagree	Strongly Disagree	Don't know
----------------	-------	----------	-------------------	------------

27. Which of the following *best describes* the Health Committee's role in health services?

A partner, working alongside the local health facility to jointly address community concerns and health requirements.	A powerful resource for health facilities that provides useful information that is taken seriously by health facilities.	A source of information that MAY or MAY NOT be considered in managerial actions.	A group that sometimes makes comments to the health facility but usually has NO real effect on service provision.	A body that exists in isolation of health services but has NO impact on service provision.	Don't know
---	--	--	--	---	------------

28. The Health Committee's impact on *how* services are provided at the clinic is:

Great, always has a definite impact	Large, usually has an impact	Moderate, sometimes has an impact	Limited, Rarely has an impact	None, never makes an impact	Don't know
-------------------------------------	------------------------------	-----------------------------------	-------------------------------	-----------------------------	------------

NEEDS ASSESSMENT

29. The Health Committee is involved in the development of programmes/services that are offered by the Clinic.

Always	Often	Sometimes	Rarely	Never	Don't know
--------	-------	-----------	--------	-------	------------

30. Which statement *best describes* **WHO decides WHICH services/programmes are provided** at my community health facility:

Jointly by the HC and the heads of health facility in the community.	The HC in my community advocates for certain services/programmes on behalf of the community but the ultimate decision is made by health professionals at the facility.	By health professionals working at the community health facility	Entirely by individuals working and living outside your community.	Don't know
--	--	--	--	------------

31. Which statement *best describes* how the **health needs** of my community are determined:

From information put-together by the community using data collected by community members.	Jointly by local recommendations and information gathered by non-community members.	Jointly by health professionals at the community health facility and information gathered by non-community members.	By people living and working outside the community using information gathered outside the community.	Don't know
---	---	---	--	------------

VRAELYS: Gemeenskaps Deelname in Gesondheid

AGTERGROND TOT DIE STUDIE

Baie dankie dat jy ingestem het om deel te neem aan hierdie studie.

Ons wil uitvind hoe jy jou gemeenskap se deelname sien ten opsigte van hul gesondheid in jou gemeenskap.

Die beantwoording van die 5 bladsy vraelys behoort jou so 20 minute te neem.

Moet asseblief nie jou naam êrens op die vraelys skryf nie.
Jou antwoorde sal anoniem gehou word – met ander woorde
niemand sal jou kan identifiseer as die persoon wat hierdie
vraelys voltooi het nie.

DEMOGRAFIE

In watter **gemeenskap** bly/werk jy?

(Jy mag meer as een opsie omkring, indien van toepassing)

Is jy:

- Lid van 'n Gemeenskaps Gesondheids Komitee (GK)
- Lid van die gemeenskap
- Werk jy by die Gemeenskaps Gesondheid fasiliteit

Vir hoeveel jaar was:

- Jy 'n lid van hierdie **GK**? _____ **Titel:** _____
- Jy 'n lid van hierdie **gemeenskap**? _____
- Werk jy al by hierdie **gesondheid fasiliteit**? _____ **Titel:** _____

GESLAG (manlik of vroulik?) _____

OUDERDOM (Hoe oud is jy?) _____

MODERTAAL (eerste taal): _____

Vir elkeen van die volgende vrae, omsirkel of maak 'n kruisie "X" langs die antwoord waarmee jy die meeste saamstem:

LEIERSKAP

1. Die Kliniek in my gemeenskap het 'n Gesondheid Komitee (GK)

Ja	Nee	Weet nie
----	-----	----------

2. Mense in die gemeenskap was **verkies** in die Gesondheid Komitee.

Ja	Nee	Weet nie
----	-----	----------

3. Die Gesondheid Komitee verteenwoordig die **diversiteit** van die gemeenskap.

Ja	Nee	Weet nie
----	-----	----------

4. Die leierskap van die Gesondheid Komitee het **verander met tyd** ooreenkomstig met die behoeftes en wense van my gemeenskap.

Ja	Nee	Weet nie
----	-----	----------

5. Leierskap van die Gesondheid Komitee is meeste mense wat by die **gesondheids fasiliteit werk**.

Ja	Nee	Weet nie
----	-----	----------

6. Meeste van die besluite wat deur die Gesondheid Komitee gemaak word, word deur 'n **enkele persoon** gemaak.

Ja	Nee	Weet nie
----	-----	----------

7. **Besluite** wat deur die Gesondheid Komitee gemaak word reflekteer die **belange** van die meerderheid in die gemeenskap.

Ja	Nee	Weet nie
----	-----	----------

8. Die Gesondheid Komitee **werk saam** met die gemeenskap se kliniek:

Altyd	Gereeld	Partykeer	Min	Nooit	Weet nie
-------	---------	-----------	-----	-------	----------

9. Die **fasiliteit bestuurders** woon Gesondheid Komitee vergaderings by:

Altyd	Gereeld	Partykeer	Min	Nooit	Weet nie
-------	---------	-----------	-----	-------	----------

10. Die mense wat by die **kliniek werk** woon Gesondheid Komitee vergaderings by.

Altyd	Gereeld	Partykeer	Min	Nooit	Weet nie
-------	---------	-----------	-----	-------	----------

11. **Wyk verteenwoordigers** woon Gesondheid Komitee vergaderings by:

Altyd	Gereeld	Partykeer	Min	Nooit	Weet nie
-------	---------	-----------	-----	-------	----------

12. **My gemeenskap is bewus** van die rol en funksies van die Gesondheid Komitee.

Meestal	Gedeeltelik	Min	Nooit	Weet nie
---------	-------------	-----	-------	----------

13. My **gemeenskap ondersteun** Gesondheid Komitee aktiwiteite waneer hulle daarvan weet.

Meestal	Gedeeltelik	Min	Nooit	Weet nie
---------	-------------	-----	-------	----------

14. Die Gesondheid Komitee het **nie** genoeg verteenwoordiging deur groepe wat maklik misgekyk word nie (soos byvoorbeeld vroue, kinders, arm mense en vlugteling).

Ja	Nee	Weet nie
----	-----	----------

15. Die Gesondheid Komitee lig gesondheids probleme van sensitiewe groep in die gemeenskap uit (soos byvoorbeeld vroue, kinders, arm mense en vlugteling).

Ja	Nee	Weet nie
----	-----	----------

ORGANISASIE

16. Die strukture van die Gesondheid Komitee was op die gemeenskap afgedwing.

Definitief	Ja	Nee	Glad nie	Weet nie
------------	----	-----	----------	----------

17. Die strukture van die Gesondheid Komitee was 'n uitvloeisel van die gemeenskap se behoeftes.

Definitief	Ja	Nee	Glad nie	Weet nie
------------	----	-----	----------	----------

18. Die Gesondheid Komitee behoort hoofsaaklik aan die gemeenskap.

Definitief	Ja	Nee	Glad nie	Weet nie
------------	----	-----	----------	----------

19. Die Gesondheid Komitee het met tyd verander soos die gemeenskap se behoeftes verander het.

Definitief	Ja	Nee	Glad nie	Weet nie
------------	----	-----	----------	----------

HULPBRON MOBILISEERING EN TOEKENNING

20. Hulpbronne in die **kliniek** kom van die gemeenskap (bv. van gebruikersfooie, en vondsinsamelings) .

Alles	Meeste	'n Matrige hoeveelheid	Bietjie	Geen	Weet nie
-------	--------	------------------------	---------	------	----------

21. Hulpbronne vir die Gesondheid Komitee kom van die gemeenskap.

Alles	Meeste	'n Matrige hoeveelheid	Bietjie	Geen	Weet nie
-------	--------	------------------------	---------	------	----------

22. Die **Gesondheid Komitee het geen beheer** oor hoe fondse geallokeer word aan gesondheids in die gemeenskap nie.

Definitief	Ja	Nee	Glad nie	Weet nie
------------	----	-----	----------	----------

23. Die Gesondheid Komitee is betrokke by besluite aangaande die begroting en verspreiding van hulpbronne aan gesondheids dienste of programme in die gemeenskap.

Definitief	Ja	Nee	Glad nie	Weet nie
------------	----	-----	----------	----------

24. Lede van die Gesondheid Komitee word vergoed vir hulle tyd.

Ja	Nee	Weet nie
----	-----	----------

BESTUUR VAN GESONDHEIDSDIENSTE

25. Maak gesondheids personeel al die beslute oor hoe dienste verskaf word met geen radpeging (input) van die Gesondheid Komitee?

Definitief	Ja	Nee	Glad nie	Weet nie
------------	----	-----	----------	----------

26. Die Gesondheid Komitee het niks of geen **toesighoudings rol** in die kliniek nie.

Definitief	Ja	Nee	Glad nie	Weet nie
------------	----	-----	----------	----------

27. Watter een van die volgende beskryf die Gesondheid Komitee se rol in gesondheids dienste die *beste*.

'n Vennoot wat saam met die gemeenskap se gesondheids fasiliteit werk om saam die gemeenskap se probleme en gesondheids behoeftes aan te spreek.	'n Belangrike hulpbron van bruikbare informasie vir gesondheids fasiliteite wat erken word deur gesondheids fasiliteite.	'n Bron van informasie wat miskien of miskien nie deur bestuurders in ag geneem word nie.	'n Groep wat partykeer kommentaar lewer aan die gesondheids fasiliteit maar geen ware impak op dienslewering het nie.	'n Groep wat verwyderd van die gesondheids dienste bestaan en geen ware impak op dienslewering het nie.	Weet nie
--	--	---	---	---	----------

28. Die impak wat my gemeenskap se GK het op *hoe* dienste gelewer word by my kliniek is:

Wonderlik, het altyd 'n definitiewe impak.	Groot, het gewoonlik 'n impak.	Matig, het partykeer 'n impak.	Beperk, selde 'n impak.	Niks, het nooit 'n impak nie.	Weet nie.
--	--------------------------------	--------------------------------	-------------------------	-------------------------------	-----------

BEHOEFTES BEPALING

29. Die Gesondheid Komitee is betrokke by die ontwikkeling van programme of diense wat gelewer word in die gemeenskap.

Altyd	Gereeld	Partykeer	Selde	Nooit	Weet nie
-------	---------	-----------	-------	-------	----------

30. Watter stelling bied die *beste beskrywing* van wie besluit watter dienste of programme aangebied word deur jou gemeenskaps gesondheids fasiliteit:

Gesamentlik deur die GK en die hoofde van die fasiliteit in die gemeenskap.	Die GK in my gemeenskap voer aan vir sekere dienste/ programme namens die gemeenskap maar die uiteindelijke besluit word deur gesondheids personeel by die fasiliteit gemaak.	Deur gesondheids personeel wat by die gemeenskaps gesondheid fasiliteit werk.	Heeltemal deur individue wat werk en leef buite jou gemeenskap.	Weet nie
---	---	---	---	----------

31. Watter stelling is die *beste beskrywing* van die proses waardeur die **gesondheids behoeftes** van my gemeenskap geidentifiseer word:

Van informasie wat bymekaar gesit is deur die gemeenskap met data wat deur gemeenskaps lede bymekaar gemaak is.	Deels van plaaslike voorstelle en informasie wat bymekaar gemaak is deur mense wat nie van die gemeenskap is nie.	Deels deur gesondheids personeel by die gemeenskaps gesondheids fasiliteit en informasie wat deur mense buite die gemeenskap bymekaar gemaak is.	Deur mense wat buite die gemeenskap leef en werk met informasie wat buite die gemeenskap bymekaar gemaak is.	Weet nie
---	---	--	--	----------

APPENDIX E

TOPIC GUIDE: Key Informants

- 1. Strong Health Committee?**
 - a. Reasons

- 2. Weak Health Committee?**
 - a. Reasons

- 3. Moderate Health Committee?**
 - a. Reasons

- 4. Other potential key informants**
 - a. Contact details

- 5. Access to HCs**
 - a. Set-up meeting

- 6. Access to health facilities**
 - a. Contact details

TOPIC GUIDE:

In-depth Interviews with service providers / HC members

1. Description of the Health Committee (HC)

2. Relationship between HC and Community Health Facility (CHF)

Probes:

- *Frequency of contact*
- *Purpose of contact*
- *HC meetings – who attends? How often?*

3. Factors influencing the relationship between HC and CHF

Probes:

- *How does facility staff feel about the HC? Why?*
- *How does the HC feel about facility staff? Why?*

4. Roles and responsibilities of the HC?

Probes:

- *What do you see as the major role/purpose of the HC?*
- *Has the HC ever been involved in the development /implementation of health services or programmes?*
- *Do you think the HC should play this role/function? Why or why not?*

5. Barriers to meaningful community participation via the HC

Probes:

- *What is ideal position of HC?*
- *What things prevent this ideal situation from taking place?*

6. Enabling factors to meaningful community participation

Probes:

- *What sorts of things make the HC operate the way it does?*

7. Relationship between participation and the right to health

Probes:

- *Examples of things HC has done in your community/at the facility?*
- *What sort of projects/activities is the HC busy with?*
- *Collaboration between HC and CHF?*