Title : **The pendulum of participation: exploring shifting participation of Health Committees during the Covid-19 Pandemic in Cape Town sub-districts**

By

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Abstract

Community participation is a vital component of public health with meaningful participation centred around empowering communities, establishing trust and developing collaborations between community members, government, health professionals and other key stakeholders. Despite widespread acknowledgment of the importance of community participation, there are numerous barriers to meaningful participation. Power dynamics and the spaces where participation takes place impact both the level and quality of participation. This qualitative study explores how participation in health committee spaces was affected during the Covid-19 pandemic and how the relationship between the state and health committees evolved during the pandemic. Health committees are a form of institutionalised participation situated as part of primary health care clinics and consist of community representatives, clinic managers and municipal political representatives. A function of these committees is to bridge the gap between community members and health facilities. Focus group discussions were conducted with two health committees located in Gugulethu and Manenberg, two economically marginalised areas in Cape Town, South Africa. Participants in the study were comprised of health committee members. Transcripts were analysed using a thematic analysis approach. Initial data analysis was inductive. Two conceptual frameworks: Arnstein's Ladder of Participation and Gaventa's notion of invited and invented spaces were used to interpret the findings. The study found that pre-Covid, the relationship between health committees and the state was limited, with little collaboration. During the pandemic, health committees responded to community needs and filled gaps in the state's reach. Subsequently, the state recognised its limits and the need for collaboration with community actors to reach communities. This brought about an opening of previously closed spaces to include health committees in more meaningful forms of participation. However, like a pendulum swinging back and forth, participation closed back down. In this context, health committees challenged the 'invited' space and invented their own spaces for participation. A number of challenges with invited participation were identified: lack of recognition, inadequate inclusion in state decisions, planning and implementation of interventions, lack of resources and state support and power dynamics. The study concludes that health committees occupy complex spaces and places of contestation where different actors continuously negotiate the dynamics of the space. Shifting participation requires a redistribution of power, the establishment of partnerships and trust and the creation of innovative, neutral spaces for collaboration.

Abbreviations

DOH	Department of Health
FGD	Focus Group Discussion
GHC	Gugulethu Health Committee
HC	Health Committee
ICF	Informed Consent Form
MHC	Manenberg Health Committee

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Table of Contents

Part A: Protocol

Research Question

To what extent can facilitated film viewings foster community engagement between health committee members and health workers and promote community-based solutions in response to the Covid-19 pandemic?

Purpose of the Study

This study will be a qualitative research study to explore the extent to which facilitated film viewings foster community engagement between health committee members and health workers and promote community-based solutions in response to the Covid-19 pandemic.

Research Aims / Objectives

The objectives of this study are to:

1) Understanding how facilitated film viewings impact on participant's intention to address communication between HCs and health workers. (The viewing of a documentary film The Lockdown: Community Perspectives followed by a focus group discussion. This process in this study is referred to as 'facilitated film viewings').
2) Identifying factors that foster or hinder community engagement
3) Understanding how community-based solutions are developed and implemented

Background / Significance

Amidst a pandemic, engaging with communities, particularly marginalised communities is imperative.(1, 2) During the Ebola pandemic, 2014-2015, community engagement was a key factor in reducing the spread of the disease.(3) Communities were engaged in the development and implementation of interventions and emphasis was placed on developing trust and strengthening relationships between communities, government and health officials.(3) Now in 2021, this is the second year the world is battling with Covid-19. First identified in Wuhan, China in December 2019, Covid-19 is an infectious disease caused by a respiratory pathogen (SARS-CoV-2).(1) Differing from the Ebola and HIV epidemics in Africa there was limited to no community engagement in the responses to Covid-19.(3-5) To curb the spread of the virus, countries implemented a variety of preventative measures which included: restrictions on movement (lockdown); social/physical distancing; hand washing\hand sanitising; mask wearing in public ; self-isolation (separation from

others if you have Covid-19) and quarantine (separation from others when you suspect you have Covid-19). (6-9)

Globally, countries imposed hard lockdown where schools were closed, international and domestic travel was halted; restrictions on mass gatherings were put in place; social gatherings and social visits were not allowed and people had to remain at home unless for essential food shopping and medical care; exercise was restricted and both the formal and informal trade sector experienced closures and disruptions to business.(6, 7, 10, 11) South Africa went into hard lockdown on the 26 March 2020.(12) People's experience of the lockdown has varied immensely with some finding the lockdown to be stressful and inconvenient, whereas other people faced immense challenges and hardships when the lockdown was implemented. There was an increase in gender based violence (GBV); many lost their jobs as both the informal and formal work sectors were shutdown; health services were affected or closed due to Covid-19 infections; it was impossible for people to socially/physically distance; and people went hungry as they were unable to afford food.(13-16) Later, a system with five lockdown levels was implemented with lockdowns adapted to suit different needs such as the pandemic context, and economic considerations and infection rates and numbers.(17) This risk-adjusted approach was guided by a number of factors: the infection levels in the country; the rate of transmission of the virus; the social and economic impact of the lockdown; and the extent to which health facilities can manage the infections.(17)

The approach to minimise the spread of Covid-19 infections was a top-down approach lacking in community engagement. Community members were not adequately consulted nor were they actively involved in the decision-making processes.(13, 15) Identifying specific community needs and priorities required to address and effectively implement Covid-19 preventative measures was lacking.(13, 15) Communities differ in terms of their access to clean water, nutritious food and healthcare, social-political-cultural structures/beliefs, social norms and values – all of which impact behaviour and responses to outbreaks.(3, 8) Engaging communities is critical to identify context specific barriers, such as environmental conditions, educational level, communication and information mechanisms used to share information around Covid-19; and access to resources.(2, 3, 8, 18)

Community engagement can be defined in numerous ways - it refers to the strengthening of relationships and trust-building between community members, health authorities, government and decision-makers through listening to communities and incorporating their voices into decision-making processes and policies.(2, 18) It is where health needs are identified by communities and communities are involved in the development and implementation of interventions.(19) Developing

trust between communities and health workers can foster a sense of ownership of interventions, and allow communities to implement and adhere to interventions. (2, 18, 19)

Numerous barriers to community engagement have been identified. These barriers include lack of accountability on behalf of the state and the inability or slowness of redressing inequalities within health services and communities; lack of ownership by communities; the attitudes of health workers towards community engagement; poverty, inequality; education levels; power dynamics; lack of support and funding; lack of understanding of existing community practices, beliefs and values.(2, 18, 20, 21) Trust is also an important issue. There has been research indicating that low trust influences how populations respond to Covid-19 and the lockdown.(22, 23) In societies with higher levels of trust in government, health workers and health services, there has been evidence of higher acceptance of lockdown regulations.(22, 23) Interventions to reduce the spread of Covid-19 infections are hindered by these barriers (2, 20, 21) Community engagement can improve communities' knowledge and understanding of the virus and the preventative measures put in place. This understanding and gained knowledge, means that communities may engage more readily with the health messages and adhere to intervention measures.(2, 18, 24) Through their increased agency which comes with gaining knowledge and understanding of a topic or situation, communities may share this knowledge with others.(25)

Since community engagement is key to combating infectious disease, health committees (HCs) can be a bridge to community engagement to strengthen health services and health systems.(18, 24) HCs in South Africa (SA) are legislated statutory bodies that work alongside health services to ensure collaboration and partnership between communities and the health system.(18, 24) In this study, when referring to HCs, the reference pertains to South African HCs. They are composed of one or more local ward councillors, the head of the health facility and one or more members of the community. (18, 24) Challenges faced by HCs are lack of monetary support; unrepresented member makeup; weak relationships between members and health workers; lack of trust, limited structure and lack of accountability mechanisms.(24, 26) HCs can give voice to communities to speak about their health needs and challenges.(24) However, HCs are often disempowered and unable to meaningfully impact health requirements. In the Western Cape (WC), in SA, there is little engagement from HCs in decision-making processes and policy drafting.(24)

With HCs being a bridge to communication and engaging communities in their health decisions, facilitated film discussions can address barriers to communication such as lack of trust, difference in socio-cultural-political beliefs, and strengthening relationships through open discussions around sensitive topics.(27, 28) Documentary film discussions have been shown to allow the viewers to talk

about their feelings and grapple with complex and challenging topics.(27, 28) Unlike traditional media campaigns and media messages which focus on changing people's behaviour (e.g. to get people to wear masks; to adhere to social/physical distancing; to remain at home), facilitated film viewings can provide people with a means to discuss and share opinions and devise solutions to identified issues.(27, 28) Facilitated film viewings can thus help to identify barriers; risks and challenges to adherence to interventions and can instil confidence and trust between viewers.(27, 28) Documentary films present stories that are relatable to people's lived experiences and by having facilitated screenings and discussions about the film, this provides space for people to understand each other and develop new understandings and perceptions together.(27, 28) These facilitated film viewings can also promote a sense of responsibility for the well-being of self and others.(27, 28)

This study proposes to use facilitated documentary film discussions to facilitate communication between health committee members and health workers. These discussions will also explore new community-based solutions as well as how communities can facilitate an environment in which it becomes possible to adhere to the standard non-surgical interventions. The documentary film to be shown – The Lockdown: Community Experiences was developed as part of a Masters in Public Health (MPH) practicum. The film produced by the student researcher of this study aimed to capture and understand people's experiences of lockdown in different communities in Cape Town, South Africa. Interview snippets are used to showcase community experiences to help students, academics, researchers, decision-makers and the broader audience understand what lockdown has meant for people.

Literature Review

Engaging communities in all health aspects, including decision-making processes, identifying issues and finding solutions to health challenges is important to ensure equitable and accessible access to healthcare for everyone regardless of race, socio-economic status, religion, location, age, gender and cultural beliefs.(29) One of the goals of the United Nations 2030 sustainable development goals (SDGs) is that of universal health coverage (UHC).(29) Entering into the sixth year of the implementation of the SDGs limited progress has been made, with many people, particularly those in disadvantaged and marginalised communities having limited to no access to quality health care and services.(29) The World Health Organisation recognises that a gap is the engagement and participation of communities in achieving health goals and universal health coverage (UHC).(29)

Engaging with communities to manage infectious disease outbreaks, with communities taking a key role in the response and ensuring a collaborative approach to interventions is important for successful management and reducing damage and deaths.(3) In the case of the Ebola and HIV

epidemics in Africa, there were many barriers which included, people being suspicious as to whether the disease actually existed, and people questioned the motivation of the government and other international organisations.(3, 5) This led to people not adhering to the preventative and protective measures put in place to curb the Ebola epidemic.(3) In order to address these barriers faced during the Ebola epidemic, community engagement was key.(3) Building trust and strengthening relationships between community leaders, government officials and the community to understand and alter messages accordingly, helped to change people's perceptions and behaviour towards the epidemic.(3) These community engagement practices contributed to managing the Ebola outbreak.(3) In contrast to the Ebola outbreaks where communities were engaged and part of the decision-making processes and intervention implementations, there was a lack of community engagement with communities either being poorly involved or not involved at all in the planning and implementation of interventions to curb the spread of Covid-19 infections.(3, 4) Community engagement is critical in the Covid-19 pandemic to: 1) identify barriers to uptake of non-surgical interventions; 2) improve knowledge of the 'science' behind interventions; 3) improve trust in identified interventions; 4) improve implementation and adherence to local interventions; 5) strengthen relationships with local leaders to facilitate trust and 6) community monitoring of interventions.(3-5, 20)

Community engagement is defined as the development of relationships between people that enable collaboration to address issues and create solutions together that align with mutual needs and goals.(29, 30) It focuses on the values of trust, accessibility, equity, transparency, autonomy and accountability and developing partnerships between community members, government, health professionals and other key stakeholders.(29, 30) Community engagement is crucial to the provision of health services.

However, research has identified numerous barriers to community engagement which include community mistrust in government and health authorities; lack of accountability on behalf of the state and the inability or slowness of redressing inequalities within health and communities; lack of ownership by communities (where communities are not involved and leading the process of identifying priorities, support, resources, solutions and relevant community programmes); the attitudes of health workers; poverty, inequality and education levels; power dynamics; lack of support and funding; lack of understanding of existing community practices, beliefs and values.(2, 18, 20, 21) These studies are from Africa (South Africa, Liberia, Sierra Leone, Zimbabwe) and India.(4, 5, 20, 22) Health committees (HCs) can be seen as mechanisms of change and a bridge to community engagement that has the ability to strengthen health services and health systems.(24)

HCs are voluntary community groups that work alongside health services to ensure a partnership between communities and the health system and to give voices to communities in terms of health needs, barriers and facilitators.(24) There are differences between HCs both within countries and across countries and include the level of involvement of HCs in decision-making processes; differing legislation specifying roles and responsibilities of HCs; and how members are appointed, whether members are elected or appointed by the community or health professionals.(24) In South Africa (SA), the White Paper on Transforming the Health Services outlined the role of HCs where HCs were set-up to be a link between communities and the health system through active public participation in the planning, provision and decision-making processes around health services and the health system.(24, 26, 31) HCs could thus hold public officials accountable and ensure that progress towards health goals was monitored.(24) However, the intentions of the White Paper, was not carried through in the National Health Act, which provides for HCs to be established at all clinics, but leaves it to provincial it to the provincial legislation to outline roles of HCs.(24) This uncertainty has meant that HCs practice their roles in different ways and face different challenges.(18, 24)

In SA, HCs face numerous challenges which include lack of monetary support; member makeup being unrepresentative of the community; infrequent meetings; weak linkages between HCs members and the rest of the community; and lack of structure and a policy framework as guidance and accountability is lacking.(24, 26) HCs are not engaged with nor is there effective partnerships between HCs, health workers and government. Barriers such as lack of trust, weak relationships, power dynamics and misunderstanding of community needs, values, beliefs and environment hinder community engagement and diminish the value HCs can bring.(18, 26, 32)

In the African context, where countries face structural challenges, weak health systems and people living with little or no income, food and support, community engagement is imperative to address these challenges which are further compounded during epidemics such as Ebola and Covid-19.(4) In South Africa, with alert levels (various levels of lockdown) being implemented since March 2020, people have been required to change their behaviours to reduce the spread of Covid-19 infections. These preventative measures, such as mask wearing; physical/social distancing; no social gatherings; self-isolation and quarantine have been difficult for people to adhere to due to lack of physical space to distance themselves from others, lack of income to provide food and care for families, misconceptions around Covid-19, distrust in the state and health authorities, competing priorities, cultural and social values and beliefs.(4, 8) Understanding that communities are dynamic and that community groups are heterogenous with people having different socio-cultural beliefs and opinions which can conflict with and negatively affect interventions is important.(4, 8) In order to understand specific community dynamics and find mutually acceptable solutions that people will adhere to

requires community engagement which means facilitating and promoting community trust, and relationship strengthening between the state, health authorities, community leaders, members and key stakeholders.(4, 8)

In relation to Covid-19, engaging communities is critical to identify context specific challenges, such as living conditions, educational level, communication and information mechanisms used to disseminate information around Covid-19, access to resources and trust in authorities and health services.(2, 3, 8, 18) There are many lessons we can learn from the Ebola outbreaks in Africa that can be applied to the Covid-19 response.(4, 8) Community engagement in the context of Covid-19 can foster trust, build and strengthen relationships through transparent and open communication that aims to understand community priorities, values, beliefs and available resources.(2, 18-21) This trust building and understanding can empower communities along with their involvement in decision-making processes, development and implementation of interventions to take ownership of the intervention and preventative measures and thus encourage other community members to adhere to the interventions put in place.(2, 3, 20, 21) This is more likely to result in adherence to interventions and preventative measures and successful behaviour change.(2, 3, 20, 21) If the barriers of lack of trust; weak relationships between HCs and health workers, lack of ownership of interventions and ideas, and power dynamics facing HCs are addressed, then HCs can be vehicles to promote community engagement, and bring about change and transformation in both health services and the relationships between communities, health professionals and government officials.(24, 32) This is particularly the case with infectious diseases such as Ebola and also applies to the current Covid-19 pandemic.(3, 33)

Short films have been used in qualitative research to engage communities around HIV research both in terms of stigma perceptions; HIV-related risk and HIV research involving men who have sex with men (MSM).(27, 28, 34, 35) These studies from Africa (South Africa, Lesotho, Mozambique Kenya and Nigeria) used documentary films as communication tools to facilitate discussion and engage communities through facilitated film viewings and subsequent discussions.(34, 35) Kombo et al, 2017, and Lapinski et al, 2008, show that facilitated film viewings can act as prompts for discussions that address HIV related stigma and provided an opportunity for conversations between MSM and wider community members.(34, 35) In the Steps for the Future media advocacy project in Southern Africa, Levine, 2007, films were made that explored issues around HIV/AIDS that delved into topics around gender inequality, trust, poverty, rape, stigma, fear, death, sex, racism and political oppression.(27, 28) These studies found that documentaries have the ability to break down silences and allow people to discuss complex and challenging issues and creates spaces for facilitated and transparent discussions to take place.(27, 28, 34, 35) These films speak to the lived experiences of

people and the facilitated discussions allows the audience to share their feelings and opinions about the explored topics.(27, 28, 34, 35) Audiences are active participants and the facilitated viewings and discussions have the ability to move people towards new understandings, perceptions and solutions to issues.(27, 28, 34, 35) These facilitated viewings can facilitate trust, confidence and strengthen relationships between people.(27, 28, 34, 35) Cinema and facilitated film viewings can therefore be tools to foster community engagement due to the nature of shared experiences and open discussions around the explored topic of the film.(27, 28, 34, 35)

This study will use a documentary film: The Lockdown: Community Perspectives, to facilitate discussions around Covid-19 and the resultant lockdown. This film was produced in 2020 by the student researcher of this study (currently undertaking her Masters in Public Health at the University of Cape Town), and captures community members' experiences of the lockdown. These facilitated film viewings will form the basis to initiate discussions around Covid-19 and the lockdown. The study will explore the extent to which facilitated film viewings foster community engagement and promote community based solutions.

The research in this literature review comes from the United States, Africa and South Africa in the form of quantitative and qualitative research using in-depth interviews and focus group discussions.1-27 The research includes understanding the role of HCs in community engagement in relation to communicable diseases and strengthening and building trust and relationships in health systems and health services as well as understanding power dynamics in these relationships.1-27 The reviewed literature and research relate to the current research question and study in terms of background and insight into the importance of community engagement and how this has been lacking in the response to Covid-19.

Methodology

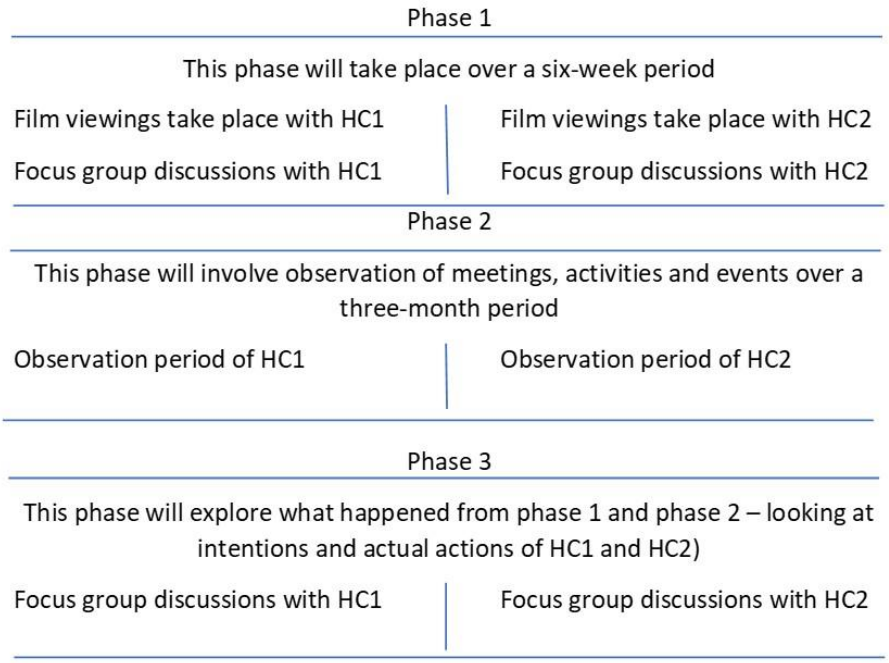
Study Design

This will be a qualitative study to explore the extent to which facilitated film viewings and discussions around Covid-19 and the lockdown can support community engagement and promote community-based solutions. Two facilitated film viewings will take place with two health committees from the Klipfontein sub-district in Cape Town, South Africa. The Klipfontein sub-district is chosen due to prior relationships with HCs in the area.

Each film viewing will be followed by a focus group discussion (FGDs) with members of each FGDs being HC1 and HC2 respectively (phase one). These two FGDs will be followed by a three-month observation period where the student researcher will observe HC meetings, events and activities (phase 2). Following this observation period, two more FGDs will take place with the two HCs

exploring intentions set by HCs in phase one and actual actions that took place during the observation period (phase three). See Figure one below for a diagrammatic illustration of the study design:

Figure 1: Diagrammatic illustration of the proposed study design



Population and sampling

Participants will be members of two HCs that fall within the Klipfontein sub-district in Cape Town, South Africa. One FGDs will be with members from HC1 and the second FGDs will be with members from HC2. The number of participants in each FGD is reduced due to Covid-19 protocols of maintaining social/physical distancing and ensuring everyone is safe.

Inclusion and exclusion criteria

All participants will be over the age of 18 years and will be both male and female.

Location of the research

The research will be conducted in communities in the Klipfontein sub-district in Cape Town, South Africa. The facilitated film viewings, FGDs and observations will be held in buildings that allow for social/physical distancing between participants. The Klipfontein district is made up of the following areas: Manenberg, Heideveld, Athlone, Nyanga, Gugulethu, Hanover park.(36) Almost all of the areas in the Klipfontein district are affected by poverty, high rates of unemployment, health challenges and gang violence.(37)

Recruitment and enrolment

Participants will be recruited from two HCs in the Klipfontein sub-district in Cape Town, South Africa. The two HCs will be approached during HC meetings for participant recruitment. The HCs in this study are the participants. When HC members are contacted for recruitment it will be made clear that their participation is voluntary and that if they decide to partake in the study, that they can withdraw their participation at any stage of the research process.

Research procedures and data collection methods

This study will involve two FGDs and film viewings followed by a three-month observation period between phase 1 and phase 3 (see Figure 1 above for an illustration of the study design). Depending on Covid-19 and the lockdown restrictions, FGDs and the film viewing will be face-to-face. Each FGDs will be one to two hours long (20 minutes for the film viewing and 30 to 40 minutes for the FGDs) long held over a period of four to six weeks.

At the start of each FGDs a short documentary – The Lockdown: Community Perspectives will be shown to each of the two HCs. This film captures people's experiences of the lockdown from various low socio-economic areas in Cape Town, South Africa and will be the basis for facilitated discussions around Covid-19, the lockdown and the challenges faced by communities. These facilitated discussions will be aimed at facilitating community engagement through listening to community members around what the challenges were and are in terms of Covid-19 and lockdown and how communities can be worked with to navigate these challenges and facilitate community-based/identified solutions. These facilitated discussions will be guided by an interview guide with open-ended questions to explore and understand the challenges communities face and to discuss/develop solutions to these challenges.

There is an inherent power imbalance both between the researcher and the participants as well as between participants themselves.(38) This may mean that participants feel pressured to answer 'correctly' or in a certain way so as to please either the researcher or the other participants, or both.(38) Participants will be advised to be honest in the communications and that there is not right or wrong answer but rather a discussion and exploration of issues and challenges to try and minimise the power dynamics.

This observation phase will be conducted to provide insight into HCs intentions and action. The follow-up FGDs with the two HCs will provide a space for discussions around the intent and actions as well as the relation to thoughts, perspectives, attitudes and opportunities for application.

Data analysis

The FGDs will be in English and will be audio recorded so that the transcripts can be qualitatively analysed. Prior to participation in the study, the purpose of the study and the role of the participants and the researcher will be explained to the participants and all participants will be asked to sign an informed consent form (Appendix 1 & 5). All identifiable participant information will be excluded from any of the data analysis and write up of the results. Each audio file will be transcribed for ease of analysis and all the audio files and the transcripts will be kept in a secure locked cabinet in the researcher's office (the MPH student), as well as on a shared DropBox folder which will be shared with the supervisors of the MPH student.

Data will be analysed using a data analysis software program – Nvivo or DeDoose. Thematic analysis will be used to categorise and make sense of the data for discussion.(39, 40) Inductive codes will be developed from the data and once all the transcripts are coded, codes will be refined into themes as they pertain to the research aim.(39, 40)

Rigour

An observation period between the two focus groups will be conducted to strengthen the results and rigour of the study.

Rigour within the data analysis will be established through constant comparison of the data, the identified codes and themes.(39, 40) The codes and themes will also be reviewed by the supervisors of this student thesis to ensure rigour.(39, 40) Each transcript will be compared with other transcripts and will not be considered on its own. This will allow the data to be considered as part of a whole rather than as a separate fragmented piece of information.(39, 40)

Researcher bias and characteristics of the researcher are important aspects to consider as these can all influence the analysis of the data.(38) To minimise researcher bias and influences, reflexivity is important in qualitative research.(38) Member checking during the FGDs in phase 1 and phase 3 by relaying what was said in the FGDs back to participants, for example: I understand you are saying that…is this correct will ensure rigour of this study. will be used as a way to guard against misinterpretation and bias. Fieldnotes will be written up following each FGDs and there will be a debrief session between the student and the supervisor which will allow biases and any issues to be identified and addressed. The student researcher will also keep a journal during this study to document the process and their feelings thoughts and decisions as a way to address researcher bias and minimise misrepresentation that can take place. The researcher will also check in with participants during the FGDs that what has been said has been interpreted in the correct manner by

reflecting back to participants what has been said.(41) The student researcher will be closely supervised to reduce the risk of researcher bias and misinterpretation.(41)

Description of risks and benefits

Potential risks and discomforts, minimising risk and risk classification

The overall risk of this study is minimal. Potential harms in qualitative research identified by Richards and Schwartz, 2002, are risks to participants which can entail anxiety and distress; power imbalance; misinterpretation; and identification of participants.(38, 41) Qualitative studies involved in depth exploration and understanding of challenges participants face and these discussions can lead to participants feeling anxious and distressed due to the information shared either by themselves or by others. This is due to the open-ended nature of the questioning in qualitative research.(38) Where required, participants will be referred to the trauma centre or the counselling centre: Community Counselling and Training Centre and the Saartjie Baartman Centre for Women and Children.

There is also the risk that participants may see these FGDs as therapeutic sessions and the researcher needs to be aware of this and their role in the study – that of researcher rather than therapist.(38) Debrief sessions and reflection can assist with identifying and navigating potential power imbalances.(38)

Specific risks of doing FGDs during Covid-19 will be minimised by conducting these FGDs and film viewings in well-ventilated buildings, ensuring that participants are sitting 1.5m apart from each other. Masks will be worn during the film viewings and the FGDs and hand sanitisers will be provided for participants to use upon entering the room and as required during the sessions. If participants are ill on the day of the film viewing and the FGDs then these will be rescheduled, or the participant will be unable to attend the session to ensure the safety of others. HC members will be screened for symptoms and contact as per Covid-19 procedures. HCs are currently meeting as committees and these FGDs will occur at the end of these HC meetings. HC members are also familiar with safety procedures as they have received training and practice these learnings in their meetings and daily activities.

It is also important to ensure that any identifiable characteristics of participants have been eliminated from transcripts and from the write up of this study to ensure confidentially and the privacy of participants.(38, 41) This will be achieved by using non-identifiable markers when transcribing the audio files.

Potential benefits

The aim of this study is to use film viewings to facilitate community engagement and promote community-based/identified solutions. The potential benefits are that the forward approach to Covid-19 and lockdown will involve community engagement and shift from a top-down, vertical approach to a more horizontal, bottom-up approach to dealing with the pandemic. This can then be used as a basis for future preventative and intervention measures for Covid-19 and future disease outbreaks.

Another potential benefit is that participants and community voices are heard in terms of the challenges that they face due to Covid-19 and the resultant lockdown that has been imposed. The development of relationships and trust between community members and those working in the health system can develop.

Alternatives to participation

N/A

Harm: benefit ratio

There is minimal risk – besides the risks posed by Covid-19 and measures will be implemented to minimise this risk (identified in the section above around potential risks). In this study, the benefits outweigh the harm and there is an opportunity for open discussion around Covid-19 and the lockdown and how community members have been affected. It is a chance for people's voices to be heard and for people to share their experiences and to develop solutions to challenges that have risen.

Informed consent process

Process

Informed consent will be obtained from HCs during HC meetings prior to the commencement of the film viewings, FGDs and the observation period. The research study will be outlined to HCs during these meetings and will explain where the FGDs will take place, the length of the FGDs, who will be present during the FGDs, and the nature of the topics to be discussed during the FGDs. HCs will be given the opportunity to ask questions and seek clarity around the study as required (see Appendix 1 & 5 for an example of the consent form). Hard copies of the signed consent forms will be given to members of the HCs. These informed consent forms will also be scanned and saved on the shared Dropbox for storage and the hard copies will be stored in a locked cabinet in the student researcher's office. There will be no repercussions for HCs members who do not wish to participate in this study and this will be explained to participants.

Immediately prior to the commencement of the FGDs, the student researcher will discuss the set of norms for the discussions. These will include that when a someone is speaking, others will not speak over them and give them a chance to speak; participants will refrain from shouting at other participants; the need for confidentially and privacy of these groups (complete confidentiality cannot be guaranteed in FGDs); and the expectations of the group (which are to watch the video and have discussions around the challenges people faced due to Covid-19 and the resultant lockdown and to identify possible solutions going forward).(41) This briefing prior to the start of the FGDs can give participants another opportunity to withdraw from the study if they choose to do so at this stage.(41) A debriefing following each FGDs will take place where the content that was discussed will be summarised to participants and confidentiality and anonymity can be reiterated.(41) Concerns/ issues that arose can be further addressed along with participants reactions to these issues.(41)

Capacity to consent

All participants are over the age of 18 and as members of HCs, will have the capacity to consent.

Comprehension of information

Once the research study has been explained to participants and the informed consent form read and given to HC members, they will be asked to summarise what the study and the FGDs will entail to ensure comprehension of the information supplied. Hard copies of the informed consent form will be given to members. HC members will be given the opportunity to ask questions and seek clarity around the informed consent form and the research study.

Withholding information

No information will be withheld from participants

Consent and assent forms

All participants in the study will be over the age of 18 years and the consent forms will be for adults. The consent forms will be in English as the enrolled participants will be competent in English. A copy of the consent form is attached as Appendix 1 & 5.

Privacy and confidentiality

Personal information such as age, gender and profession will be collected in this study to describe the population demographics. Demographic information will be collected via a survey handed out at the beginning of each FGDs (see Appendix 3 & 6). Names of participants will be removed from the transcripts and numbers for each participant used. Names and other personal identifiable data will also be removed from the writeup of this project.

Hard copies of the transcripts and fieldnotes will be kept in a in a locked cabinet in the student researcher's office and the scanned transcripts and the audio files will be stored on a shared DropBox folder, which will be shared with the student researcher and the supervisors. The data will be stored for five years and after these five years the hard copies will be shredded and disposed of and the DropBox folder will be deleted with all the data from the research study. DropBox is a secure cloud storage solution with only the shared individuals (the student and the supervisors) having access to this folder.

Reimbursement for participation

Participants will be served water, tea, coffee and fruit for the duration of the film viewing and the FGDs. Transport reimbursements of between R20 -R50 will be given to participants.

Emergency care and insurance for research-related injury

This qualitative research study has minimal risk to participants and the researcher and UCT carries a no-fault insurance policy which covers injuries incurred in the research process should this be required.

What happens at the end of the study?

The findings will be presented to the participants and the wider community in a research dissemination discussion morning. This will be hosted by the student researcher and will be an opportunity to present the findings of the study to both participants and stakeholders. A summary document will also be shared with the health committee and other health committees and relevant stakeholders so that the findings may be further discussed and incorporated where applicable into future community-based solutions to address Covid-19 and lockdown challenges.

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Part B: Journal Article

The pendulum of participation: exploring shifting participation of Health Committees during the Covid-19 Pandemic in Cape Town sub-districts

Target Journal: *PLoS One*

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Abstract

Community participation is a vital component of public health with meaningful participation centred around empowering communities, establishing trust and developing collaborations between community members, government, health professionals and other key stakeholders. Despite widespread acknowledgment of the importance of community participation, there are numerous barriers to meaningful participation. Power dynamics and the spaces where participation takes place impact both the level and quality of participation. This qualitative study explored how participation in health committee spaces was affected during the Covid-19 pandemic and how the relationship between the state and health committees evolved during the pandemic. Health committees are a form of institutionalised participation situated as part of primary health care clinics and consist of community representatives, clinic managers and municipal political representatives. A function of these committees is to bridge the gap between community members and health facilities. Focus group discussions were conducted with two health committees located in Gugulethu and Manenberg, two economically marginalised areas in Cape Town, South Africa. Participants in the study were comprised of health committee members. Transcripts were analysed using a thematic analysis approach. Initial data analysis was inductive. Two conceptual frameworks: Arnstein's Ladder of Participation and Gaventa's notion of invited and invented spaces were used to interpret the findings. The study found that pre-Covid, the relationship between health committees and the state was limited, with little collaboration. During the pandemic, health committees responded to community needs and filled gaps in the state's reach. Subsequently, the state recognised its limits and the need for collaboration with community actors to reach communities. This brought about an opening of previously closed spaces to include health committees in more meaningful forms of participation. However, like a pendulum swinging back and forth, participation closed back down. In this context, health committees challenged the 'invited' space and invented their own spaces for participation. A number of challenges with invited participation were identified: lack of recognition, inadequate inclusion in state decisions, planning and implementation of interventions, lack of resources and state support and power dynamics. The study concludes that health committees occupy complex spaces and places of contestation where different actors continuously negotiate the dynamics of the space. Shifting participation requires a redistribution of power, the establishment of partnerships and trust and the creation of innovative, neutral spaces for collaboration.

Key words***:*** community participation, invited spaces, power, health committees, Covid-19

Introduction

Community participation is a key component of public health, with the historical roots of participation stemming from social justice movements driven by the notion of people reclaiming their power.(1, 2) Participation is at the core of the Declaration of Alma-Ata, which was the result of a large international conference on primary health care in 1978. Article Four of the Declaration states that, "people have the right and duty to participate individually and collectively in the planning and implementation of their health care".(3, 4) Meaningful participation should encompass working together with community members, health professionals, government, and other key stakeholders to identify and address issues impacting the health of the public/community.(1, 5) Community participation can be defined in numerous ways with the definition below capturing the essence of participation:

> *'…a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change.'(6)*

The literature around participation focuses on empowering communities and building rapport and trust between communities and government.(7-9) There is a strong emphasis on collaboration and partnership.(5, 10, 11) One can understand participation as a lens for assessing empowerment, where communities have access to resources and information which are seen as tools to challenge and hold those in power accountable.(10, 11) Community participation is an iterative rather than a linear process where community and the state (understood as organs of the state including the Department of Health and health services) identify issues, problems and solutions together on an ongoing basis. Thus, one could understand participation as a mechanism to improve the health and wellbeing of community members through empowering communities and providing them with the resources for change. However, despite widespread acknowledgement of the importance of community participation, there is general agreement that participation is rarely done well with many barriers to meaningful participation.(8, 12, 13)

Degrees and forms of participation can be understood using two conceptual frameworks: Arnstein's Ladder of Participation (7) and Gaventa's (14) idea of invited and invented spaces.(7, 9, 14-16) The Ladder of Participation (7) has eight rungs with the bottom rungs being non-participation (manipulation and therapy), followed by tokenism (informing, consulting and placation) and the top rungs representing citizen power (partnership, delegated power and citizen control).(7, 9) Each rung has a different name and speaks to a different form of participation. As the degree of participation is

increased, the form of participation changes.(7, 9) Power dynamics impede and constrain participation to the lower rungs of Arnstein's ladder.(7, 14, 15)

The spaces where participation takes place is important to consider as people bring their histories and past experiences into these spaces and therefore spaces are often not neutral.(14-16) Cornwall (16) and Gaventa (14) use the terms closed, invited and invented to describe spaces that have different implications for participation. In closed spaces, decisions are made "behind closed doors" with no place for community inclusion.(14) State decision-making processes tend to take place in closed spaces, according to an older more traditional approach to public health. (14) Those with power make decisions for and about community members with no room for community discussion or participation.(14) Invited spaces, on the other hand, are places where there is usually some form of participation, yet participation is limited and restricted.(7, 9, 14, 16) These spaces are an opening up of participation where communities are invited into state-created and state-managed spaces to participate in some way.(14, 16) Here community members can hear, and sometimes contribute to policy discussions and are informed to some degree about state decisions, plans and interventions. However, these spaces are still usually constrained and institutionalised with the power resting wholly with the state.(14-17) Finally, invented/claimed spaces are organic spaces where more meaningful participation might take place.(14, 16, 17) These spaces are often a product of the restrictions of invited spaces and an opposition response towards those who hold the most power.(14-17) Invented/claimed spaces arise from common goals and the need to uplift and empower individuals and communities.

As we examine the places where participation takes place and begin to understand the different degrees of participation that occur in different spaces, power is an important consideration.(15, 17) Power dynamics have a significant impact on how the abovementioned types of spaces function.(15) In addition to Gaventa's notion of power, Veneklasen and Miller's (18) framework of "forms" of power help to further unpack how power works in these spaces. Research highlights how for participation to shift towards citizen power, there needs to be a paradigm shift in terms of who holds power and control.(7, 9, 14-17) Power thus needs to be redistributed so it is more evenly shared between the state and communities.(15, 17)

Community participation and health committees in South Africa

In South Africa, a common form of institutionalised participation in public health are health committees (HCs) or clinic committees, situated as part of primary health care clinics.(19) HCs consist of community representatives who act as a bridge between community members and health facilities. The envisioned role of HCs as a bridge is to navigate and facilitate communication between

service users and the health facility. Challenges and facilitators to services and access to the clinic are meant to be brought to HCs and then these taken back to the facility manager to be addressed as applicable. However, this form of partnership requires a good relationship between the facility manager, the HC and the community members. HCs then also require training, resources and capacity building to empower their members and provide the necessary support to perform the functions. HCs are comprised of these community representatives, both elected and non-elected members- while this discussion and difference in membership type is important, it is beyond the scope of this study-, the health facility manager and the ward councillor (a municipal political representative).(20, 21) Community participation and HCs have been around in various forms in South Africa for a long time, with HCs becoming statutory bodies in 2003 as part of the National Health Act.(19-21) The role and function of HCs differs from province to province with some provinces having better functioning and more active HCs than others.(19, 21) Each HC is associated with a particular health facility in an area and HCs are the link between the facility and the community.(20) Often, the main role of an HC is to share and manage complaints and cleaning in these clinics.(22)

Research shows that HCs face numerous challenges which include lack of clarity around their roles and function, little to no funding support, lack of resources and minimal state support.(19, 22, 23) For active HCs, meetings are held monthly in the health facility with the facility manager present. Ward councillors are reportedly often absent from these meetings.(22, 23) HCs are often comprised of older, unemployed women. Despite all the important work that they do, HCs often feel that they are unrecognised, pushed to the side, underfunded and excluded from discussions that involve the health and wellbeing of their communities.(23) The role of HCs as structures for community participation is to bridge the gap between the health system and communities, yet the challenges they face hinder this collaboration.

Challenges managing epidemics and the Covid-19 context

While many of the challenges (mentioned above) faced by HCs are built into the structure of local health systems and their contexts, an additional recent challenge to participation has been the Covid-19 pandemic. The current Covid-19 crisis has been a challenge worldwide and now at the beginning of 2022, almost two years on, we are still dealing with Covid-19 and its challenges. Infection rates have been increasing both globally and in South Africa, with another wave of infections expected in South Africa as the country enters Winter.(24, 25) Covid-19 and the preventative measures put in place to curb the spread of infections—lockdown, social distancing, wearing masks and hand washing/sanitising—have taken its toll on everyone around the world, with those in marginalised communities increasingly impacted due to their social circumstances.(5, 26-29)

Overcrowded living conditions, unemployment, lack of water, food, electricity and sanitation issues have made adhering to Covid-19 protocols difficult.(27, 30, 31) Covid-19 not only added new challenges but also exacerbated and perpetuated these pre-existing inadequate living conditions, along with intensifying health inequities and deepening the divide between the rich and the poor.(5, 27, 29) In South Africa, an already struggling public health system was further taxed with health services coming to a standstill or being inaccessible.(32, 33)

Years of discrimination, racism, oppression and corruption have also perpetuated community mistrust of the state and health officials. This distrust impacts community decisions around Covid-19 messaging, vaccine uptake and preventative measures. (29, 34) Myths surrounding the Covid-19 vaccine are driven by this distrust, social media and conspiracy theories. Covid-19 preventative measures such as mask wearing, social distancing and hand washing/hand sanitising were often not adhered to, either because these messages were ignored or because of people's inability to adhere to these measures.(35, 36) The South African response to Covid-19 has been a top-down approach with interventions and protocols developed by the state with the guidance of professionals and experts in various fields.(37) Absent from these state planning and decision-making spaces were the voices of community members—these spaces were essentially closed to communities.(30, 37)

The value of community participation in previous epidemics is clear. The Ebola outbreak in 2014-2015 was an instance where community participation was crucial, with community members working as part of the management and intervention process.(28, 30, 37-39) Community leaders were essential as links to the community and assisting with infection identification and control measures. Community participation is also important to sustain these prevention and control measures in the long term. Community participation was also influential during the HIV/AIDS pandemic in improving access to treatment, HIV testing and counselling, raising awareness, education and reducing stigma.(29, 39) The value of community participation in pandemics is related to community leaders being familiar with the areas they live in and understanding the specific challenges in their own environments.(30) Working in partnership through building dialogues and trust between the lay public, health professionals and government, can empower communities to develop community-led interventions and ensure that prevention measures are suitable, tailored to their context and adhered to. Lessons learned from the Ebola outbreak and HIV/AIDS epidemic spotlighted key features of effective community participation.(30, 39) Firstly, participation was a critical component of effective management of these crises and secondly, participation evolved organically over the course of these crises.(30, 39) There was a move to a more collaborative, horizontal approach in contrast to a top down one. Spaces developed and became

available for community members to be involved in discussions around the planning and implementation of interventions.

Experiences and knowledge gained from previous epidemics have shown how opening of usually closed spaces for participation is a step towards more meaningful forms of participation. However, these invited spaces while important, are often problematic for participation with HCs experiencing limited or superficial participation. Various factors including power dynamics between the state and community, distrust of the state, deeply entrenched social inequities and poor socio-economic conditions, lack of accountability and limited resources of the state, inability for community organisation and misrepresentation of community are all key factors that make invited spaces difficult.(14-16) Given these pre-existing challenges to participation, it is important to consider how participation may have changed with the Covid-19 pandemic. During these disruptions to normality, participation might have become even more important but harder to do well, in the context of crisis. In instances where a more top-down approach was utilised, was participation with the state reduced? In instances where there was more cooperation and partnership between the state and communities, was participation better? In other instances, the state might be unable to fully respond to community needs. Did community structures step in to fill this gap? In these instances, HC participation in addressing public health problems may increase but may not be supported by or coordinated with the state. Or was the reality some combination of all of these possibilities? In the public health responses to the pandemic, the limits of state power may be revealed. Analyses of the ways in which community structures stepped in to fill these gaps in state capacity show that there is a need and urgency for such structures to be empowered to act in these spaces.

Socio-economic challenges and inequities which are normally barriers to participation and exacerbated during the pandemic may have further impacted participation. Did the fear and confusion surrounding the pandemic and the general mistrust of government affect community trust of the state? How did power relations between the state and communities affect participation? These are important questions to answer if we want to better understand how participation unfolds under pandemic conditions so that we might better support participation in future responses. The aim of this qualitative study was to explore how participation in HC spaces in Gugulethu and Manenberg, two economically marginalised areas in Cape Town, South Africa was affected during the Covid-19 pandemic. We wanted to understand what happened to the usual invited spaces of HCs during the Covid-19 pandemic and what these insights might teach us about community participation during a crisis and beyond.

The objectives of this study were to:

1. Observe the roles and activities that HCs were engaged in during the Covid-19 pandemic
2. Describe the changing relationship between HCs and the state
3. Explore the changes in the level and form of community participation that occurred during a pandemic, and how meaningful participation might be sustained
4. Explore additional lessons learned about participation from the pandemic

Methodology

This was an exploratory, qualitative study exploring the roles and nature of the relationship between HCs and the state during Covid-19. Two active HCs that are part of the Klipfontein subdistrict in South Africa's Western Cape province took part in the study. Participants came from HCs working in Manenberg and Gugulethu, two areas in Cape Town. These two HCs (Manenberg and Gugulethu) were chosen to be part of this study due to prior relationships between the HCs and the student researcher. Both the MHC and the GHC are well-functioning HCs with good relationships with the facility managers and linkages to the community. Each of these HCs meet monthly at the linked health facility with the facility manger being present for these meetings. Both of these areas are economically marginalised and are located on the Cape Flats, about 18km from Cape Town city centre.(40-42) These areas are a product of *apartheid* legislation, widespread "forced removals" (removing people from their homes on the basis of their race and against their wishes to isolated or under-served areas) and especially the Group Areas Act of 1950, an apartheid "separate development" policy that spatially divided and restricted people by race to designated areas.(40, 42-44) Both communities are overcrowded and are impacted by high crime rates, unemployment, violence and substance abuse and extremely high rates of infectious and non-communicable diseases.(40-42)

Focus group discussions (FGDs) were held to collect data from HC members. The study was designed in three phases (see Figure 1 below). Prior to the commencement of Phase 1, the first author contacted the two HCs and outlined the study and was subsequently invited to attend HC meetings and explain the study to HC members. During this period, the first author attended Covid-19 vaccine training workshops and observed monthly HC meetings and health forum meetings (where HC members and community organisations get together to discuss their challenges and find places of intersection and collaboration). These observations were conducted over a period of six weeks. This phase allowed the first author to build rapport with the HC members while waiting for ethics approval.

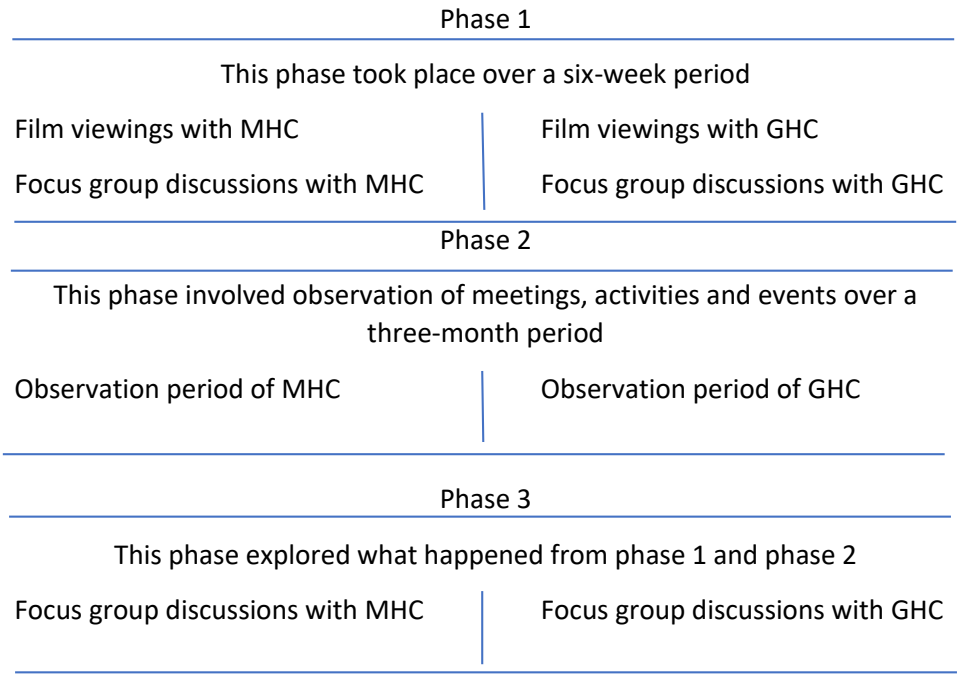
Ethics approval was obtained from the University of Cape Town's Faculty of Health Sciences Human Research Ethics Council (HREC) (see Appendix 4), and Phase 1 of the study was undertaken (see

Figure 1 below illustrating the three phases of this study). It involved showing a film, 'The lockdown: community perspectives', followed by FGDs with each HC. The film was a short documentary produced in 2020 as part of the first author's Masters in Public Health practicum module. The film, originally planned as an intervention tool, instead became a tool for discussion around the evolution of HCs, government and the community. The film served as an ice-breaker allowing HC members to speak to ideas in the film as a starting point for discussion. One FGD was conducted with the Gugulethu HC (GHC), facilitated by the first author. The Manenberg HC (MHC) FGDs, due to the larger number of members, was split into two FGDs, one facilitated by the first author and the other by a trained facilitator. Participants in Phase 2 comprised of 22 members from the MHC, 21 females and one male. Participants from the GHC comprised of three males and seven females. Both groups had the same age range, from 45-70 years.

Phase 2 of the study was a second observation phase following the initial round of FGDs. This phase took place over a period of three months where the researcher observed HC meetings, activities, and events that HC members were involved in. Observations were recorded in a notebook and during the analysis phase, triangulated and integrated across the datasets. Phase 3 involved follow-up FGDs with the GHC and MHC. Members from the previous FGDs attended these sessions and for the MHC, the follow up group only included participants who had also attended Phase 1 FGDs. However, due to the fluidity of community engagement work, some HC members from the GHC group were unable to attend and thus their group included participants who had not been part of the first FGDs. This could be due to different mechanisms in the running of each HC and the motivation and availability of participants. As this research is attempting to understand changes over time, part of the focus group discussions was getting HC members to speak about how things were before Covid-19. These responses to HC status and involvement with the state relate to observations and reflections by HC members after the fact.

For follow up FGDs with the GHC, there were eight participants ranging in age from 35-70 years and including two male participants. For the MHC follow ups, there were 18 participants ranging in age from 45-70 years, with one male participant. Different topic guides were used for each FGD (see Appendices 2 & 6).

Figure 1: Diagrammatic illustration of the study design



Informed consent forms (ICFs) were given to each participant prior to each FGD (see Appendix 1 & 5). Participants were given an opportunity to read the ICF themselves, followed by the researcher reading the form out loud. Participants were asked if they had any questions or if anything was unclear from the ICF. Forms were signed by participants, which also gave permission to audio record the sessions. FGDs, ICFs and topic guides were in English. The audio recordings were transcribed by the first author. The transcripts from the MHC FGDs by the trained facilitator (who was fluent in Afrikaans), were translated and transcribed by an Afrikaans translator/transcriber as MHC members spoke more in Afrikaans than in English. FGDs were conducted in English with participants speaking a mix of English, Afrikaans (in the MHC FGDs) and isiXhosa (in the GHC FGDs). Meetings and discussions were held with the first author and supervisors following coding of each phase to assist with the focus of the research. Audio recordings were uploaded and stored on both NVivo 12 and a secure Google Drive cloud storage folder for safekeeping.

Transcripts were uploaded to NVivo 12, a qualitative data analysis software programme, where the data were coded. An inductive analytic approach was used and codes were identified from the data. Based on this inductive approach, the study evolved differently to the anticipated protocol. Data were analysed using the stages from Braun and Clarke.(45) Familiarising oneself with the data (phase one from Braun and Clarke(45)) was done via the lead researcher transcribing and reading the

transcripts.(45) Prior to this stage, the first author had met with her supervisors (second and third author) to debrief and discuss the salient points of each FGD after it had concluded. The same was done after each phase of the research. The data was coded using NVivo and codes were categorised and later combined and merged where needed to start forming groups. Coding categorisation was performed using mural.co (a digital platform for visual ideas and problem solving). NVivo codes were transferred to mural.co, where the lead researcher (NK) was able to move the codes around, group codes and merge codes where necessary. A visual template of the codes was developed which allowed the lead researcher (NK) to make connections between groups of codes and to identify possible themes in the data. Following this, these categorised codes were then added to an A3 sheet of paper where they were further reorganised and groups. These groupings were presented to the supervisors for discussions until two final themes with two sub-themes were identified. These themes and sub-themes are discussed in detail in the Findings section below.

Findings

Two main themes were identified from the data. The first theme (*'Nobody will hold us back': HCs are active, recognising and filling gaps in the State's reach*) explores how the roles and activities of HCs expanded during Covid-19. It attempts to explain how HCs recognised gaps in the state's reach and responded to community needs during the crisis. Pre-Covid, the relationship between HCs and the state was limited, with little partnership and collaboration between the two. The second theme (*'Government must work hand in hand with us': the State realises their limits and participation shifts*) focuses on the state's recognition of its own limits and how this realisation led them to open up participation with HCs. However, like a pendulum swinging back and forth, participation closed back down.

'Nobody will hold us back': HCs are active, recognising and filling gaps in the State's reach

HC engagement prior to Covid

Prior to Covid-19, the extent of HC activities outside of their regular meetings involved cleaning at health facilities and fielding client complaints. HC members met monthly at the health facility they were connected to in their respective communities. The facility managers attended these meetings, giving updates to the committee involving the health clinic. The facility managers were often unable to remain for the full length of these meetings. Updates included new health initiatives being implemented at the clinic, child illnesses that spiked during certain periods, complaints and compliments surrounding the clinic staff and the services provided, and how the services evolved during Covid-19. For example, the long waiting times and length of clinic queues were discussed

during MHC meetings, with this being a problem particularly during rainy or hot weather when people had to wait for long periods of time outside the clinic.

These issues were brought up and discussed during HC meetings, yet there was no scope to follow up or implement HC suggestions, such as alternate waiting venues or outside covering for those waiting, along with providing food and water to the waiting patients. There was little opportunity for HC members to be properly involved in planning health initiatives and interventions, in response to the new information and changing needs they observed. Their role was one of listening and seeing how they could support the current approach to health service provision, rather than being given opportunities to help improve or fill gaps in provision.

While HCs attempted to improve health services, they also identified and hoped to intervene in health issues outside the clinics. Topics discussed by HC members during these meetings focused on the social determinants of health and ranged from blocked drains in the community, to people having no electricity, no rent money or no food. HC members themselves were involved in community feeding schemes and soup kitchens, ensuring that their communities were fed. Being part of the community meant that they were able to quickly identify issues within the community and begin working toward or advocating for appropriate help and solutions. HCs tried to address these issues by bringing them to the attention of the City of Cape Town. During my time working with the HCs, the ward councillors were absent from these meetings. There was no connection with this potentially powerful local politician to discuss community challenges and solutions. HCs and the state were functionally separate from each other. HCs repeatedly tried to address these issues at the local level, though to a large extent, these are systematic issues that should be addressed by the national government structures. Yet the state often remained unresponsive to community needs and HC suggestions.

Changing roles during the Covid pandemic

The HC roles, activities and relationships described above started to change during the initial stages of Covid-19. The state, whether due to insufficient resources or an inability or unwillingness to reach communities, had critical gaps in addressing community needs. HCs recognised and attempted to fill these gaps, meet their community's needs and support the state's mission to reduce the spread of infections. They empowered themselves by taking ownership, creating and expanding their role and by putting pressure on the Department of Health (DOH) to be included.

> *No authority came to us as, health committee members to say how you can we do X, Y and Z… this is our plan for the people on the ground can implement in the community. The pressure came from us in order for the, the, the sub-district, health*

forum's management to pressurise and say, when are you going to get the health committees involved in the whole story? (Manenberg HC member)

Examples of this role expansion included the ways HCs assisted with enforcing infection prevention measures like social distancing, hand sanitising and mask-wearing while people queued outside the clinics. This helped clinic staff focus on their duties of providing healthcare. HC members spoke about how their informal role as 'social workers' also expanded. This may be because the lockdown meant people were forced to be at home together and tensions in the home often increased, making the risk of child abuse or neglect more urgent.

To attempt to lower infections, the state tried to roll out Covid-19 vaccinations once they were available, but HCs realised that the state was unable to reach everyone at community level. HCs stepped in and assisted the state with supporting vaccine uptake in their own areas. In the FGDs, HC members mentioned that they were doing 'so many things' (to manage the pandemic and meet community needs), 'too many to remember'. For example, through conversations with their communities, HCs found that numerous myths about the vaccine were in circulation, making people hesitant to vaccinate. Historical and ongoing mistrust of the state may have compounded people's vaccine hesitancy. To address vaccine hesitancy and increase uptake, HCs received training from community organisations and the state. It is unclear from the data whether this training was initiated by the state, sought out by HCs, or some combination thereof. However, what is clear is that there was a small but important moment of cooperation between HCs and the state. HC members were educated around how vaccines work in the body, with specific focus on the Covid-19 vaccine. Members also attended facilitation training courses to upskill and run these workshops.

Having these skills, HCs hosted and facilitated vaccine training workshops with community leaders and community members in a variety of settings and areas to increase the reach. During HC vaccine workshops, participants talked about vaccine myths, which included tracking devices being inserted when one received the vaccine, being turned green or into an alien, becoming impotent or unable to get an erection and even death. Through the training HC members received, members gained the skills to facilitate community workshops to mitigate the impact of these myths on vaccine uptake. HC members themselves described feelings of being empowered as they organised and facilitated these workshops and activities. They also appreciated seeing the response to their efforts when, for example, community members requested more workshops to learn about the vaccine and become 'vaccine ambassadors' to run these workshops in their own communities.

Wanting to further engage, HC members also spoke to their communities about their own vaccine experiences through door-to-door visits to try and reduce fears. HCs went so far as to register

people for the vaccine. They spoke about helping people navigate the online government portal, particularly the elderly, sometimes using their own mobile data or airtime. These were new roles that HC members created for themselves during the pandemic.

> *"Hm. Even when they start with numbers of people that need to be vaccinated. We are the ones that goes all out. We started the company of registering the community. Because, they didn't even know how to go to the grassroot level to educate people about doing the online registration the time that this Covid-thing started" (Gugulethu HC member)*

> *"The people had to register, register themselves online and that was problematic. They never, couldn't get it right until our group – [name] sent us a proper link and we could register people by the 100's and that is exactly what we did. We took it upon ourselves, remember we used our own data and everything" (Manenberg HC member)*

As HCs members live in and are part of the community, they felt a deep connection to helping their community and reducing the impact of and infections from Covid-19. This connection seems to have been a driving factor in their expanding roles during the pandemic. Rather than sitting back and waiting for the state to act, they empowered themselves through action and their new self-established roles. HCs created new spaces, activities and roles, not entirely without the state but taking a more active and independent role in supporting the state approach as well as community needs.

In relation to Arnstein's (7) ladder of citizen participation, HC participation moved from the 'lower rung' to a 'higher rung', where HCs had more influence and better self-defined roles.(7) Pre-Covid and during the initial responses to the pandemic, HCs were informed of preventative measures and there was a one-way flow of information from the state to HCs, representative of the lower rungs of participation in the ladder model. However, as the pandemic unfolded, we see how HC participation shifted to the higher rungs of the ladder, with a slightly elevated level of partnership between the state and HCs.(7) These higher levels of participation are evident in the collaboration around the vaccine workshops and addressing community vaccine hesitancy. Yet there were still limits to this partnership, with HCs still lacking real power to impact state decisions.

Despite HCs often feeling at the mercy of the state and lacking in power and authority, the pandemic made them feel a sense of urgency to start acting and doing things differently. Realising the value they bring and feeling empowered by their expanded roles may have also allowed them to put pressure on the state to increase participation. The new roles that HC members created for themselves during this pandemic intensified their enthusiasm for working together and they were

genuinely excited about realising their potential for impact and the important role they could play. These moments of taking on – and succeeding at – new activities confirmed their ability to help. This meant that when the state started to engage with them, they were charged up and ready to engage. However, engagement ultimately remained insufficient. As the pandemic unfolded, participation opened up but closed down again, due to a variety of reasons including conflicting agendas and persistent power dynamics.

'Government must work hand in hand with us': The state realises its limits and participation shifts

From the start of the pandemic, the state was overwhelmed. Implementing and ensuring adherence to protective measures, mask-wearing, social distancing and eventually, vaccine uptake were high priorities. The state was also soon confronted with limits and gaps in their ability to address community needs and ensure adequate reach. With vaccine hesitancy among South Africans high, uptake varied from community to community, with socioeconomic, demographic and geographical variables influencing vaccine hesitancy.(46, 47) Currently, 48% of the adult population in the Western Cape is vaccinated.(48) Vaccine hesitancy and insufficient access to the vaccine resulted in low vaccination amongst community members and may be linked to the generational social inequities where people felt that they were forgotten, left behind and not cared about.(46, 49) This distrust of the state may have influenced vaccine decisions, making it unlikely that communities would trust the state and therefore vaccinate. Being unable to reach all members of communities brought about more reliance on HCs by the state to meet community needs.

Prior to Covid-19 HCs had little interaction with the state but during the crisis, the state needed community assistance and participation increased. An example of this is illustrated with the vaxi-taxi initiative. Vaxi-taxis were ambulances with medical doctors that came into communities providing people with access to the Covid-19 vaccine. Essentially, they were mobile vaccination stations. These stations were initiated by the state but required the assistance of HCs in order to be successful. HCs were needed to identify safe spaces for the mobile vaccine clinics to be positioned and were relied on to spread the message to communities of the date, time and placement of these mobile vaccine sites. The vaxi-taxi initiative was an effective space for collaboration and participation. Due to all the changes and the urgent need to curb the spread of Covid-19, HCs stepped up to assist despite feeling excluded from decision making and planning.

> *"They recognize us when they want us to help them. When there is a way of going to the community, they will start recognize our health committee members" (Gugulethu HC member)*

> *"Right, but they still do what they want to without our input. They come and they say, that the rollout from a popup here and a pop up there, and then they say um, they ask they look for venues, right, but then we as the health committees, are good enough to source those venues. so all the people that came to this venue for instance, no-one paid us" (Manenberg HC member)*

Initially HC members felt excited about engagement with the state and believed that their work and their value were being recognised. The pendulum had swung in their favour. Participation with HCs increased specifically with the first rollout of the Covid-19 vaccine. They were included in the planning and the organisation of the rollout and the community attendance. They had a role and were available to help register people at venues and ensure social distancing and mask wearing. This was a shift in the relationship between HC and the state from pre Covid where they felt they were not recognised at all. It is interesting to note that some participants felt strongly that there had not been a shift at all, as expressed by this Guglethu HC member:

> *Personally, I don't think that health community members, uhm, health committee people are being recognised (Gugulethu HC)*

This is likely to be the result of a different understanding of what recognition and participation is. It is unclear from the data but this participant may believe that recognition is likened to partnerships where they are completely involved in every stage of the decision-making process and implementation. Despite the abovementioned positive shift toward increased involvement, all HCs clearly felt that there was still a long way to go towards full partnership and collaboration with the state.

Indeed, participation and inclusion levels were different for subsequent vaccine community initiatives. Now, the pendulum had begun to swing back, and engagement decreased. HC members felt that their recognition and participation had shifted back, with them being pushed aside and no longer needed or included in planning and discussions. They were excluded from the planning and organisation of the second phase of the vaccine rollout. When members arrived at community vaccine sites, they were told that they were not needed. HC members felt pushed aside and used. HCs felt that they had implemented processes for the smooth running of these community vaccine sites, and once these systems were in place, had been replaced by other community organisations. There was also little opportunity for HCs to be involved in the planning of these mobile vaccine sites, and little opportunity to feedback, for example, on the need for water and food for those waiting to get vaccinated. They felt ignored and excluded from these later vaccine drives.

Members attributed this change from an increase to a decrease in participation to the state's inclusion of alternative community organisations which were seen to be relied on for Department of Health (DOH) initiatives. However, there could be other reasons as well. HC members said that the state's engagements with them were often *ad hoc* and not well planned out. This swinging participation could be attributed to these other organisations crowding HCs out, or local political conflicts, or inadequate planning. Whatever the reason was, the important fact is that the state could retract or offer participation at will, which demonstrates that the state still held all of the power. This momentary shift in power and participation highlights how sharing of power was fleeting and that there is still a resistance to more lasting or meaningful redistribution of power and changes to the status quo. These observations and statements are inferences based on the student researcher's own experiences and observations regarding the state's motivation. Speaking to and interviewing the state and public officials was beyond the scope of this study.

This is a clear illustration of the ways that power dynamics can have a determining influence on degrees and levels of participation.(15, 50) VeneKlasen and Miller (18) talk about power being negative or positive, depending on its form and expression. 'Power over' is on the negative end of the power spectrum and conforms to the most common way of thinking about power – as a means of coercion and domination.(18, 50) Shifting to more positive aspects of power, 'power with' speaks to collaboration and sharing of power.(18, 50) 'Power to' refers to the recognition that everyone has the power to shape their own existence.(18, 50) 'Power within' relates to individuals realising their own worth, capacity and what they can offer the world.(18, 50) These different types of power help to explain shifts in power and how participation changed over time for HCs. Pre-Covid, power was situated with the state holding 'power over' HCs. As the pandemic unfolded and state spaces were opened to HC members, power dynamics appeared to shift to one of more collaboration, or 'power with'. Then, as HCs invented their own spaces of participation and realised their power to make a difference and the importance of their role and value, HCs were able to be more vocal in state-invited spaces. However, probably because the state still held ultimate decision-making power and a balance and sharing of power had not yet been achieved, participation closed back down. The Covid-19 crisis made the state realise that they needed HCs more, but it was far from an equal power balance.

> *When they are wanting to do something, they planning to do something, they mustn't do the planning without us. Because, most of the times they doing, they planning, they doing without us, but those things need to be done in the community. … because all of us we staying in the corners of the community… So, the work can*

work smoothly. That's why the work is not work smoothly, because they are side-lining us" (Gugulethu HC member)

Another example of this opening up and closing down of spaces for participation came when HCs became part of monthly DOH meetings. Pre-Covid, HCs met once a month in person at the clinic with the facility manager, yet the ward councillor was never present, even though they are required by law to be part of the health committee. HC members understood that collaboration with the state is important for effective community, health service upliftment and change and Covid-19 infection management. At the request and insistence of HC members, they were included in DOH planning and decision-making discussions that they were not privy to before. The state invited HCs to partake in the DOH Zoom planning meetings. These took place monthly, in addition to HC meetings, and it is possible that the state's recognition of their limits and the HCs' insistence on being included allowed an opening up of this space.

… but it was also health committees that put pressure on the department because every time, something was posted to C1 [participant name] then she shares it with the rest of us… And from the pressures, that were placed on them [the DOH], in that last meeting that you were in, then they recognised us. That was a few months back. So then they made this chat open then they added us to this chat. Right, but they still do what they want to without our input (Manenberg HC member)

HC members were optimistic about this inclusion but they found the opportunities for genuine participation disappointing. There were also a number of barriers to participation by HCs in these Zoom meetings. HC members did not refer to any barriers to access in terms of technological support and knowledge about devices. Instead, barriers more commonly included a lack of data and limited access to technological devices capable of supporting Zoom functionality. The lack of data to attend the Zoom meetings was brought to the attention of the DOH but HCs indicated 'that when you ask for resources, they [DOH] say they don't [have]'. Power dynamics were thus still evident, as Zoom conference calls are an elitist and difficult to access space in which the State still holds most power. It may also be that the state did not know how to facilitate proper participation. These meetings were also hosted by the state which could have influenced the nature of these spaces – HCs might have felt that they had limited ability to fully articulate and participate in these meetings as the agenda was already set. They felt that they were there to listen to Covid-19 updates rather than be heard, share ideas and collaborate together around pandemic responses. HCs spoke about the space being a waste of time and found it discouraging. Zoom can also be impersonal, particularly if the internet connection means that one's video during the call needs to be turned off.

And another thing. Those zoom meetings they only need our information. They don't have any information as a health committee. So then, if they wanted to move forward, then they know in our zoom meetings who is going to ask questions. So, that's why the zoom meeting was not fruitful for us. Because, there was no education from their side. They only needed education from our side to keep on moving in their stats. Whenever there is a gap, especially in M1 [area name], their numbers were down, then they need one of our health committees. They say we must assist at M1 [area name], because, they said, M1 [area name] numbers are very down (Gugulethu HC member)

The Zoom meetings were discouraging to HC members and likely reduced their participation. On the other hand, people may have appreciated the perceived anonymity of participation, but we are not sure as this was not explicitly expressed. These Zoom spaces seem to be a start to engaging with HCs but there still seems to be a resistance to properly sharing power, with the state being stuck in a more traditional, older approach that occurs in closed and invited spaces. There were several inevitable barriers to the Zoom meetings, but they could have been made more participatory if the agenda was set by both the state and HCs, with each sharing the floor to facilitate.

During the hard lockdown, with restrictions on movements and people staying at home, participants were also unable to hold their monthly HC meetings in person at the clinic. Alternate ways to communicate were needed and HC members used WhatsApp groups and messages as a means to keep communication channels open and flowing. WhatsApp is a free phone messaging and calling platform that uses your phone's internet connection (either via mobile data or WiFi) and is particularly useful for group messages and calls.(51) HC WhatsApp groups consisted only of HC members and were separate from state WhatsApp groups. As members knew each other, living in the same community and having worked together on HCs for numerous years, there was a sense of safety and comfort in these HC WhatsApp groups. Members could communicate freely and discuss ideas and concerns in relation to Covid-19 and community challenges. State WhatsApp groups were an additional space where HCs were included and seemed to be a better and more useful space than Zoom for collaboration and updates on state interventions.

I actually feel good about this WhatsApp group of our health care. Cause, whatever happens, they send it out to you. On a daily basis you know exactly what is happening within your surrounding community. Whatever change, they let you know (Manenberg HC member)

State WhatsApp groups could have been more effective than the Zoom meetings because of the simpler technology that WhatsApp uses. WhatsApp was a platform that was used widely prior to Covid-19 and HC members may have been more familiar and at ease with using it. Via WhatsApp,

people can type messages which remain on the smartphone and can be read and accessed at a later stage, whereas Zoom requires an on the spot, synchronous response. This asynchronous versus synchronous approach could have also played a role in HC members feeling comfortable in the latter setting. Asynchronous communication allowed them more time to think through and propose a response.

> *…and then you can see it and go back and if you still don't understand it then you can ask Interviewer/participant C. Interviewer C, what is this about, and if she is not available, you can ask someone else... The WhatsApp group is very informative (Manenberg HC member)*

The self-created HC WhatsApp group was a space that they invented for themselves to communicate and share ideas. It allowed them to remain in touch in between meetings and during hard lockdown when face to face HC meetings were unable to take place. WhatsApp seems to have created an environment of doing and connecting that was empowering and enabled them to think through ideas to assist the state in the Covid-19 response.

HCs are part of invited state spaces acting as a bridge between the health system and the community. However, invited spaces are often limited for a variety of reasons. The DOH Zoom meetings, state WhatsApp groups and vaxi-taxi interventions were expansions of state spaces where HC members and the state remained on unequal footing. These spaces represent an opening of participation, yet the state still held the actual decision-making power with the HCs being constrained by the role of listening and actioning state decisions, rather than collaboration. Rather than being new and collaborative, these spaces were fleeting, opening and closing for particular reasons mostly due to the state's fluctuating need for support, as was illustrated with the vaccine rollout where initially HCs were included in the process and then subsequently excluded. HCs saw these invited spaces as restrictive, so they started to create spaces of their own which were more open in comparison. In these created HC spaces, the power was held by HC members. Here, we are drawing links between the interplay of power and frameworks of degrees of participation and invented/invited spaces. Invited spaces typically mean less meaningful participation between the state and HCs – the power is unevenly distributed and heavily weighted on the side of the state. Invited spaces are important because decisions are made in these spaces, offering opportunities for community input on changes to the health system and its policies. However, when invited spaces limit community influence and participation, community members may explore alternatives. Invented spaces can be seen as action-focused, as in this example where HC members created alternatives to their challenging conditions. Invited and invented spaces should not be considered as

mutually exclusive alternatives but rather as potentially complementary spaces. We need to consider the intersection of these two spaces, making invited spaces more open, innovative and creative and bringing lessons learned from invented spaces into invited ones. Below we offer insights about invited spaces, the interaction between invited and invented spaces, and ways to enhance and sustain community participation.

Discussion

The importance of community participation is acknowledged globally, yet evidence suggests that it is usually not done well, with HC participation being no exception.(12, 52) South Africa has made a commitment to community participation with HCs being a vehicle to community engagement and a vital vehicle for participation.(53) This study explored how community participation and invited spaces of HCs were impacted during the Covid-19 crisis. Next, we discuss key themes that emerged from study findings and offer lessons that can be learned from the pandemic to enhance and sustain community participation in public health decision-making.

Relationship between spaces, power and participation

When considering participation, we need to think about the interplay between participation, power and the spaces where these play out. Gaventa (14, 15, 50) outlines the PowerCube framework as a means to explain and understand the relationship between changes in power relations and approaches to change.(14, 15) Power comes in different forms and Gaventa (14) proposes the following types: a) visible power, which includes formal rules, procedures and includes more formal structures of power; b) hidden power, where those with influence maintain control over decision-making and setting the agenda and these dynamics consciously or unconsciously exclude those who hold less power; and c) invisible power, which incorporates the psychological context and internalised discourses of power.(14, 15) Invisible power influences and shapes how people think about where they fit in the world and in turn shapes their values and beliefs about themselves and others.(14, 15) These internal discourses can disempower individuals and maintain the status quo of participation.(14, 15) For meaningful participation to take place, all these levels of power need to be explored and addressed, including the internal ideas individuals hold about themselves and the value that these individuals bring to different contexts.(7, 14, 15)

Power and empowerment are two sides of the same coin, with one embedded in the other. These concepts need to be considered together, as empowerment is a form of power; the ‘power within’ (18). This notion of the ‘power within’ which refers to the power we have in ourselves, if cultivated, can enable people to draw out and express their own power.(14, 18) It is about people realising both their value, importance and their own power and the power others have over them. With the

broadened scope and roles that HCs carved out for themselves, they started to realise their inner power. This realisation allowed HC members to voice their opinions, which were less prominent pre-Covid 19. When they felt that the state's invited spaces for collaboration and partnership were not as they should be, HCs invented and claimed their own spaces. So, for participation and citizen power to be enhanced, it is important to think about the concepts of both power, spaces and participation, and how these interact with one another. Arnstein's (7) ladder of community participation and 2) Gaventa's (14) notion of invited/invented spaces and power are well-aligned with each other and together, they provide a useful framework for understanding how HC participation evolved during the Covid-19 crisis.(7, 14-16)

Previous research highlights how the dynamics of power impact the spaces of participation with the different kinds of spaces (closed, invited and invented) enabling different kinds of participation. At the lower rungs of Arnstein's (7) ladder, non-participation and tokenism take place where decision-making spaces are closed or marginally open or invited spaces.(7) Gaventa (14) speaks about how these closed spaces are also referred to as 'provided spaces', where the elite make decisions behind closed doors and civil society works to open up these spaces through promoting transparency, accountability and community partnership.(14) HCs are part of bounded spaces where they are invited by the State to partake in health services and the health system. Only certain members of the community are allowed (invited) to participate in these spaces.

These state spaces were further opened to HCs during Covid-19 as the state was confronted by its limits and HCs recognised the value and importance they could offer. Cornwall (16) refers to Clay and Schaffer's notion of 'reshaping existing spaces and renegotiating boundaries'.(16) The findings from this study highlights how state spaces were starting to be reshaped and relationships thought of in a new way through the Zoom meeting and state WhatsApp groups. Cornwall (16) explains how spaces are not neutral and we fill these spaces with our history and past experiences. The Zoom platform, while different from in person meetings, was still a state space where historical discourses of being discriminated and disempowered were at play. These Zoom spaces began to increase participation, moving it up Arnstein's (7) ladder to the rungs of partnership and increased citizen power. Initially, there was excitement and anticipation about what could be achieved by being part of these state spaces but barriers and challenges dampened this enthusiasm. Socio-economic power dynamics were also at play, as access to Zoom is somewhat elite and privileged in the local context. Members were required to have access to technology and stable internet to partake in these meetings. These were attempts to rethink the position of HCs in relation to health and the community. In the opening up of these invited state spaces, HCs were privy to state ideas and decision-making processes. However, invited spaces remained institutionalised and even though HCs

were consulted with, they were mainly informed by the state. While these are still vital steps toward participation, there was little opportunity for HCs' ideas to be realised and considered within these invited spaces.

Sites of resistance

The literature on participation also refers to invited spaces as potential 'sites of resistance'.(16, 54) According to bell hooks (55, 56), sites of resistance are when places of marginalisation and discrimination can actually become places of possibility and opportunity. hooks (55, 56) argues that these sites, rather than being a hindrance, can instead allow us to think about innovative ways of being in the world and working together with each other.(16, 54-57) HCs, rather than accepting the way invited spaces were run, first acknowledged the barriers of access, lack of resources and limited decision-making power to the state, but then spring-boarded off these spaces to invent spaces of their own, where they were in control and could discuss ideas freely with HC members. Bounded invited spaces, while constraining to HCs, strengthened their drive to invent their own spaces. The 'power to' encompasses people's ability to realise that they can make a difference.(18) HCs realised their own power to bring about change through the evolving scope and expansion of their roles and offerings to both the state and the community during the pandemic. There is importance placed on strategically choosing which space is the most effective and considering the influences of spaces on each other and community participation.

The relationship and value of both invited and invented spaces

Due to the restrictions of the state invited spaces, and HC members feeling that they went unheard and unseen in these spaces, HCs invented spaces of their own. These claimed or invented spaces which Cornwall (16) refers to as 'organic' spaces, arise from common concerns and goals and range from spaces invented by community organisations or social movements to pre-existing spaces often outside of institutionalised spaces where people get together to discuss, debate and share ideas.(14, 16)

HC work during the vaccine rollout was an important illustration of participation and invented spaces. The state's reach was limited and both parties (state and HCs) realised the value each could play in increasing vaccine uptake. HC members, for example, went door-to-door and spoke to community members about the vaccine and why it is important to get vaccinated. Historically, community distrust of the state and access to the Covid-19 vaccine are features of vaccine hesitancy and the reluctance by community members to trust state initiatives. Being trusted members and living in the community helped HC members to minimise issues of trust by sharing their own experiences of the vaccine and facilitating community vaccine training workshops. They invented

roles for themselves that assisted both the state and the community. These invented HC spaces, which were facilitated by HC members, were more equal and balanced in terms of power dynamics. HC members during the FGDs expressed how they felt - that these invented/claimed spaces they created were safe spaces where they could freely share ideas and thoughts with each other. These invented spaces allowed them to develop ideas and be part of their own decision-making process. This brings us to the relationship between invited and invented spaces.

The relationship between invited and invented spaces is important to consider as the latter is often the product of the former. In invited spaces, participation for HC members was less meaningful because power had not really been redistributed. A possible failing of these invited Zoom, WhatsApp and state spaces for HCs may be the lack of a redistribution of power. In these invited spaces, the state still had control with HCs having no mechanisms to ensure their ideas and voices were both heard and actioned by the state. This is where the intersection of the two spaces is important. There is a lot to learn from invented spaces which can make invited spaces more productive and meaningful. We propose that both of these spaces are important and actually help each other.(14, 16) For instance, invented spaces are important as they provide opportunities for HCs to develop their 'power within'. Invented spaces can be empowering places and build ideas of opposition, potentially allowing HC members to have confidence in their agency and voices in invited spaces. By developing their 'power within', HC members could enter invited spaces and challenge the status quo by recognising the power dynamics at play and their own value and importance they could bring to these state spaces.

By creating new roles for themselves, HC members felt empowered and strengthened. Realising what they could offer allowed them to voice their needs to be included in discussions and planning to the State. Realising one's value and importance is empowering in itself. Cornwall (16) refers to Freire's Pedagogy of the Oppressed (58), which describes how discourses of discrimination make it difficult for communities to see themselves as having the power to facilitate and drive change. A feeling of being empowered and realising their value allowed HCs to start challenging these discourses of discrimination and lack of power. HCs were, therefore, able to approach the DOH and request to be included in the discussions and planning regarding Covid-19 community interventions. Pre-Covid, HCs did not feel they could make this request, or the need was less urgent. The state may have honoured this request due to its recognition of the limits of top-down power and intervention in the pandemic response. HCs were then invited to and included in DOH meetings which they had previously been excluded from.

This research illustrates the fluidity of spaces and the importance of both invited and invented spaces for participation.(14-16) Our findings illustrate the complexity of these spaces and places of contestation, where different actors continuously negotiate power and influence. Previous literature also shows how invented spaces are not necessarily independent from the state but rather, are *community-led* spaces that are equal to invited spaces, with both spaces being equally important and with value to add.(14, 16, 17) It seems that for more meaningful participation to take place and be sustained, the intersections between invited and invented spaces and associated power dynamics need to be considered. Pre-Covid, HCs were rarely invited into state spaces with participation being extremely limited. During the pandemic, the roles and scope of HC evolved with a shift to more meaningful participation with the state. The benefits of participation during epidemics such as the Ebola outbreak in 2015/106 and the HIV/AIDS epidemic have been cited in literature.(8, 30, 37, 39) Covid-19 gave us another glimpse into participation, how important it is and the importance of considering sustainability. These insights provide some lessons from the pandemic to both enhance and sustain community participation in future.

Lessons learned from Covid-19 about participation

These recommendations are aimed at policy makers and health system practitioners. Yet fellow researchers also need to consider power dynamics both within research and the health system and how these dynamics and the spaces participation occurs in, impact relationships. Firstly, despite the restrictions and barriers to participation within invited state spaces, these places are still meaningful in their own way. Invited spaces can stir up the power in individuals to invent their own spaces and realise their own power. These invented spaces and the empowering feelings they produce mean that community members bring their growth back into invited spaces to facilitate better participation. Research indicates that it is insufficient to reform invited spaces to bring about meaningful participation and that the architecture and organisation of a space influences the dynamics of the space and can perpetuate dynamics of power and control.(14, 16) Access to resources to ensure that HCs can function and participate in invited state spaces will impact power dynamics. Having access to shared resources is the beginning of further opening up partnership and collaboration and means that there is an understanding of the importance of sharing power and respect and mutual support between the state and HCs.

Since spaces of participation are also filled with our historical pasts, it is also imperative to consider more neutral spaces where both HC and the state are on more even footing.(14, 16) We propose that there needs to be innovative thinking about these spaces. HC members and the state should decide on spaces together and should come up with mutually agreeable ways to partner, on an

equal footing. A start is for state representatives to be present at HCs meetings and have the venue of these meetings rotate between community and state venues. This would allow for improved transparency and may open the way to sharing resources, as each is regularly invited into the space of the other. Neutral spaces that are less historically disempowering may also help to remove less obvious barriers to participation. Coordination, support and resources are needed to assist HCs to navigate these state-provided spaces.

Our findings indicate that HCs want to be included in planning, intervention rollout and decision-making processes. To achieve this, HCs should be included regularly in DOH meetings, setting an institutional precedent. Conversely, the state needs to be part of regular HC meetings. Going forward, mechanisms to ensure attendance of ward councillors and facility managers at HC meetings would help to create trust and partnerships between the state and HCs. This would be a step toward power redistribution. Covid-19 has shown us how HCs are part of the health system and that this inclusion needs to be institutionalised and recognised by health professionals. Shared facilitated workshops by HC members and health professionals can help bridge this divide between HCs and health professionals. Here, the value of each role and what each has to offer can be recognised and acknowledged. This crisis saw the state recognise their limits and HC stepped in to fill these gaps. For this to be sustained, the state should continue to empower HCs by allowing them to facilitate and develop community interventions with the support and guidance of the state.

Establishing partnerships and developing trust occurs over time. Doing so as quickly as possible may help with managing epidemics in the future, as the relationship and ways of working together would be in place already. As HCs understand communities and their needs best, including them in the planning of health interventions and coming up with ideas together to improve health services and community health is important and will help tailor interventions appropriately for different settings. HC members are trusted by the community and the information they share is more likely to be trusted than when coming from the state and this is a redistribution of power shifts the norm and empowers HCs. Both the health-related messages received by the public and who delivers these messages matters – here, HCs can play a critical role. Community interventions for the future, whether in response to a crisis or to uplift communities, are likely to be better received by community members when facilitated by the community. The state can move into a role of guidance and support to allow HCs to sustain and inform their own interventions.

Limitations

Even though participants were competent in English, some spoke a mix of Afrikaans (in the MHC FGD), isiXhosa (in the GHC FGD) and English during the FGDs. Non-English contributions were

translated by others in the group but the essence of what was being may have been diluted by translation. Future research should consider these language barriers and conduct FGDs with research assistants who can facilitate FGDs in different languages. Another limitation is that the MHC and GHCs were quite active in comparison with some others in the province, so the process of participation may have differed for HCs that were less active. HCs that were less active may have had different experiences of participation during the pandemic and future research should consider research with both active and less active HCs to further add to our understanding of how community participation is shaped by relationships, power and levels of action and influence.

Conclusion

Community participation is undeniably important for public health but the spaces within which participation occurs is shaped by our past. Spaces are not neutral and elements of social history, personalities and what defines us and our relationships can influence both invited and invented spaces. As we attempt to understand community participation, we see that different forms of power (power over, power with, power to and power within) are intertwined with varying degrees of participation. The Covid-19 pandemic, similar to Ebola and the HIV/AIDS epidemics, illustrated once again the critical role of community members in building trust and developing rapport between individuals, the health system and the state. As the crisis unfolded, the state realised limits to their community reach and this awareness allowed for participation to open up and HCs were invited into previously closed spaces. HC members through their activities and self-defined roles felt empowered to insert themselves into state invited spaces. When participation reverted to the status quo of being less participatory, constrained and restrictive, HCs created their own spaces for participation. In these HC invented spaces members could share ideas, thoughts, discuss challenges and solutions. Members felt that they owned and held the power within these spaces. Invented spaces were different from invited spaces as the tensions surrounding power were lessened. However, invited and invented spaces do not represent a rigid dichotomy but should rather be viewed as spaces that stimulate each other. Going forward and considering the sustainability of community participation, power needs to be redistributed and equalised between HC and the state. We recommend that more neutral and shared spaces are created for HC meetings and that the state is required to be present, that as trusted members of their communities HCs should be involved in decision-making, planning and implementing community interventions, and that HCs require access to resources and state guidance and support to implement self-designed interventions.

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Appendices

Appendix 1: Informed Consent - Phase 1

Purpose

You are invited to participate in a research study exploring the extent to which film viewings focusing on Covid-19 and the resultant lockdown can facilitate community engagement and promote community-based solutions. This study is being conducted by a Masters of Public (MPH) student and supervisors in the School of Public Health and Family Medicine (SPHFM) at the University of Cape Town (UCT), South Africa. You are invited to participate in this study because you are a member of a health committee.

Procedure

Participation in this study is voluntary. Not participating in this study will not affect any work, benefits or services received now or in the future. If you agree to participate in this study, you would participate in a focus group [a group discussion] with five to six other members from your health committees in the focus group. The focus group will be led by Natasha Kannemeyer. At the start of each focus group, a short film (20 minutes in length) – The Lockdown: Community Experiences, produced by the MPH student researcher of this study will be shown. This film will be the basis for discussion and community engagement. The focus group will be between one to two hours, including 20 minutes allocated to watching the film. Please note that there are no right or wrong answers to focus group questions as the researchers would like to hear as many viewpoints as possible and allow for everyone to contribute their thoughts, feelings and ideas.

The focus group will be audio-recorded in order to accurately capture what is said. The student researcher will ask several questions and there will be a note-taker present. If you participate in this study, you may request that the recording be paused at any time. You may choose how much or how little you want to speak during the group. You may also choose to leave the focus group at any time.

Benefits and Risks

Participating in this study may not benefit you directly, but it will help us learn the challenges that communities face due to Covid-19 and the lockdown and to facilitate community engagement. We do not envision any significant risks related to participation in this study. Participants may feel some pressure to reveal feelings or experiences to the group. We will reduce the risk of Covid-19 by

conducting the film viewings and FGDs in well-ventilated buildings, all participants will wear masks and be seated 1.5m apart. There will be hand sanitisers available for use upon entering the venue and as required.

Confidentiality and Privacy

The information you will share with us if you participate in this study will be kept completely confidential to the full extent of the law. Participants will be asked not to use any names during the focus group discussion. Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the focus group to others. Reports of study findings will not include any identifying information. Audio-recordings of the focus groups will be kept on a password-protected computer in Natasha Kannemeyer's (at UCT) locked office. After the focus group recording is typed it will be destroyed. The typed transcription will be kept on the password-protected computer and any printed copies will be kept in a locked file cabinet in Natasha Kannemeyer's locked office. Professor Leslie London, Dr Hanne Haricharan, Associate Professor Chris Colvin and Natasha Kannemeyer (student researcher) will be able to listen to the recording or read the typed version of the recording.

Contact

If you have any questions about this study, please contact Natasha Kannemeyer via email: natasha.kannemeyer@uct.ac.za. If you have any questions about your rights as a research participant, please contact Professor Leslie London, SPFHM, UCT via email: Leslie.london@uct.ac.za

Your signature on this consent form indicates that you agree to participate in this study.

You will be given a copy of this form to keep, and a copy of this consent form will be kept by the student researchers in a locked cabinet in their office.

I have read the consent form and all my questions about the study have been answered. I understand that the focus group will be recorded. I agree to participate in this study.

By signing this form, I agree to participate in this focus group discussion. By signing this form, I also agree to having this focus group discussion recorded.

Print name:

Signature:

Date:

Appendix 2: Focus Group Discussion Topic Guide - Phase 1

Phase 1: FGDs with the two HCs

1) What stood out / resonated with you from the film?
2) What other challenges did you face during lockdown and as a result of Covid-19 that may not have been illustrated in the film?
3) What in your opinion could have been done differently in terms of Lockdown and the responses to Covid-19?
4) How did things differ for you between level 5 and the current level 1 lockdown?
5) What was your role / involvement as a HC during Covid-19?
6) How was the engagement between HCs, health workers and government during lockdown and Covid-19?
7) What would you change for the future in terms of community engagement and the involvement of HCs?
8) What does community engagement look like for you as a HC member?
9) How do you as HCs envision your role / involvement with communities and the health system?

Phase 2

Not applicable as this is an observation phase

Phase 3: Follow-up FGDs with the two HCs

1) In what ways have your activities and interactions differed as HCs from the film viewing?
2) What challenges did you as HC face?
3) What were the positive aspects you faced as HCs?
4) Do you feel that there has been a change / shift in how your HC functions / relates compared to when we watched the film?

Appendix 3: Demographic Information

Name:

Age:

Gender:

Role in the health committee:

Profession:

How long have you been a health committee member:

Appendix 4: Ethics Approval

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room G50- Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: hrec-submissions@uct.ac.za
Website: www.health.uct.ac.za/fhs/research/humanethics/forms

19 May 2021

HREC REF: 195/2021

A/Prof C Colvin
Division of Social Behavioural Sciences
Public Health & Family Medicine-FHS
Email: cj.colvin@uct.ac.za
Student: knnnat004@myuct.ac.za

Dear A/Prof Colvin

PROJECT TITLE: THE EXTENT TO WHICH FACILITATED FILM VIEWINGS FOSTER COMMUNITY ENGAGEMENT BETWEEN HEALTH COMMITTEES AND HEALTH WORKERS AND PROMOTE COMMUNITY-BASED SOLUTIONS IN REPSONSE TO THE COVID-19 PANDEMIC. (MASTERS CANDIDATE: MS N KANNEMEYER)

Thank you for your response letter, addressing the issues raised by the Faculty of Health Sciences Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

This approval is subject to strict adherence to the HREC recommendations regarding research involving human participants during COVID -19, dated 17 March 2020 & 06 July 2020.

Approval is granted for one year until the 30 May 2022.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

The HREC acknowledge that the student: Ms Natasha Kannemeyer will also be involved in this study.

Please quote the HREC REF 195/2021 in all your correspondence.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, FACULTY OF HEALTH SCIENCES HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938
NHREC-registration number: REC-210208-007

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use: Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH 2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki (2013) guidelines. The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

Appendix 5: Informed Consent – Phase 3

Purpose

You are invited to participate in a research study exploring the extent to which film viewings focusing on Covid-19 and the resultant lockdown can facilitate community engagement and promote community-based solutions. This study is being conducted by a Masters of Public (MPH) student and supervisors in the School of Public Health and Family Medicine (SPHFM) at the University of Cape Town (UCT), South Africa. You are invited to participate in this study because you are a member of a health committee.

Procedure

Participation in this study is voluntary. Not participating in this study will not affect any work, benefits or services received now or in the future. If you agree to participate in this study, you will participate in a focus group discussion with other member from your health committee. The focus group will be held by Natasha Kannemeyer. This is the second focus group discussion, a follow on from the first focus group discussion where a short film: The Lockdown: Community Experiences, produced by the MPH student researcher was shown. Please note that there are no right and wrong answers to focus group questions as we would like to hear as many viewpoints as possible and allow for everyone to contribute their thoughts, feelings and ideas.

The focus group will be audio-recorded in order to accurately capture what is said. The student researcher will ask several questions and there will be a note-take present. If you participate in this study, you may request that the recording be paused at any time. You may choose how much or how little you want to speak during the group. You may also choose to leave the focus group at any time.

Benefits and Risks

Participating in this study may not benefit you directly, but it will help us learn the challenges that communities face due to Covid-19 and the lockdown and to facilitate community engagement. We do not envision any significant risks related to participation in this study. Participants may feel some pressure to reveal feelings or experiences to the group. We will reduce the risk of Covid-19 by conducting the film viewings and FGDs in well-ventilated buildings, all participants will wear masks and be seated 1.5 m apart. There will be hand sanitisers available for use upon entering the venue and as required.

Confidentiality and Privacy

The information you share with us if you participate in this study will be kept completely confidential to the full extent of the law. Participants will be asked not to use any names during the focus group discussion. If names are used, these will be removed from the transcripts. Please be advised that the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidently. The researchers would like to remind participants to respect the privacy of your fellow participants and not repeat what is said in the focus group to others. Reports of the study findings will not include any identifying information. Audio-recordings of the focus groups will be kept on a password protected computer in Natasha Kannemeyer's (at UCT) locked office. After the focus group recording is typed, it will be destroyed. The typed transcription will be kept on the password-protected computer and any printed copies will be kept in a locked file cabinet in Natasha Kannemeyer's locked office. Professor London, Dr Hanne Haricharan, Associate Professor Chris Colvin and Natasha Kannemeyer (student researchers) will be able to listen to the recordings or read the typed version of the recordings.

Contact

If you have any questions about this study, please contact Natasha Kannemeyer via email: natasha.kannemeyer@uct.ac.za. If you have any questions about your rights as a research participant, please contact Professor Leslie London, SPFHM, UCT via email: Leslie.london@uct.ac.za

Your signature on this consent form indicates that you agree to participate in this study.

You will be given a copy of this form to keep, and a copy of this consent form will be kept by the student researchers in a locked cabinet in their office.

I have read the consent form and all my questions about the study have been answered. I understand that the focus group will be recorded. I agree to participate in this study.

By signing this form, I agree to participate in this focus group discussion. By signing this form, I also agree to having this focus group discussion recorded.

Print name:

Signature: Date:

Appendix 6: Focus Group Discussion Topic Guide – Phase 3

Questions related to the film:

1. Can you tell me what you remember about the film we watched in our previous session?
2. What were some of the things from the film that stayed with you?
3. Was there anything in the film that you did not agree with or that confused you? How so?
4. Tell me about any new ideas that you had from watching the film and the discussion. (prompt: In what ways did the film make you think about engagement and HCs?)
5. In what ways did things change for you [as a HC member] after watching the film and the discussion?
6. Do you think the film motivated you in any way? (yes - Can you tell me a bit more about that? Prompt: no – How come?)

Questions relating to shift in engagement:

1. I remember from our previous session you spoke about HC members being unrecognised but now you are getting recognition. How has this changed since the previous session. Or from the beginning?
    a. Why do you think there has been a shift?
    b. How do you feel about these changes?
    c. Why do you think these changes happened?

2. Last time, you spoke about taking complaints and helping with social distancing at the clinics, what other activities have you been involved in as a HC member in relation to Covid-19 since our last focus group discussion? Probe: what did you think about these new activities?
    a. How did they come about?
    b. How did being involved in these different activities make you feel?

3. I want to ask some questions around the Zoom meetings and the WhatsApp groups you spoke about:
    a. Who invited you to the Zoom meetings? Who invited you to the WhatsApp groups?
    b. What are these meetings about?
    c. Why do you think you were invited to these meetings?

d. How did you experience these meetings?
e. How could they be better/different?
f. Do you think these meetings made a difference? If so, in what ways??

4. Do you think that these engagements with HC members will continue after Covid-19? In what ways and how?
    a. What do you think needs to change for this to be even better than it is?
    b. How can it be sustained?

5. What role do you think HC can play in future pandemics?

Questions relating to the reflective space:

1. In what ways did this space create an opportunity to talk about your own experiences with Covid-19?
2. How can you create these spaces yourselves?
3. I heard about the Wellness retreat in November, tell me a bit more about this? Where did this idea come from? [wondering if it came from the FGD]
4. Is there anything else you would like to add?