

Health committee participation in South Africa during the COVID-19 pandemic: a shifting picture

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Background

Community participation is an important component in disease outbreak management during times of systemic disruption. However, community participation was lacking in South Africa during the COVID-19 pandemic. It is known that participation at community level faces numerous barriers locally and globally, with efforts towards meaningful participation often being inadequate. The spaces (referring to invented, invited and closed spaces for participation) where participation takes place impact the level and quality of participation.

Methods

The aim of this chapter is to explore how participation in health committee spaces was affected during the pandemic, and how the relationship between the state (the Western Cape Department of Health (WCDH)) and health committees evolved during this period. Health committees are linked to primary care facilities and include community representatives, facility managers, and municipal political representatives (ward councillors), functioning as a bridge between community and health facilities.

This qualitative study was conducted in three phases. In phases one and three, focus group discussions were held with health committees in two economically marginalised areas in Cape Town, South Africa. Phase two involved a three-month observation of committee activities. Both inductive and deductive content analysis were used to analyse the findings. In the deductive analysis, two conceptual frameworks – Arnstein's Ladder of Citizen Participation and Gaventa's notion of invited and invented spaces – were used to interpret the findings.

Results

During the COVID-19 pandemic, health committees responded to community needs and carried out tasks that the WCDH failed to do. The Department recognised the limits of its pandemic response and the need for collaboration with community actors. This recognition led to an opening up of previously closed spaces to include health committees in more meaningful forms of participation. While there was an opening up, barriers in these spaces hindered participation. Health committees accordingly expanded their roles and empowered members to include themselves in WCDH spaces and invent their own spaces for participation.

Conclusions

The COVID-19 pandemic illustrated the critical role health committees can play in disease outbreak management. The interplay between invited and invented spaces is highlighted as an important consideration for meaningful participation. Health committees should be actively involved in decision making and implementation processes for participation in invited spaces to be meaningful.

Introduction

Community participation is a key factor in effective public health practice. Collaboration, partnership, and empow-

erment between community members, health professionals, government and other key stakeholders are at the core of meaningful participation.¹ Previous epidemics (e.g. the Ebola outbreak of 2014-2015 and the HIV

and AIDS epidemic in South Africa) highlight the value of community participation as a critical component in effective management of these crises.²⁻⁴

Degrees and forms of participation can be understood using two conceptual frameworks: Arnstein's Citizen Ladder of Participation,⁵ where degrees of decision-making and participation increase with each rung of the ladder, and Gaventa's^{6,7} framework of closed, invited, and invented spaces. Participation often occurs at the lower rungs of Arnstein's ladder where there is limited participation in decision-making, either non-participation (manipulation and therapy) and/or tokenism (informing, consulting, placation).⁵ Power dynamics impede participation and restrict it to the lower rungs of Arnstein's ladder.^{5,8}

The spaces (referring to invented, invited and closed spaces for participation) where participation takes place are important considerations as people bring their histories and past experiences into these spaces. Participatory spaces are thus never neutral.^{6,7} State decision-making processes tend to take place in closed spaces, 'behind closed doors' with no place for community engagement.^{6,7} Invited spaces, on the other hand, are meant to open up participation, yet these are often also limited and restricted.⁶ Here, communities are invited into state-created and state-managed spaces to participate in some way. Invented/claimed spaces are organic spaces created by communities where more meaningful participation might take place.⁶ Invented spaces often occur as a result of the restrictions of invited spaces, and as an opposition response towards those who hold the most power (similar to the concept of sites of resistance by bell hooks).^{6,9,10} Sites of resistance arise from discrimination and marginalisation and the desire to uplift and empower communities. Power dynamics have a significant impact on how participation unfolds in different types of spaces.^{11,12}

In South Africa, the National Health Act (2003, section 42)¹³ stipulates the establishment of health committees (HCs) as part of primary health care facilities. However, the form and functioning of HCs is governed by provincial legislation.¹³ In the Western Cape, the Western Cape Health Facility Boards and Committees Act, 2016¹⁴ outlines the structure, duties and powers of HCs, with members including community representatives, a health facility manager, and a ward councillor (municipal representative).^{14,15} It is unknown how many HCs have been established according to the National Health Act and it is important to note that some HCs are established independently.

This chapter focuses on the experiences of community representatives in HCs in the Western Cape. The envisioned role of HCs is as a bridge between communities and the health system so as to facilitate communication between service users and health facilities. However, HCs often feel unrecognised, pushed aside, under-resourced and excluded from broader health discussions.¹⁶ The pandemic caused systemic disruptions to the health sys-

tem and it is important to consider how participation may have changed as the pandemic unfolded.

The aim of this chapter is to explore how participation in HC spaces was affected during the COVID-19 pandemic and how the relationship between the Western Cape Department of Health (WCDoH), a key organ of the state, and HCs evolved during this period. The chapter explores what happened to the invited spaces of HCs and what these insights might teach us about community participation during a crisis and beyond.

Methods

This qualitative study explored shifting participation between HCs and the WCDoH in two economically marginalised areas in Cape Town, South Africa, during the COVID-19 pandemic.^{17,18} Both communities were overcrowded, with a quadruple burden of disease.^{17,18} Based on the research team's prior experience of working with these HCs, it was known that the committees were active in their communities, with supportive relationships with clinic managers.

The study was conducted in three phases. During phases one and three, focus group discussions (FGDs) were held with HCs, conducted by the first author (NK). Twenty-two HC members from Cuttle (21 women and one man) and 10 HC members from Stoneway (three men and seven women), respectively, participated in phase one. Area names used here are pseudonyms.

Due to the fluidity of community engagement work, phase three included 18 and eight participants from Cuttle and Stoneway, respectively. Ages of HC members ranged from 45 to 70 years. Phase one included discussions around the nature of participation prior to the pandemic, while phase three explored how participation had shifted during the pandemic. Phase two involved a three-month observation period of HC activities. Observations were recorded in a notebook, integrated, and triangulated across the datasets during analysis.

Ethics approval was obtained from the University of Cape Town's Faculty of Health Sciences Human Research Ethics Council (HREC 195/2021). The data were transcribed verbatim and analysed thematically.^{19,20}

Both inductive and deductive content analysis were used to analyse the data. In the deductive analysis, two conceptual frameworks – Arnstein's Citizen Ladder of Participation and Gaventa's notion of invited and invented spaces – were used to interpret the findings. Different stages from Braun and Clarke's thematic analysis were followed.¹⁹ Findings reported here are from the FGDs and observations.

Key findings

Pre-pandemic collaboration between HCs and the WCDoH was limited. HC roles expanded during the pandemic and members responded to community needs and carried out tasks to assist with infection control. The

pandemic saw an opening up of previously closed WCDoH spaces. The two themes below describe how invited and invented spaces influenced participation.

'Nobody will hold us back': active HCs and expanding roles

This theme was used to explore the expanding activities and roles of HCs during the COVID-19 pandemic in South Africa. To assist with infection management and control, HCs took it upon themselves and enforced infection-prevention measures – social distancing, hand sanitising, mask wearing – while people queued outside health clinics, waiting to be seen by health providers. These initiatives stemmed from HC recognition of the need to support health systems and protect communities. HC members mentioned that they were doing 'so many things' (to manage the spread of infections and meet community needs), 'too many to remember'.

So, there is a lot that health committees are doing but they [the Department] don't see it. We are doing that voluntarily. We don't get money, but it's in us to help our society, you know. (Cuttle health committee [CHC] member)

The expanded roles and activities of HCs enabled them to insert themselves into WCDoH invited spaces. Realising the value of their [HC] work, meant that members were able to approach the WCDoH and request inclusion in the pandemic response.

No authority came to us as health committee members to say "how can we do X, Y and Z ... this is our plan for the people on the ground, can you implement it in the community?" The pressure came from us in order for the sub-district, health management to pressurise [the Department] and say, "when are you going to get the health committees involved in the whole story?" (CHC member)

HCs empowered themselves by taking ownership and creating and expanding their roles, and by putting pressure on the WCDoH to be included in the pandemic response.

Another instance of HC roles and activities broadening relates to the COVID-19 vaccine rollout. HCs stepped in to assist with vaccine acceptability and uptake among community members. HC members spoke to their communities about their personal vaccine experiences through door-to-door visits to try and reduce fears. HCs assisted with registering 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.

Even when they [the Department] started with numbers of people that needed to be vaccinated, we were the ones who went all out. We started registering the community. Because they [the Department] didn't even know how to go to the grassroots level to educate people about doing the online registration the time that this

COVID-thing started (Stoneway health committee [SHC] member)

As HC members lived in and were part of their communities, they felt a deep connection to their people, and because of this connection, they wanted to help reduce the impact of COVID-19. This connection seems to have been a driving factor in their expanding roles during the pandemic.

Ja [yes], what is the slogan that we made in the struggle? 'There is nothing for us, without us.' They [the Department] know that there is a HC, they make plans without us ... they come with these plans finished. We want to be part of these plans. (CHC member)

Rather than sitting back and waiting for the WCDoH to act, HCs empowered themselves through action and their new self-established roles. HCs created new spaces, activities and roles, not entirely without the WCDoH but taking a more active and independent role in supporting a WCDoH approach as well as community needs.

Despite HCs often feeling at the mercy of the WCDoH and lacking in power and authority, the pandemic made them feel a sense of urgency to start acting and doing things differently. Realising their value and feeling empowered by their expanded roles may also have allowed them to put pressure on the WCDoH to increase participation.

The vaccine ... let me start with the registration: if the community workers, if the community health committee was not there, then they [the Department] cannot do the registration alone, in the facilities. We as SHCs, divided ourselves, then to go to the community, where we register our elderly people. We did make a relationship with them [the Department] by helping them with the numbers. (SHC member)

The new roles HCs created for themselves intensified their enthusiasm for working together, and these moments of taking on – and succeeding at – new activities confirmed their ability to help.

Currently we are playing a role and we are doing something, but in the process, we are promoting the HCs. So now we are on WhatsApp groups, which the sister is on, the area manager is on, which in the past has never happened. (CHC member)

Participation evolved, with HCs being included on WCDoH WhatsApp groups and recognised for their work. However, engagement between HCs and the WCDoH ultimately remained insufficient. As the pandemic unfolded, participation between HCs and the WCDoH intensified but then closed down again, largely due to conflicting agendas and persistent power dynamics.

Okay, to me it was a very good experience for my first time ever [to assist with vaccine rollout]. It was quite exciting to me to operate with the people inside ... the doctors. So, they were also excited, the doctors. Because they saw what we were doing. We were working very hard with them, hand in hand ... The second time [the

second phase of vaccine rollout] it was a bit strange to us because we were all put aside, you see ... I had a bad feeling because I was shut down. But, nevertheless, we health workers, we work very hard and very well and we got a very good communication with each other. (CHC member)

During the second phase of the vaccine rollout, HCs felt that they were pushed to the side and other organisations were more involved. Among HC workers there were feelings of being used. HCs did express a strong sense of empowerment in relation to the work they did on their own for their communities, but there was still a sense of being disempowered in relation to the WCDoH and the invited space, which was controlled by the WCDoH as an organ of the state.

'Government must work hand in hand with us': moments of participation

This theme reflects the moments of meaningful participation that occurred between the WCDoH and HCs. From the start of the pandemic, the WCDoH was confronted with limits in its ability to address community needs. With vaccine hesitancy high among South Africans, uptake varied from community to community, with socio-economic, demographic, geographical and sociocultural variables influencing vaccine hesitancy.^{21,22}

An example of increased participation between HCs and WCDoH officials was the Vaxi-Taxi initiative – mobile, community vaccination stations. These stations were initiated by the WCDoH 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 they were relied on to spread the message to communities regarding the date, time and placement of these mobile vaccine sites. Vaxi-Taxis were 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.

Right, but they still do what they want to without our input. They come and they say "rollout a pop up here and a pop up there", and then they ask us to look for venues, right, but then we as the health committees are good enough to source those venues. (CHC member)

Participation with HCs increased specifically with the first rollout of the COVID-19 vaccine. They were included in the communication and tasked with assigning safe areas within the community for the mobile vaccine stations. HCs were asked to 'spread the word' about the days, times and location of the Vaxi-Taxis and to assist with infection management on the relevant days. HC members had a role to play and were available to help register people at venues and ensure social distancing and mask wearing. Despite the positive shift toward increased involvement, HCs still felt that there was a long way to go towards full partnership and collaboration with the WCDoH.

Indeed, participation and inclusion levels were different for subsequent vaccine community initiatives. HC members felt that their recognition and participation had shifted back, and that they were pushed aside and no longer needed. HCs felt that they had implemented processes for the smooth running of these community vaccine sites, and once these systems were in place, they had been replaced by other community organisations. There was also little opportunity for HCs to be involved in planning of these mobile vaccine sites, and little opportunity to give feedback, for example on the need for water and food for those waiting to get vaccinated.

Another example of the 'opening up and closing down' of spaces for participation came when HCs became part of monthly WCDoH meetings. Pre-pandemic, HC meetings with the WCDoH were virtually non-existent. During the pandemic, HCs were included in WCDoH planning and decision-making discussions that they had not been privy to before despite their persistent effort to be included. The WCDoH invited HCs to partake in WCDoH Zoom planning meetings. It is likely that the WCDoH's recognition of its 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] she shared it with the rest of us ... And from the pressures that were placed on them [the Department] in that last meeting that you were in, then they recognised us. That was a few months back. So then they made this chat [WhatsApp chat] open, then they added us to this chat [WhatsApp group]. Right, but they still do what they want to without our input. (CHC member)

HC members were optimistic about this inclusion, but they found the opportunities for participation disappointing. There were also several barriers to participation in the Zoom meetings. Barriers 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 WCDoH, but HCs indicated 'that when you ask for resources, they [the WCDoH] say they don't [have]'. It may also be that the WCDoH did not know how to facilitate proper participation. These meetings were also hosted by the WCDoH, 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 around pandemic responses. HCs spoke about the space being a 'waste of time' and found it discouraging.

Those Zoom meetings they [the Department] only need our information. So that's why the Zoom meeting was not fruitful for us. Because there was no education from their side. They [the Department] only needed education from our side to keep on moving in their stats. Whenever there is a gap, especially at Stoneway, when their numbers were down, then they need one of our health

committees. They say we must assist at Stoneway, because they said Stoneway numbers are very down. (SHC member)

These Zoom spaces appeared to be a start to the WCDoH engaging with HCs, but there still seemed to be resistance to sharing power properly. There were several inevitable barriers to the Zoom meetings, but the meetings could have been made more participatory if the agenda had been set by both the WCDoH and HCs, with each sharing the floor to facilitate.

Contested spaces

HCs are part of institutionalised, invited spaces acting as a bridge between the health system and the community. However, these invited spaces are often limited for a variety of reasons. The WCDoH Zoom meetings and Vaxi-Taxi interventions were expansions of invited spaces. These spaces represent an opening up of participation, yet the WCDoH still held the actual decision-making power, with HCs being limited to listening and actioning state decisions, instead of collaboration. Rather than being new and collaborative, these spaces were fleeting, opening and closing for particular reasons, mostly due to the WCDoH'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 that were more open in comparison. These invented spaces can be viewed as sites of resistance,^{9,10} where marginalisation, discrimination, and exclusion in invited spaces result in positive action and creation of spaces for transformation. In these invented HC spaces, the power was held by HC members. Here, links can be drawn between the interplay of power and frameworks of degrees of participation and invented/invited spaces. Invited spaces typically mean less meaningful participation between the organs of the state and HCs – the power is unevenly distributed and heavily weighted on the side of the state.¹¹

Invited spaces are important because decisions that have real impact can be 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.^{6,7} Invented spaces can be seen as action-focused,⁶ for example where HC members created alternatives to their challenging conditions. Under certain circumstances, invented spaces can also offer more influence than invited spaces. The sections below offer insight into invited spaces, the interaction between invited and invented spaces, and ways to enhance and sustain community participation.

Discussion and recommendations

The importance of community participation is acknowledged globally, yet evidence both locally and globally sug-

gest that it is usually not done well, with HC participation being no exception.^{23,24} South Africa has made a commitment to community participation, with HCs being an institutionalised structure for community engagement and a vital vehicle for participation.²⁵

HCs often participate in invited spaces, created by organs of the state to partake in discussions and decisions around health services and the health system. The findings from this study highlight the attempts to rethink the position of HCs in relation to health and the community as the WCDoH realised the value of engaging with communities in their response to the pandemic. In opening up these invited spaces, HCs were privy to policy roll-out discussions within the WCDoH and decision-making processes. However, these changes did not seem to be intentional on the part of the WCDoH. Rather, their attitude towards HCs and openings in participation occurred under certain circumstances and in certain contexts. Often when there was a crisis the WCDoH saw the value of engaging with community structures. Even though HCs were consulted, the invited space remained mainly a space controlled by the WCDoH.

HCs realised their power to bring about change through the evolving scope and expansion of their roles and offerings to both the WCDoH and the community during the pandemic. The environmental and structural spaces where participation took place were an important consideration. The particular structural and socio-economic barriers (lack of data, limited access to technological devices to support Zoom) within the invited spaces, for example Zoom meetings, highlight how even when invited spaces are opened to communities for engagement, the physical space impacts degrees of participation. Hence consideration should be given to how to enable participation in invited spaces, for instance through ensuring that there are no barriers.

The COVID-19 pandemic, similar to the Ebola epidemic in West Africa and the HIV and AIDS epidemic in South Africa, illustrated once again the critical role community members can play in disease outbreak management. Invited spaces can stir up the power in individuals to invent their own spaces and realise their own power. Invented spaces and the empowering feelings they produce mean that community members take their growth back into invited spaces to facilitate better participation. In HC-invented spaces, members could share ideas and discuss challenges and solutions. Members felt that they owned and had 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. These spaces should not be considered as mutually exclusive alternatives but rather as potentially complementary. 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.

Despite the restrictions and barriers to participation within invited spaces, these places are still meaningful in their own way. However, participation could be improved through improving access to resources to ensure that HCs can function and participate in invited spaces. This will impact power dynamics and facilitate participation. 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 of respecting, supporting and acknowledging the importance of HCs.

Since spaces of participation are filled with our historical pasts, it is also imperative to consider more neutral spaces where HCs and the WCDoH are on a more even footing.^{6,7} This study proposes that there needs to be innovative thinking about these spaces. HC members and the WCDoH should decide on spaces together and should come up with mutually agreeable ways to partner. A start is to ensure that the facility manager is present at HC meetings, and to have the venue of these meetings rotate between community and state venues. These changes require a redistribution of power and HCs can encourage the WCDoH to share neutral or equal spaces through continued activism, participation in WCDoH spaces, and insistence on inclusion. The process of becoming stronger and more confident in invented spaces can assist in leveraging HC positions and roles within the health system to persuade the WCDoH to share power and shift towards more meaningful participation. More broadly, HCs can use their experiences from the invented spaces, and they can perhaps remind health authorities of the positive results of previous collaborative work during COVID-19. Coordination, support and resources are needed to assist HCs to navigate these state-provided spaces. The findings of this study indicate that HCs want to be included in planning, intervention rollout and decision-making processes. To achieve this, there should be collaboration between the WCDoH and HCs. It would be useful for representatives of HCs to have regular meetings with the WCDoH. For this to happen, HCs should be organised at sub-district and district level.

Mechanisms to ensure attendance of municipal representatives and facility managers at HC meetings would help to create trust and partnerships between the WCDoH and HCs. This would be a step toward power redistribution. The COVID-19 pandemic 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 workshops facilitated by HC members and health professionals can help bridge the divide between HCs and health professionals. Here, the value of each role and what each has to offer can be recognised and acknowledged.

The COVID-19 crisis saw the WCDoH recognise the value of HCs, but the collaboration was limited. Establishing partnerships and developing trust occurs over time. Improving trust and building on the experiences during the COVID-19 pandemic may help with managing epidemics in the future, as the relationship and ways of working together would be in place already.

As HCs understand their communities and the needs of their communities best, including them in health-intervention planning and idea generation to improve health services and community health is important and will help tailor interventions appropriately for different settings. HC members are trusted by their communities. The information they share is more likely to be trusted than when coming from the WCDoH, and this redistribution of power shifts the norm and empowers HCs. The health-related messages received by the public, and who delivers those messages, both matter. HCs can play a critical role here. Community interventions in 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 WCDoH can move into a guiding and supporting role, and allow HCs to sustain and inform their own interventions.

Several factors in this study limit the ability to transfer these findings to other settings. The two HCs in this study were quite active compared with other HCs in the province, which may have had a different experience. The roles described in provincial policies also differ significantly from province to province, and these findings may not be transferable to other provinces where the structure and function of HCs are different. Regardless of these limits to transferability, however, these findings suggest some important lessons about how degrees of participation can change due to various circumstances and factors, lessons that may be relevant to HCs in other settings. Future research should consider research with both active and less active HCs to further our understanding of how community participation is shaped by relationships, power and levels of action and influence.

Abbreviations

Abbreviation	Description
CHC	Cuttle health committee
FGD	Focus group discussions
HC	Health committees
SHC	Stoneway health committee
WCDoH	Western Cape Department of Health



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