Chapter 15
Participatory Health Research in South Africa

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Introduction

In this chapter, we will explore participatory health research (PHR) in social and behavioural health within the South African context and, in particular, how participation is operationalized in PHR in South Africa. Especially important to consider is that PHR is implemented within a particular historical and community context that necessarily will determine how participation is operationalized. In South Africa, the most defining contextual factor that permeates all praxis is still the legacy of apartheid. In the present context, this emerges as an enormous gap between the rich (still largely White) and the poor (still largely People of Colour), as South Africa remains one of the most unequal societies in the world (Chitiga et al. 2015). Regarding health issues, this appears as a bifurcated health system: one for the rich and another for the poor. While 1994 marked the official end of institutionalized apartheid rule in South Africa and the adoption of one of the most progressive constitutions in the world (Worden 2011), the effects of decades of racism and economic disparity continue to reverberate to this day.

Health disparities are inextricably linked to equity and social justice, especially with regard to the fair distribution of resources and availability of care and treatment. Highly affected by the social determinants of health, and specifically the powerful remnants of apartheid—including inequitable, highly discriminatory political, economic and health systems—the burden of disease in South Africa is concentrated amongst poor Blacks (Coovadia et al. 2009). Chronic disease rates—

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especially hypertension, diabetes and cancer—have alarmingly increased in South Africa (Steyn et al. 2006), and the country continues to battle some of the highest rates of HIV/AIDS in Africa (Gouws and Karim 2010). Furthermore, while there have been various progressive policies adopted in relation to health, it is not surprising that the implementation of these policies has been challenging, especially given the limited and compromised infrastructure, including severe fragmentation of the overall healthcare system (Coovadia et al. 2009). Thus, access to care and treatment is a still huge concern as most South Africans do not have private health insurance and mainly use public health services, which generally offer excellent care, but are hugely overburdened and infinitely under-resourced (Coovadia et al. 2009).

Unsurprisingly, apartheid policies directly impacted health research. Historically, medical and behavioural research in South Africa was seen as the domain of the ruling class, steeped in power dynamics and reflective of the limited voice of the marginalized majority (Deacon 2000). Furthermore, poverty accompanied by alarming rates of violence, specifically gender-based violence, and the biggest HIV epidemic on the African continent (Gouws and Karim 2010) greatly influences research foci.

Highly relevant to PHR is that apartheid was dismantled largely because of a strong, participatory movement, which highlights the significance of grassroots engagement in determining outcomes, including health outcomes (Coovadia et al. 2009). Building local capacity and partnerships was another defining feature of the anti-apartheid movement, as well as the core understanding that local insiders are critical agents of social change. Furthermore, South Africa's global importance propelled by its past inglorious human rights abuses and its rather exemplary (not perfect) transition to democracy has itself garnered considerable outsider interest and support as demonstrated by various international partnerships and financial aid (Habib and Taylor 1999). These research partnerships are of particular relevance to a discussion of PHR, as some of these partnerships may inadvertently perpetuate the power dynamics of the financially powerful North and the pigeonholed "needy" South (Tomlinson et al. 2006). The emancipatory, equalizing philosophy of PHR not only has an intuitive resonance with South Africans, but these values are at the core of its own social and political endeavours.

While context and level of engagement are important in determining participatory frameworks, participation in health research is dependent on various facilitating factors which include trust, community entrée and access, funding, community partners and opportunities for mutual benefit. If not present, these factors can just as easily serve to impede participatory efforts. Specifically, power imbalances and inability to share power through the distribution of resources and building local capacity can severely interfere with participatory health efforts. PHR, at best, is necessarily time consuming as the relational elements required for the successful conduct and dissemination of research are being tended to. The next sections will discuss PHR in the South African context with specific reference to the following elements: participation, formative research, partnerships, community advisory boards and building capacity. We acknowledge that there are numerous other central features of PHR; however, in this chapter we focus on key aspects most relevant in South Africa.

PHR in the South African Context

Participation

Meaningful participation is the overarching principle in participatory health research (Cornwall and Jewkes 1995; International Collaboration for Participatory Health Research 2013), and the importance of participatory health approaches to tackle issues of health disparity has been recognized by the World Health Organization (WHO). In its strategy for national health in the twenty-first century, the WHO acknowledged the essential role of all stakeholders, from the government to community members themselves, to be included in all phases of healthcare design: from planning to implementation and follow-up (Rohrer and Rajan 2016). Therefore, it may be no surprise that operationalizing participation is one of the most vexing questions to PHR and critics alike. In social and behavioural research, participation occurs on a continuum. Ideally, in PHR the participation of stakeholders is included at the design, data collection, analysis and dissemination phases.

There are many different forms of participation in South African research. Musesengwa and Chimbari (2017) provide an important overview of community engagement practices in Southern Africa. Community members frequently provide input on the design of intervention materials and on the development of culturally appropriate intervention protocols (Mabunda et al. 2016; Mosavel et al. 2005; Remien et al. 2013; Wechsberg et al. 2015; Woodsong et al. 2014). Specific strategies for seeking community feedback to inform the research design include broad stakeholder meetings with the research team, healthcare providers and community members. Several of these strategies are also accompanied by the integration of laypersons in the role of community researchers. In these cases, community members are trained to conduct interviews and collect data (Bradley and Puoane 2007; Mosavel et al. 2005) or to facilitate the actual intervention (Batist et al. 2013).

Who Is the Community?

PHR is largely conducted in location-based, marginalized communities and/or communities who are experiencing a major health disparity. International media accounts of South Africa simplistically portray the country's population as Black or White. In reality, South Africa's population is made up of a number of racial and ethnic communities which have their own cultural and linguistic traditions. Post-apartheid, South Africans continue to grapple with apartheid era racial classifications; however, there is a strong recognition at the societal level of the social construction of race and the continued barriers and privileges associated with race and ethnicity.

However, PHR is not only confined to racial/ethnic communities but also includes any group that may be bound by commonalities including geography (urban vs. rural), identity, illness (such as cancer, diabetes, etc.) or a health need. Because PHR is conducted with communities that are often in dire need of services, and the

research process can often be long and laborious, communities and researchers alike struggle with the "service delivery versus research dilemma" even as they commit to the relationship-building principles of PHR (Simon et al. 2007). Some communities may find the time spent on conducting formative research as frustrating, given that they would rather that the researchers focus on the intervention, while other communities may welcome researcher efforts to understand the community's experiences and perspectives. In our own research in South Africa, we found that utilizing the principles of PHR allowed us to provide an early "deliverable" to the community in the form of training and capacity building which helped to mediate, if only slightly, the inevitable tension that arises from a community's immediate needs for change (Mosavel et al. 2005).

Who Are the Researchers?

In addition to assessing the degree of participation, identifying the role of the researcher in this process is also critical. In participatory research there is a required acknowledgement of the identity and positionality of the researcher (Maxwell et al. 2016; Simon and Mosavel 2011) as this element influences the dynamics relevant to PHR. Researchers who are perceived as similar to the community in terms of race, language or culture may experience more initial implicit trust than researchers who are perceived as outsiders (Richman et al. 2012; Simon and Mosavel 2011). The implicit trust and insider-outsider dichotomy are also an issue for international researchers; one can argue that, depending on positionality, there are varying degrees of distance between researcher and community (Tomlinson et al. 2006).

Participation in health research is rooted in a community's history and their relationship with researchers. Since the transition to democracy in 1994, there is an emerging, highly educated, Black workforce, and this includes academics with research careers. Prior to 1994, most researchers were middle-class Whites. Due to apartheid era constraints, there were fewer Black and Coloured individuals able to receive formal research training; thus they were frequently excluded from this specialization (Tomlinson et al. 2006). More recently, local South African universities are graduating thousands of Black researchers (South Africa Department of Higher Education and Training 2014), and there are many Black academics who are conducting social and behavioural research which is inevitably informed by their own lived experiences. While these are important shifts that may facilitate greater participation, further research is needed to assess whether these shifts have made a difference. As highlighted earlier, given the dominance of the Northern agenda, there is a concern that Black researchers may still be reproducing that agenda and ways of doing research that impede participation or the production of local knowledge (Daniels 2011).

Who Are the Participants?

Who is participating and why are also questions that must be critically analysed, as its answer(s) may provide guidance about key stakeholders who may be absent (Cornwall and Jewkes 1995). While participation by the intended community of

focus is critical, there are various other stakeholders who are not usually included, such as the private sector and stakeholders who may not be comfortable with the usual participatory structures.

Participation is often an outcome of the relationship with community, the use of effective outreach strategies and the use of trusted community members as front-line workers (Kingori 2013). Often not discussed is that effective participation presupposes a belief in an outcome that will be of benefit to the community. A scepticism about social change or even more intermediary change is a key reason why broad-based participation may be challenging. This is of central importance in the South African context. The vigorous civic participation that emerged during the apartheid era—and still seems present—is based on the premise of social change, with the research agenda often considered secondary to this premise. In South Africa, there is the recognition that behavioural research designs *must* include community participation, even if such research designs would not necessarily meet the definition of PHR. Furthermore, there is the understanding that broad sector input is critical and that the community—alongside other key stakeholders, such as frontline healthcare provider staff—must be an integral part of the participatory health approach.

It is also important to consider the dual roles that are often required in PHR: that of participant and researcher. Unlike traditional mainstream research, the fluidity of the participant-researcher boundary provides both opportunities and challenges for research. "Participants" can take on various roles from providing data to informing research questions and instruments, collecting data and even contributing to data interpretation and the implementation of interventions. A similar tension emerges for the primary researcher, in that different roles may be required for collecting data and dissemination of research findings, compared to the tasks and roles required for facilitating interventions that emerge from these findings. This multiplicity of roles also raises ethical challenges for issues like confidentiality, anonymity and informed consent (Williamson and Prosser 2002).

While community member-as-researcher can enrich data by establishing legitimacy within a community and offering an insider perspective of the findings, there are also challenges that must be considered. One such challenge we encountered while training and working with community researchers from a resource-poor and socially fragmented community in South Africa was the mental burden and stress taken on by the community researchers as they managed their own personal struggles "coupled with the emotional stressors induced by their increased exposure to the conditions in their community" (Mosavel et al. 2011, p. 150).

PHR in the Context of Formative Research

PHR is particularly important in the context of formative research in South Africa. Two types of formative research are commonly conducted. First, the more typical formative research which is driven by the local academic-community partnership or agenda where the primary goals are community entrée, needs assessment and facilitating participation. The second type of formative research includes

intervention or programme development which seems to be driven by the many different international research collaborations, in particular the implementation and testing of interventions from Northern countries.

Community Entrée

Entrée into the community is an important foundational goal of PHR. During the formative stage, research teams use various participatory strategies to foster trust-building and to mobilize participants. Strategies that have been used in South Africa include information sessions, key informant interviews, focus groups and surveys (Lazarus et al. 2014; Mosavel et al. 2005; Ramjee et al. 2010; Simwinga et al. 2016; Tucker et al. 2013).

In this stage, it is important that "community" be defined broadly to include all stakeholders directly and indirectly affected by any proposed research. Interested stakeholders include, although are not limited to, government officials, civic leaders, community residents, traditional leaders, healthcare providers, etc. Particularly relevant in South Africa is obtaining permission from the community's traditional leaders which is often seen as a critical first step for building a trusting relationship and gaining acceptance for the project (Simwinga et al. 2016; Treves-Kagan et al. 2017). For example, Ramjee et al. (2010) consulted with political and traditional leaders in the community who, in turn, consulted with community members to gain support for their HIV prevention research. Several research projects have also engaged laypersons as ambassadors who can assist in navigating and bridge-building between academic researchers and communities where there may be varying levels of mistrust, scepticism and misalignment of needs. To access an especially difficult-to-reach community, men who have sex with men, Tucker et al. (2013) spent 3 months networking with leaders of the community to gain trust and buy-in and ultimately was able to utilize these leaders as ambassadors to identify and engage other community members. Formative research provides the opportunity to build credibility and research integrity specifically by seeking and incorporating community feedback and identifying or modifying the research focus to address community priorities or anxiety (Mosavel et al. 2005).

Intervention/Programme Design

The other type of formative research in the South African context is that of programme or intervention development. For example, Remien et al. (2013) relied on a local team of researchers, clinicians and patients to address language and cultural differences (such as concepts of illness and treatment) when adapting an HIV intervention from the USA for use in South Africa. Similarly, Wechsberg et al. (2015) used community focus groups to understand the local context which resulted in modifications to the core elements, delivery style and structure of the

HIV prevention intervention they were adapting. While inclusion of youth in the research process has been limited, there are examples where youth have been engaged to help inform intervention design. In one such example, researchers sought to develop tobacco, drug and alcohol prevention materials for adolescents. They utilized a photo-voice methodology in which adolescents representing differing races were provided cameras and were asked to document the people and things they considered important in their lives. Through group discussion of the photos, the researchers were able to gain a better contextual understanding of adolescent lives which was used in the development of educational materials (Strecher et al. 2004).

Formative research that involves the community from the outset of the project as well as addresses issues such as trust, scepticism and the misalignment of agendas increases the likelihood of sustainable research agendas, with mutual benefits for both researchers and community members. For example, when we initiated our participatory health research project in Cape Town, we were narrowly focused on cervical cancer, and it was only due to the many meetings we conducted with varied stakeholders that we learned the importance of expanding our conceptual framework to encompass cervical *health (women's health more broadly)* rather than only *cancer* thus acknowledging that poor women face health challenges beyond just cancer (Mosavel et al. 2005). Unfortunately, it is not uncommon for imported programmes, interventions and research—primarily driven by the need to generalize findings and interventions—to entrench Northern agendas and Western concepts, in spite of the intentions of those conducting the projects (Daniels 2011; Lau and Seedat 2015; Tomlinson et al. 2006).

Partnerships in PHR

Partnerships are essential to facilitate engagement in the translation and dissemination of research outcomes and to ensure sustainability beyond the scope of the research funding. There are many well-documented challenges associated with community-researcher partnerships, not least of which are the power dynamics, differing values and constituents and conflicting perspectives.

Academic Partnerships

Academic institutions in South Africa, not unlike universities elsewhere, are being called to collaborate with government, private sector and communities to address the various health manifestations of social, political and economic inequities (Brown-Luthango 2012). While many academic institutions explicitly specify community engagement as part of their role, it is unclear to what extent equal partnerships are established, and many of the difficulties present in other contexts also seem to be present here.

Collaboration and participation are greatly facilitated when there is a recognition of the varying expertise amongst partners, especially the expertise of community stakeholders (Marks et al. 2015). For some academics, it can be challenging to embrace the expertise of community members as it counters the traditional research paradigm and the way researchers are trained in academic institutions. It can be difficult for researchers to accept or value the insider expertise of community members or to understand how the community perspective can lend validity and scientific integrity to the research (El Ansari et al. 2002; Kearney et al. 2013).

International Partnerships

International research partnerships abound in South Africa, many of which are HIV intervention related (Desmond Tutu HIV Foundation 2015). Communities, researchers and the scientific field, more generally, are greatly benefiting from cross-sector and international collaborations. Partnerships in general, and with international researchers in particular, are invaluable to stakeholders (inside and outside South Africa) and have significant potential to positively impact practice and health outcomes.

However, with international NGOs there is more of a need for researchers to understand the local culture, politics and dynamics amongst the stakeholders (Costella and Zumla 2000; Tomlinson et al. 2006). International researchers often enter the collaboration with a limited understanding of the interplay between stakeholders or the implicit values or expectations of the partners (Nama and Swartz 2002). Furthermore, these international partnerships are characterized by unequal and divergent assets. Most importantly, it is likely that international partners will be in a position to provide financial resources to the partnership. The imbalance of financial contributions can often lead to concerns about power and value and invariably determines who sets the research agenda (Edejer 1999; Jentsch and Pilley 2003). With funding often being generated from Northern international partners, this inequality means that for both the researchers and communities from the South, power is structurally located with the Northern partner and thus can significantly impact on all aspects of the research. In all partnerships, and in particular in international partnerships, it is imperative that roles and responsibilities as well as power dynamics, benefits and burdens of implementation are recognized, deliberated and addressed (Costello and Zumla 2000; Jentsch and Pilley 2003).

Community Advisory Boards (CABs)

The engagement of an advisory group is usually seen as a foundational element for most participatory research (Newman et al. 2011). In general, CABs are established at the discretion of researchers or the funder's requirements. CABs are used in

various projects, many of which are HIV/AIDS related (Ramjee et al. 2010; Reddy et al. 2010). CABs usually have diverse roles in participatory research, with the major task being the provision of input to researchers. Within HIV/AIDS research, CABs appear to have an important monitoring role. Reddy and colleagues did a study of CABs in HIV vaccine trials in South Africa. Their findings suggest that the use of CABs in South Africa is primarily researcher-initiated and research-driven, with the overall goal to provide community input and scientific oversight (Reddy et al. 2010). However, there are several questions about the effectiveness and participatory nature of CABs, specifically questions about the selection of CAB members, to what extent they represent community voice, and whether CABs are independent or merely serve as a gatekeeper. Some of these unanswered questions have resulted in a preference for the terminology *community advisory groups* instead of boards (Reddy et al. 2010).

Building Capacity for PHR

Using an asset-based approach which builds on the existing strengths in a community—whether those strengths are people, organizations or social structures—is considered to be an important principle in PHR. Given the focus on social transformation, it is not surprising that capacity building is so prominent in some South African research. In fact, in the South African context, capacity building may be considered as important an outcome as the research itself. Building the research capacity of the community providers can be considered one form of levelling of power and provides a means for local participants to set their research agenda and address issues they see as important (Tomlinson et al. 2006). The engagement of laypersons in participatory health research in South Africa, both in the role of community/peer researcher and as a community health worker (CHW), is ostensibly used as a capacity-building strategy capitalizing on existing community strengths. These strategies also have the effect of addressing the important community need of building research capacity (El Ansari 2005; Mitchell et al. 2005; Mosavel et al. 2005).

The evolution of the CHW is a part of South Africa's economic, political and healthcare response to the HIV/AIDS crisis (Clarke et al. 2008). CHW are usually hired by NGOs and provide outreach to improve access to care and act as the middle person between the healthcare system and the community (Nxumalo et al. 2013; Schneider et al. 2008; Suri et al. 2007). While there is debate about the appropriate training, role and support for CHW, there is consensus that they are an integral interface between the community and the healthcare system (Friedman 2005). CHW are primarily utilized for health promotion purposes (Friedman 2005), and while there is mention of the potential benefit utilizing CHW to collect health data (Suri et al. 2007), their research role is less well-defined. Bradley and Puoane, for example, discuss the important role of CHW in identifying their community's concerns and the benefits of involvement in all aspects of the research process, from collecting

data to developing training programmes, and directing the interventions (Bradley and Puoane 2007). While there are arguably various ways to build capacity and utilize the strengths of the community in South Africa, the CHW movement as an engagement strategy has resulted in tangible improvements to health outcomes and health policy (Clarke et al. 2008; Schneider et al. 2008).

Community researchers or laypersons in the role of peer researcher engaging with the community are another key capacity-building and asset-based strategy used in social and behavioural research. There is, however, a distinction between the role of CHW and that of community researcher. Community researchers, or peer researchers, have less of a health promotion role, their tasks being more specifically centred on research. For example, Batist et al. (2013) trained five community members to conduct an HIV prevention intervention for a community of men who have sex with men. In this capacity, the community researchers participated in the planning and facilitation of the research and intervention activities, including recruitment of participants, dissemination of information and healthcare referrals (Batist et al. 2013). Photo-voice projects are another participatory technique for engaging community researchers. In utilizing the photo-voice methodology to improve collaboration between CHW and teachers in preventing HIV in young people, Mitchell et al. (2005, p. 268) have suggested that by engaging in the research, "it has opened up an important space for groups to take action themselves. They are not waiting for the research team to come back to give them answers."

However, the use of community members in participatory research also raises a number of challenges. Mosavel and colleagues, in a cancer prevention community-based needs assessment, trained laypersons as community researchers to recruit and conduct interviews with fellow residents. The authors described various ethical considerations as well as benefits and challenges associated with the role of community researcher (Mosavel et al. 2011). Not often discussed are the tensions and difficulties the community researchers might be experiencing in their role, especially given that they are the "frontline workers" who witness up-close the harrowing and challenging conditions that they might be asked to "research" (Kingori 2013; Nama and Swartz 2002). The emotional support of community researchers is an area that has not received the investigation it warrants. Being the intermediary between the researchers/health professionals and the community is a role that can be difficult, as it underlines unanswered questions about researcher burden, credibility, conflicts and commitments.

Conclusion

The context of huge inequities and a history of citizen participation form the backdrop of participatory research in South Africa. Following the marginalization and virtual exclusion of People of Colour, there has been a far greater attempt in the post-apartheid era to involve these communities. In addition to conducting more

community-based research, it would not be inaccurate to conclude that most of the research can be characterized as *research in communities*, rather than the gold standard of *research with communities*. The challenges evident in participatory research globally emerge in South Africa; there are, as well, challenges that may be specific to the local context.

There is some consensus that research is shaped by a global neo-liberal agenda (Bayliss et al. 2011; Roberts and Peters 2008), which creates particular challenges for PHR in developing contexts such as South Africa. South Africa, like other developing countries, has a long history of "parachute" research, whereby researchers from "wealthy" or "Western" countries travel to developing countries to collect data before returning home to analyse and publish their results (Costello and Zumla 2000; Tomlinson et al. 2006). Even in cases where international researchers "embed" in the country of interest, the research agenda is often still controlled by outsiders, and research findings may not be translated into programmes for local benefit (Costello and Zumla 2000; Tomlinson et al. 2006).

At the research partnership level, a particular set of challenges emerge. The inequity and power differentials in North-South partnerships may serve to preserve the notion that developing countries must depend on the wealthier western nations to advance and progress. In the South African context, there are also the racial inequalities between Black and White researchers, as well as between historically White, well-resourced institutions and historically Black under-resourced institutions; North-South collaborations may further serve to maintain these existing inequities. In other words, there is not only a Northern-led agenda but an agenda driven by historically advantaged institutions inside South Africa which are also historically isolated from communities in need.

The potential dominance and reproduction of a Northern agenda have a huge impact on the local community agenda. Attempts to involve the community from the outset, the emphasis on capacity building and the popularity of photo-voice methodologies can all be understood as attempts to engage with power dynamics and social inequities. It serves to give voice to communities under conditions which these voices run the risk of being muted.

A focus on social transformation from the apartheid era reinforces the research vs. service delivery tension. Given the urgent and pressing needs in many communities, research is often seen as a luxury. The emergence of "relevant research" (Long 2013) can be understood as an attempt to manage this tension. The prominence of this debate (Long 2013) highlights the fact that research cannot be decoupled from some kind of action. Current manifestations include asset mapping, engaging with policy and the undertaking that data will eventually be used to improve the living conditions of members of that community. While these are important, the marked tension between social action informed by research and the large-scale civic participation reflected in service delivery protests, characterized as a rebellion of the poor (Alexander 2010), is a distinct feature of South African participatory research. South Africa's history of civic participation precedes attempts at community-engaged research and is helpful perhaps in foregrounding the social action component of PHR.

Entrée into communities remains complex and shaped by colour, class and culture as well as the daily challenges these communities face. While there is certainly greater representation in terms of class, colour and culture, like all other areas of South African society, research profiles and resources remain concentrated largely in the hands of the White minority. Furthermore, Black researchers who may have come from the communities they now serve may by virtue of their class position be quite removed from these communities.

The power-sharing philosophy of PHR resonates well and is particularly helpful for contexts like South Africa. However, the social conditions create both unique opportunities and challenges for this type of research. Perhaps the most important lesson from the South African context is the extent to which it foregrounds the need for research to be informed by a social justice agenda. Indubitably, health research is inextricably linked to social inequities and the transformation of social conditions.

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