

LONDON  
SCHOOL of  
HYGIENE  
& TROPICAL  
MEDICINE



LSHTM Research Online

Simwinga, M; Porter, J; Bond, V; (2018) Who is answerable to whom? Exploring the complex relationship between researchers, community and Community Advisory Board (CAB) members in two research studies in Zambia. *Critical public health*. ISSN 0958-1596 DOI: <https://doi.org/10.1080/09581596.2018.1440072>

Downloaded from: <http://researchonline.lshtm.ac.uk/4647094/>

DOI: <https://doi.org/10.1080/09581596.2018.1440072>

**Usage Guidelines:**

Please refer to usage guidelines at <https://researchonline.lshtm.ac.uk/policies.html> or alternatively contact [researchonline@lshtm.ac.uk](mailto:researchonline@lshtm.ac.uk).

Available under license: <http://creativecommons.org/licenses/by-nc-nd/2.5/>

<https://researchonline.lshtm.ac.uk>

1 **Who is answerable to whom? Exploring the complex relationship between researchers, community**  
2 **and Community Advisory Board (CAB) members in two research studies in Zambia.**

3  
4 **Musonda Simwinga<sup>1</sup>, John Porter<sup>3</sup> and Virginia Bond<sup>2</sup>**

5 <sup>1</sup>Zambart; <sup>2</sup>London School of Hygiene & Tropical Medicine, Department of Global Health and  
6 Development, <sup>3</sup>London School of Hygiene & Tropical Medicine, Departments of Clinical Research and  
7 Global Health and Development

8  
9 **Abstract**

10 This paper explores the accountability relationships that arise between researchers, the community  
11 and community representative structures known as Community Advisory Boards (CABs). It draws on  
12 ethnographic and case study research that documented the history, recruitment, composition and  
13 representativeness of two CABs and their relationships with researchers and communities, carried out  
14 in two studies in Zambia between 2010 and 2014. The findings revealed contradictions, nuances and  
15 imbalances in actual community participation and representation. In both studies, the general  
16 population was not given the opportunity to participate in the election of their CAB representatives,  
17 and the elected CAB members themselves were initially told to have little or no direct contact with  
18 research participants whom they were supposed to represent (unless researchers dictated otherwise).  
19 Owing to the researchers' monopoly of scientific knowledge, literacy and financial resources, power  
20 relations were imbalanced. Further, researchers were quick to ask for and formalise community  
21 commitment through the CABs whilst reticent about their own accountability to the community. Yet  
22 despite these imbalances and CABs lacking formal authority over researchers, CABs did have subtle  
23 powers arising from their wider influence in the community, which they could tap into to either  
24 support or resist research. To achieve a more balanced and open accountability between research  
25 stakeholders, more genuine participatory processes need to be built and sustained.

26  
27 Key words: Accountability, Community Engagement, Community Advisory Boards (CABs), Power,  
28 Representation

1 **Introduction**

2 Community-based research in Africa is often initiated by researchers who have considerable skills,  
3 knowledge and financial resources. Yet to conduct research that is successful and that adheres to  
4 international guidelines, active participation of local residents is necessary (Israel, Schulz, Edith &  
5 Becker, 1998; Tindana et al., 2007). In fact, participation of local residents in all stages of the research  
6 process is encouraged (Dickert, & Sugarman, 2005; Minkler, Blackwell, Thompson, & Tamir, 2003;  
7 Woolf, Zimmerman, Haley, & Krist, 2016). ‘Community engagement’ has thus become a standard  
8 practice in research programmes in sub Saharan Africa. It has several desired ends, including securing  
9 permission to enter community settings, soliciting input into studies and ensuring on-going dialogue.  
10 In bioethical discourse, community engagement is considered as an inclusive and empowering  
11 process. By developing meaningful partnerships with the people who are part of and familiar with the  
12 broader social, political and economic environments within which research is being conducted,  
13 community engagement is intended to ensure that research is relevant, protects and respects  
14 communities and participants, minimises the possibility of exploitation by researchers, and has a high  
15 chance of positively impacting communities (MacQueen, Bhan, Frohlich, Holzer & Sugarman, 2015;  
16 MacQueen, Kerry, Alleman, McClain Burke & Mack, 2006; Israel et al., 1998).

17

18 Although community engagement can take on many forms (several of which are explored in this  
19 special issue), one of the most common ones is the community advisory board (CAB). CABs are  
20 organised groups of individuals, usually volunteers, appointed or elected by ‘the community’ to  
21 represent its interests by providing input in the research process (Wakefield, 2005). CABs may be  
22 established to serve one study or many (Quinn, 2004). They are set up to perform a variety of  
23 functions. Aside from government and Institutional Review Boards/ Ethics Committees, CABs are  
24 frequently among the first groups that facilitate the entry of research studies into communities. With  
25 medical research often embedded in colonialism, residents may not trust the researchers in the  
26 absence of recognisable community representatives, and therefore CABs are considered to play an  
27 important role in building trust. CABs are also intended to provide organisation and leadership to the  
28 collaboration between researchers and communities (Newman, Andrews, Magwood, Jenkins & Faan,  
29 2011). Perhaps most importantly CABs are considered as a meaningful and effective way of countering  
30 the potential of exploitation in international research (Pratt et al., 2013).

31

32 The ability of CABs to represent community interests and to reduce exploitation depends to a large  
33 extent on the accountability mechanisms between researchers, CABs and the people they represent.  
34 Accountability can be understood as a ‘referee of the dynamics in two-way relationships’ (George,

1 2003) often between entities, organisations or individuals who may not have equal power or  
2 influence. Accountability can also be understood in terms of answerability, meaning that (research)  
3 organisations are obliged to answer to partners, provide them with information and justify their  
4 actions (Brinkerhoff, 2004). A small number of studies have suggested that, in practice, CABs often  
5 have very limited powers and ability to demand and enforce accountability. CABs have been described  
6 as 'paper councils' or 'window dressers' (Cox, Rouff, Svendsen, Markowitz, & Abrams 1998; Strauss et  
7 al., 2001), lacking the power to influence the research agenda and to reduce the potential for  
8 exploitation (Slevin, Ukpong, & Heise; Pratt et al., 2013). CABs can in this regard be viewed as  
9 appendages to research with the specific interest of enrolling the world's most poor and vulnerable  
10 into clinical trials (Petryna, 2009; Rottenburg, 2009; Nguyen, 2015). Yet, we still have very few  
11 sustained accounts of how CABs perceive their roles, how they balance their allegiances between  
12 researchers and community members and how they strive to demand and enforce accountability.

13

14 To increase our understanding of the accountability relationships between researchers, CABs and  
15 study communities, this paper draws on ethnographic and case study research with two CABs in the  
16 two medical research studies in Zambia conducted between 2010 and 2014. At the heart of this paper  
17 lies a concern with who, in practice, is answerable to whom. The findings revealed inherent power  
18 imbalances in the three layers of accountability relationships; between CABs and the community,  
19 between CABs and researchers and between researchers and CABs/community. The monopoly of  
20 scientific knowledge, literacy and financial resources of the researcher accentuated this imbalance.  
21 However, CABs had subtle powers arising from their wider influence in the community that partially  
22 offset this imbalance. To further tap into this broad based influence and to make researchers more  
23 genuinely accountable, we argue for more participatory processes.

24

## 25 **Study Setting and Methods**

26 This paper is based on PhD research conducted by the first author to explore the role and function of  
27 CABs. The research was nested within two on-going studies in Zambia which we refer to respectively  
28 as (1) the Human Immunodeficiency Virus (HIV) study and (2) the Tuberculosis (TB) study. They were  
29 conducted in two high density urban areas in Lusaka: Maliko and Kapata (pseudonyms), respectively.  
30 The HIV study was a multi-site observational cohort study aimed at understanding trends over time of  
31 sexual HIV transmission risk behaviour in HIV positive individuals under treatment. The TB study was  
32 a randomised placebo-controlled double-blind study comparing two shortened regimes for TB  
33 treatment. Recruitment of study participants was conducted within two health facilities which  
34 serviced the two respective geographical communities. Ethical approval was obtained from the

1 University of Zambia (UNZA) Biomedical Ethics Committee and the Ethics Committee of the London  
2 School of Hygiene and Tropical Medicine. Written informed consent was obtained from all  
3 participants.

4

5 An ethnographic study design and case study analytic approach was used as this approach is ideally  
6 suited for exploring social relationships through interactions with research participants (Liamputtong  
7 & Ezzy, 2005; Merriam, 2009). The first author and a research assistant spent time in the field  
8 attending CAB and sensitization meetings and observing CAB members and researchers interact in  
9 different forums.

10

11 The case study approach (Green & Thorogood, 2009) helps to illuminate cases in great depth and  
12 detail (Murray & Beglar, 2009) by using different data collection methods. Accordingly, a mix of  
13 methods was used to triangulate the findings from the CABs in the two studies. In-depth interviews  
14 (n=25) with CAB members and researchers were conducted, and, to assess individuals' experiences,  
15 key informant interviews (n= nine) were done with purposely selected residents who had knowledge  
16 of the community (opinion leaders) (Richards, 2009). Secondly, focus group discussions (n= nine) with  
17 members of the community were used to understand collective narratives. For a year and half,  
18 observations of research activities (n=33) were conducted to enable a deeper understanding of  
19 behaviour and interactions (Silverman, 2011). Finally, participatory research appraisal techniques  
20 were employed to gather background information for both communities. These included asking  
21 residents (n=eight) who had knowledge of and who had lived in the community for at least 10 years,  
22 to draw social maps and to construct historical timelines of the two communities. Selection of  
23 information rich residents for in-depth interviews and participatory appraisal research activities was  
24 carried out with the help of a local Community Based Organisation, and the Neighbourhood Health  
25 Committee which works with health facility management to identify and mitigate health challenges in  
26 communities. A Neighbourhood Health Committee was present in both communities. In addition,  
27 document analysis (n=35) was conducted to gain insight into unobservable interactions. This included  
28 documents of: CAB meeting minutes, community meetings and sensitization reports, CAB guidelines  
29 or constitution, correspondence between researchers and the CABs, study instruments and any form  
30 of records that were kept by the studies and CABs on CAB activities. All focus group discussions,  
31 participatory research appraisal and document analysis were conducted by the first author with some  
32 observations and interviews carried out by the research assistant. Interview guides and observation  
33 checklists were developed and piloted.

34

1 All interviews were recorded, while observations and data from participatory research appraisal  
2 activities were written up as field notes using a guide which divided the observations into two broad  
3 categories; field activities and meetings and or forums in which researchers interacted with the CABs  
4 and the community. Interviews conducted in the local language (Nyanja and Bemba) were first  
5 transcribed and then translated into English and were then imported into NVivo. A code book  
6 (thematic framework) was developed by the first author, with assistance from the supervisors and  
7 research assistant, consisting of both preconceived themes from the study's conceptual framework  
8 and themes which emerged from the field data. This was followed by coding of the data by the first  
9 author. Data were then charted into different matrices and tables bearing themes or variables for  
10 interpretation of the data across participants, themes and communities.

11

## 12 **Findings**

13 Themes identified through thematic analysis included the formation and composition of the CAB, the  
14 development of the CAB selection criteria, and the nature of interactions and power relations between  
15 researchers and the CABs. Other related themes included representation and legitimacy. These  
16 themes were presented and discussed in relation to accountability, leading to the identification of  
17 three layers of accountability relationships: the relationship between CABs and the community,  
18 between CABs and researchers and the relationship between researchers and the community.

19

### 20 CAB Formation, Composition and Selection of members

21

22 According to the researchers, CABs were formed to enhance community engagement through the  
23 provision of feedback, 'community voice' and advice regarding sensitization, recruitment and  
24 retention activities. The CAB for the HIV study was formed before the start of the study, while the CAB  
25 for the TB study was created after the study had already commenced. Prior to the establishment of  
26 the CAB, the Neighbourhood Health Committee played the CAB's role. The timing of the creation of  
27 the CAB was important as it determined how much influence the community had in the design and  
28 subsequent processes of the study. The CAB for the HIV study was composed of five members – three  
29 men and two women – while the CAB for the TB study was composed of 13 members, five men and  
30 eight women. The 13 members of the TB study CAB represented 12 Community Based Organisations  
31 and other interest groups. Some members belonged to more than one Community Based Organisation  
32 and several were also members of respective Neighbourhood Health Committees. All the HIV study  
33 CAB members completed senior secondary school and four attained college education and were  
34 formerly employed. In comparison, only four of the thirteen TB study CAB members had completed

1 senior education, and only three had attained a college education. The composition of the CAB was  
2 important because it reflected a broad representation of community interests and geographical  
3 spread.

4

5 The CAB members in both studies were selected using criteria determined by researchers, rather than  
6 community residents themselves. Using different criteria and guidelines, CAB members were selected  
7 with the help of the Neighbourhood Health Committees and health facility management. Some  
8 Community Bases Organisations were asked to nominate a representative using the set criteria. Of  
9 these, literacy and education were considered the most important. CAB members were required to  
10 be able to read and write, at least in their local language but preferably in English too. In the CAB of  
11 the HIV study, most members were proficient in both; but in the case of the TB CAB, some of the  
12 members struggled to read and write in English and CAB meetings were conducted in a mix of local  
13 languages and English. Observations of CAB meetings showed that comprehension was still a  
14 challenge for some CAB members. Yet the selection of literate individuals was meant to assure some  
15 level of research comprehension and by extension, increase CAB answerability to the community.

16

17 Age requirements were not explicitly stated in the guidelines/criteria. Nonetheless, all CAB members  
18 were either middle aged or older, ranging between 35 and 65 years old. Members of both CABs  
19 expressed that they considered young persons as too immature to serve on the CABs and that they  
20 may not have sufficient time as they were supposed to be in school. The reality, however, was that  
21 young people often held volunteer roles at the health facilities. Both CABs experienced high attrition  
22 in their early stages of development because some members had expected higher compensations and  
23 attendant benefits than they were offered.

24

25 Place of residence was also viewed as an important selection criterion and people residing within the  
26 community were preferred to those residing outside of it. The former was seen by the researchers as  
27 'typical' residents, who were experienced and were knowledgeable about issues faced by the  
28 communities. Thus, they were viewed as likely not only to represent their communities well but also  
29 to hold researchers to account. One HIV study CAB member said: 'when you go for interviews...they  
30 also want to find out how long you have lived in this community and how much you are known and  
31 also how respected you are in the community' (male, CAB member, HIV study).

32

33 Another criterion for researchers' selection of CAB members was people's knowledge of health-  
34 related issues. Understandably, the researchers considered knowledge of HIV and TB to be important

1 given the nature of the respective studies. Some CAB members themselves said that members must  
2 wield influence in the community for people to listen and respect them, and one factor contributing  
3 to their influence was their health-related knowledge. However, concerns were raised by residents  
4 about the bias and favouritism in the selection of CAB members, with some people alleging that  
5 volunteers in good standing with health facility management and Neighbourhood Health Committees  
6 were often picked.

7

8 The nature of CAB-community-researcher interactions

9

10 *Interactions with community members*

11 CABs performed several interfacing roles with the study communities. These included facilitating  
12 consultation and entry of the studies into the community (HIV study CAB), educating and sensitising  
13 communities about the studies and supporting recruitment and retention activities. Because the HIV  
14 study CAB was functional before the study started, it could assist researchers in organising the initial  
15 community consultation meetings. This was not the case for the TB study as its CAB was created after  
16 the study had already commenced. Instead, the Neighbourhood Health Committee played the role of  
17 a CAB until the official CAB was created. The TB study was also incidentally stopped early and all  
18 community engagement activities were consequently halted, even though the reasons for halting the  
19 study were not revealed. CAB members said researchers disrespected the community by not  
20 consulting and telling them the decision in good time.

21

22 The CABs conducted community meetings, one-on-one or door-to-door campaigns and used drama  
23 to disseminate information and educate residents about the studies. They also obtained feedback  
24 from residents using the above activities. For instance, in the HIV study, some residents questioned  
25 the scientific merits of excluding HIV-negative individuals and adjacent communities who, in their  
26 opinion, also had a high HIV burden.

27

28 Despite CAB involvement in sensitization (information giving and education) activities, findings from  
29 interviews with key informants showed that there was low awareness among residents of the  
30 existence of CABs. However, some people knew the CAB members from their other pre-existing roles  
31 in the community. This low awareness was in part because CAB members and their representative  
32 role was never explained during research specific community sensitization meetings.

33



1 Both CABs said that the researchers told them not to directly contact study participants. The main  
2 reason was not to compromise participants' privacy and confidentiality. A further reason was that this  
3 could constitute a conflict of interest and expose the CAB members to risk of violence in the event of  
4 a backlash against the studies. The CAB members expressed reservations about this guiding rule that  
5 were both pragmatic and ethical. Regarding the former, they felt that the ability to visit study  
6 participants would improve retention substantially. Regarding the latter, they felt that contact would  
7 enable them to understand the challenges participants experience so that they were in a better  
8 position to speak on their behalf. In any case, it was impossible to prevent some degree of contact  
9 between CAB members and study participants because they were familiar to each other through the  
10 CAB members' membership of other Community Based Organisations. Moreover, in the HIV study,  
11 when it became clear that they were not going to meet their recruitment targets in time, researchers  
12 authorised direct contact with potential participants by asking the CAB to conduct sensitization  
13 activities among patients at the Anti-retroviral Therapy (ART) and Tuberculosis (TB) departments,  
14 some of whom they later met at the study recruitment offices.

15

#### 16 *Interacting with Researchers*

17

18 The main channels through which the researchers and CABs interacted were the following: scheduled  
19 CAB meetings, ad hoc meetings (e.g. to review study material), training sessions, conferences outside  
20 the country and joint community sensitisation meetings. CAB meetings were the foremost channel for  
21 communicating issues raised by the community to researchers. The meetings in the TB study were  
22 infrequent and were stopped following suspension of the research. The HIV study CAB, however, held  
23 regular monthly meetings. Researchers were invited to provide study updates relating to the  
24 recruitment and retention of study participants, allowing the CAB to monitor the study's performance.  
25 Even though the HIV study provided regular updates relating to recruitment and retention, CAB  
26 members and the general community did not have access to critical study progress reports such as  
27 the Data Safety Monitoring Board (DSMB) reports.

28

29 CAB members felt that protocol development and review ought to be one of their most important  
30 responsibilities. However, the TB study CAB participated in neither because it was created once the  
31 study was already underway, while the HIV study CAB's involvement was limited to responding to a  
32 set of predetermined questions. However, both CABs were involved in reviewing Information  
33 Education Communications materials. The HIV study CAB also reviewed the Audio Computer Assisted  
34 Interview and suggested shortening the programme as well as including captions in local language.

1 CAB members also identified scientific language in study documents that would be a barrier to  
2 communication and meaningful CAB involvement.

3

#### 4 Power dynamics

5

6 Power can manifest in different forms. In this article, 'power over' and 'structural power' are used to  
7 contextualise the power imbalances and therefore the accountability relationships which existed  
8 between the community, the CABs and the researchers. 'Power over' refers to decision making models  
9 which are characterised by control- of one actor over the other (Berger, 2005). Structural power refers  
10 to institutional practices which may facilitate or hinder the action of different actors. In general,  
11 possession of knowledge about research and health by CAB members was seen as a source of power  
12 over community members as one TB study CAB member indicated: 'the difference is there, because  
13 those who are in the community have no knowledge compared to me who comes to the clinic (health  
14 facility) and learns from the researchers. So knowledge is the difference', (female, CAB member, TB  
15 study).

16

17 In fact, in reference to the influence CAB members had over the community, a key informant (opinion  
18 leader) equated the CAB's influence to that of a village headman: 'they have strong powers; they are  
19 like village headmen' (male, KII, TB study). However, most residents did not know most CAB members  
20 as CAB members but as volunteers in different capacities. When community members understood  
21 which residents were CAB members and which other volunteer roles they had in the community, they  
22 viewed them as influential. The existence of the studies therefore offered CAB members new  
23 opportunities for attaining power and social status that are comparable to traditional forms of  
24 authority.

25

26 Additionally, proximity to researchers and health facilities was seen by CAB members as giving them  
27 an advantage over other community members. Being volunteers and being found within the health  
28 facility meant that CAB members were always in the communication loop regarding forthcoming  
29 projects, studies and other opportunities. They were not shy to enquire from researchers for such  
30 opportunities. Some of them even asked for work. Therefore, some CAB members used the CAB as a  
31 conduit for other opportunities. As one CAB member indicated, even though the initial motivation for  
32 joining the CAB might be altruism, some CAB members soon began to ask for incentives, partly driven  
33 by the demands put upon them as members.

34

1 CAB members also said 'they had potential power over researchers and they could wield it if prompted  
2 to'. According to them, an important source of their power was being resident in the area and their  
3 membership of social networks within the communities. They claimed they could use this power to  
4 influence community opinion about research if they were unsure about the benefit of the study to the  
5 community and were concerned about the safety of participants: 'If the worse comes to the worst,  
6 we can influence people not to participate in that research because we have all the information, but  
7 we do not do that because it is for the good of society' (Female, CAB member, HIV study). Researchers,  
8 aware of these close-knit social networks believed that a rumour started by a discontented CAB  
9 member could damage the image and reputation of a study.

10

11 For several reasons the power of researchers over the CABs was often manifested in the latter's  
12 inability to challenge decisions and actions made by the researchers. Firstly, a lack of ownership and  
13 control of financial resources meant that the CABs had little backing to challenge some decisions made  
14 by researchers. The two CABs were nested within their respective studies and received organisational  
15 and logistical support from them, making the CABs dependent on the studies, with no alternative  
16 sources of funding. Consequently, they were cautious of making decisions that researchers might  
17 dislike. One community member, reflecting upon the material inequalities, said that: 'in a partnership,  
18 the one with more resources has an advantage over the one without' (male, key informant, TB study).

19

20 The second reason why the CAB members were often unable to challenge researchers was the  
21 asymmetry in knowledge and technical expertise. As already mentioned, CAB members were seen to  
22 be more knowledgeable than the residents. However, CAB members themselves said that their  
23 knowledge did not compare to that of the researchers. Although no CAB member cited actual  
24 situations in which they failed to challenge decisions made by researchers due to power disparities,  
25 perceptions such as: 'someone who has more knowledge than you have can cheat you without you  
26 even knowing' (female, CAB member HIV study) attest to the influence of the power disparities  
27 between the two. Some community members even suggested researchers might exploit research  
28 participants: 'you (researchers) who have money want those people who do not have money (the  
29 community) to participate in the research so that you get the information that you want' (male, key  
30 informant, TB study).

31

32 Researchers also wielded structural power. Power asymmetry was written into the CAB guidelines  
33 (although only the HIV study CAB had such guidelines). The guidelines stipulated the roles and  
34 responsibilities for the CAB and its members. Yet, the guidelines were almost exclusively targeted at

1 the organisational arrangement of the CAB and the conduct of its members for the purpose of  
2 sensitizing and communicating study related information. Nothing about the conduct of researchers  
3 or how the CAB could deal with misconduct by researchers was mentioned in the document. These  
4 guidelines reflected the concern that CAB members would use their considerable influence (discussed  
5 above) to disrupt research and jeopardise a systematic approach to data collection. For instance, in  
6 addition to the guidelines, HIV CAB members were made to sign a confidentiality note which asked  
7 them to make a strong commitment to research. There was no corresponding document for the  
8 researchers to sign that could enable them to be held accountable beyond the protocol and the ethical  
9 review process. In one CAB meeting, HIV CAB members accused researchers of only '*recognising*' them  
10 (in the more general sense of engaging with them) only when they needed help. Perhaps the most  
11 flagrant disrespect encountered was when researchers failed to forewarn the TB study CAB members  
12 about the suspension of the study.

13

14 These considerations played out in the day-to-day conduct of CAB-related activities. At all times, the  
15 researchers held the 'power of approval'. They determined the type of activities CAB members  
16 conducted in the community by reviewing work plans and monitoring field activities. Researchers also  
17 had significant control over the information that was relayed in the community. One CAB member for  
18 the HIV study believed that researchers sometimes lacked confidence and trust in the CAB. He viewed  
19 the researchers' insistence on reviewing and approving messages CAB members were to disseminate  
20 in the community as an attempt to hold back information that researchers thought would be confusing  
21 and compromise recruitment efforts. This CAB member's view was supported by the fact that the HIV  
22 study coordinator said that the study was cautious with information shared in open and stakeholder  
23 meetings, especially if a possible misunderstanding was perceived.

24

## 25 **Discussion**

26 This paper has explored the relationship between researchers, CAB members, and communities in the  
27 context of two research projects, focusing in particular on the role played by CABs. Three layers of  
28 accountability relationships were identified, namely the relationship between CABs and the  
29 community, between CABs and researchers and between the researchers and the community.

30

31 The CAB and community accountability relationship

32

33 A weak accountability relationship existed between the CAB and community mainly because residents  
34 did not directly participate in the selection of CAB members. In fact, researchers' influence on the

1 selection process resulted in the exclusion of some interest groups such as young people. Residents  
2 accused researchers of bias and favouritism. Whilst other studies in sub Saharan Africa suggest that it  
3 is a common practice for researchers to select CAB members (e.g. Marsh, Kamuya, Rowa, Gikonyo, &  
4 Molyneux, 2008), non-direct involvement of residents in the election of their representatives erodes  
5 the basis for the representatives' authority and legitimacy (Reddy, Buchanan, Sifunda, James, &  
6 Naidoo, 2010). This study suggests that a major challenge arising from the use of CABs was how  
7 residents could claim accountability from representatives whose existence they knew little about and  
8 in whose election they did not directly participate. Indeed, democratic elections are an important  
9 means by which people delegate their powers to representatives (Harrington, 2012, Reddy et al.,  
10 2010), thereby legitimizing the authority of the elected (Judge, 1999). Lack of elections (and thus  
11 legitimacy) limited the CABs accountability to the community. With CAB members selected as they  
12 were however, the CABs were far more visible to researchers as the 'accessible face of community'  
13 (Gaventa, 2004) than to the residents who they were supposedly representing. This contrasted with  
14 CAB members who perceived their main role as the bridge between researchers and the community  
15 (including study participants), linking both ends of the relationship and thus ensuring a symmetrical  
16 accountability relationship between the two.

17

18 Moreover, researchers expressly denied CAB members permission to directly contact research  
19 participants (initially, at least) and to take an active part in other study activities. Such demands by  
20 community representatives to have an active role in the conduct of research were not unique to this  
21 study. Kamuya et.al. (2013) reported that community representatives often wanted to take on 'a  
22 more proactive role including holding community outreach activities, accompanying field workers to  
23 participants' homes and being informed of all studies and participants in each area' (Kamuya, Marsh,  
24 Kombe, Geissler, & Molyneux, 2013). These observations shed light upon a dissonance between the  
25 intrinsic goals of community engagement as an empowering and participatory process and the reality  
26 in which community engagement often serves instrumental purposes (Simwinga et. al., 2016).

27

28 The CAB and researchers' accountability relationship

29

30 The CAB and researchers interacted in several forums including CAB meetings, training, and  
31 community sensitization meetings. However, this interaction and relationship was imbalanced in  
32 favour of researchers who were more knowledgeable, more skilful and better resourced. This allowed  
33 the researchers to define the relationship with the CAB at the expense of the latter. For instance, they  
34 justified the decision to deny CAB members access to study participants using the ethical argument

1 for privacy and confidentiality even though this presented the best opportunity to CAB members to  
2 be more answerable to the community. They also ensured that the CAB guidelines required the CAB  
3 members to be more accountable to research, without a corresponding requirement for researchers  
4 towards the CAB and the community.

5

6 However, opportunities for researchers to improve their accountability to the CAB and the community  
7 existed. Firstly, researchers acknowledged the instrumental role the CABs played in implementing  
8 ethical and high quality research by supporting the recruitment and retention processes of the study.  
9 Secondly, they also acknowledged the CABs influence on both the community and researchers. The  
10 CABs Influence on researchers arose from their knowledge of community dynamics, their membership  
11 of close-knit social networks and their social status. As Stoecker (2013) has observed, the power of  
12 community members manifests not only in their knowledge of the community but also in numbers  
13 and relationships. Instead of embracing these positive CAB attributes, researchers were wary of the  
14 possible detrimental effects on the studies if CAB members became discontented and used the same  
15 attributes against research. For example, withdrawing their support for studies or starting rumours  
16 about the studies. In reality, the CABs' ability to carry through any threat was undermined by their  
17 dependence on researchers for financial and institutional support. Researchers need to more explicitly  
18 acknowledge the instrumental role that CABs play in research to cultivate mutual respect and trust.  
19 This could improve not only the accountability relationship between them but also increase the  
20 likelihood that CABs will perform more intrinsic roles in future research conducted by the research  
21 institutions implementing the two studies (Tindana et al., 2015).

22

23 Reflecting on implications on the researcher and community accountability relationship

24

25 The community was not consulted during protocol development for both the TB study and the HIV  
26 study. This limited community involvement at the protocol development stage affected the ensuing  
27 researcher-community accountability relationship in three main ways. Firstly, researchers were able  
28 to retain their traditional powers over the community which usually come with ethical and regulatory  
29 approval of the protocol: the power to decide which communities to work in, which population groups  
30 to intervene in, and what recruitment and retention strategies to use without meaningful consultation  
31 of community based stakeholders. Secondly, and relatedly, the lack of and/or limited formative  
32 research in the studies missed an opportunity to build a stronger voice for the community. Such  
33 consultation would have helped researchers build strong community representation by identifying key  
34 community stakeholders eligible for election on the CABs (Simwinga & Kabero, 2014). Thirdly, ongoing

1 updates about study progress were not sufficient and hindered a successful and transparent  
2 relationship between researchers and the community. While it was not expected of researchers to  
3 hold regular community meetings to provide ongoing feedback, a higher degree of transparency in  
4 CAB meetings could have been achieved, and more information beyond recruitment and retention  
5 data could have been provided. Sharing information from sources such as the Data Safety and  
6 Monitoring Board (DSMB) reports could have been important in this regard. This could have had the  
7 additional benefit of preparing CAB members for possible participation in the interpretation and  
8 dissemination of final study results (see also Mott et al., 2008).

9

## 10 **Conclusion**

11 The two CABs in the research studies had a less well-defined relationship with community members  
12 and research participants than they had with researchers. This was mainly because they were not  
13 directly elected by residents and researchers prevented them from interacting with research  
14 participants. This eroded the basis for their legitimacy and their claim on research accountability. In  
15 spite of this, CABs had subtle powers over community members and researchers. They were highly  
16 regarded in the community because of their knowledge of research and health-related issues and  
17 because of their close association with researchers. Researchers too had a high regard for the CABs  
18 because of their influence in the community. Lack of inclusion and inadequate scientific knowledge  
19 and financial power still, however, made the CABs intractably weak. The CABs remained reliant on  
20 researchers for organisational, financial and logistical support. In essence, they were appendages to  
21 research studies to which they increasingly became more accountable while at the same time  
22 becoming less accountable to those they were supposed to represent. The 'interface' role that the  
23 two CABs occupied between researchers and communities was therefore considerably more  
24 unidirectional (with the CAB being accountable more to researchers than to communities) than its  
25 portrayal in bioethical literature. Such an unequal power dynamic in favour of researchers is far from  
26 ideal for research, especially while trying to promote the ideals of engagement, transparency, respect,  
27 trust and accountability.

28

## 29 **Acknowledgements**

30 We thank all CAB members for the TB and HIV studies for their participation in the study and  
31 Constance Mackworth-Young for useful comments and insights she provided.

32

## 33 **Disclosure statement**

34 No potential conflict of interest was reported by the authors.

1 Funding

2 This work was supported by the Commonwealth Scholarship Commission (CSC).

3

4



1 **References**

- 2 Becker, A. B., Israel, B. A., Gustat, J., Reyes, A. G., & Allen III, A. J. (2013). Strategies and Techniques  
3 for Effective Group Process in CBPR Partnerships. In ISRAEL, B. A., ENG, E., SCHULZ, A. J. & PARKER,  
4 E. A. (eds.) *Methods for Community-Based Participatory Research for Health*. Second ed. San  
5 Francisco: Jossey-Bass.
- 6 Berger, B.K.(2005). Power Over, Power With, and Power to Relations: Critical Reflections on Public  
7 Relations, the Dominant Coalition, and Activism. *Journal of Public Relations Research*, 17(1):5-28.
- 8 Brinkerhoff, D. W. (2004). Accountability and health systems: toward conceptual clarity and policy  
9 relevance. *HEALTH POLICY AND PLANNING*, 19, 371–379.
- 10 Cox, L. E., Rouff, J. R., Svendsen, K. H., Markowitz, M., & Abrams, D. I. (1998). Community advisory  
11 boards: their role in AIDS clinical trials. *Health & social work*, 23, 290-297.
- 12 Dickert, N., & Sugarman, J. (2005). Ethical Goals of Community Consultation in Research. *Am J Public*  
13 *Health*, 95(7):1123-7.
- 14 Gaventa, J. (2004). Representation, Community Leadership and Participation: Citizen Involvement in  
15 Neighbourhood Renewal and Local Governance. Institute of Development Studies.
- 16 George, A. (2003). Using Accountability to Improve Reproductive Health Care. *Reproductive Health*  
17 *Matters*, 11, 161–170.
- 18 Green, J., & Thorogood, N. (2009). *Qualitative Methods for Health Research*. London: SAGE  
19 Publications.
- 20 Harrington, P. (2012). *Democracy and Elections*. Kenya: Paulines Publications Africa.
- 21 Israel, B. A., Schulz, A. J., Edith, P. A., & Becker, A. B. (1998). Review of Community-Based Research:  
22 assessing Partnership Approaches to Improve Public Health *Annu. Rev. Public Health.*, 19, 173–  
23 202.
- 24 Judge, D. (1999). *Representation Theory and practice in Britain*. London, New York: Routledge.
- 25 Kamuya, D. M., Marsh, V., Kombe, F. K., Geissler, P. W., & Molyneux, S. C. 2013. Engaging Communities  
26 to Strengthen Research Ethics in Low-Income Settings: Selection and Perceptions of Members of  
27 a Network of Representatives in Coastal Kenya. *Developing world bioethics*, 13, 10-20.
- 28 Liamputtong, P., & Ezzy, D. (2005). *Qualitative Research Methods*. Victoria: Oxford University Press.
- 29 MacQueen K., Bhan A., Frohlich J., Holzer J., & Sugarman J. (2015). Evaluating community engagement  
30 in global health research: the need for metrics. *BMC Medical Ethics*, 16(1):1-9.
- 31 Macqueen, K. M., Kerry., M., Alleman, P., McClain Burke, H., & Mack, N. (2006). Partnering for care in  
32 the HIV Prevention Trials Network. Carolina: Family Health International.

- 1 Marsh, V., Kamuya, D., Rowa, Y., Gikonyo, C., & Molyneux, S. 2008. Beginning community engagement  
2 at a busy biomedical research programme: experiences from the KEMRI CGMRC-Wellcome Trust  
3 Research Programme, Kilifi, Kenya. *Social Science & Medicine*, 67, 721-733.
- 4 Merriam, S. B. (2009). *Qualitative Research: A Guide to Design and Implementation*. San Francisco:  
5 John Wiley and Sons.
- 6 Minkler, M., Blackwell, A.G., Thompson, M., & Tamir, H. (2003). Community-Based Participatory  
7 Research: Implications for Public Health Funding. *American Journal of Public Health*, 93(8):1210-  
8 3.
- 9 Mott, L., Crawford, E., & Group. (2008). The Role of Community Advisory Boards in Project Eban.  
10 *Journal of acquired immune deficiency syndromes (1999)*, 49, S68.
- 11 Murray, N., & Beglar, D. (2009). *Writing Dissertations and Theses*. Harlow, England: Pearson Longman.
- 12 Newman, S. D., & Andrews, J. O., Magwood, G. S., Jenkins, C., & Faan (2011). Community Advisory  
13 Boards in Community-Based Participatory Research: A Synthesis of Best Processes. *Preventing  
14 Chronic Disease*.
- 15 Nguyen, V.-K., (2015). Treating to Prevent HIV: Population Trials and Experimental Societies. In W. P.  
16 Geissler, ed. *Para-States and Medical Science: Making African Global Health*. Durham: Duke  
17 University Press, pp. 47–77.
- 18 Petryna, A. (2009). *When experiments travel: clinical trials and the global search for human subjects*,  
19 Princeton University Press.
- 20 Pratt, B., Lwin, K. M., Zion, D., Nosten, F., Loff, B., & Cheah, P. Y. (2015). Exploitation and community  
21 engagement: Can Community Advisory Boards successfully assume a role minimising exploitation  
22 in international research? *Developing world bioethics*, 15, 18-26.
- 23 Quinn, S. C. (2004). Ethics in Public Health Research: Protecting Human Subjects: the Role of  
24 Community Advisory Boards. *Am J Public Health*, 94, 918-922.
- 25 Reddy, P., Buchanan, D., Sifunda, S., James, S., & Naidoo, N. (2010). The role of community advisory  
26 boards in health research: Divergent views in the South African experience. *SAHARA-J: Journal of  
27 Social Aspects of HIV/AIDS*, 7.
- 28 Richards, L. (2009). *Handling Qualitative Data*. London: SAGE Publications.
- 29 Rottenburg, R. (2009). Social and public experiments and new figurations of science and politics in  
30 postcolonial Africa 1. *Postcolonial Studies*, 12, 423-440.
- 31 Silverman, D. (2011). *Qualitative Research*. London: SAGE publications.
- 32 Simwinga, M., Bond, V., Makola, N., Hoddinott, G., Belemu, S., White, R.,...Moore, A. (2016).  
33 Implementing Community Engagement for Combination Prevention: Lessons Learnt From the

1 First Year of the HPTN 071 (PopART) Community-Randomized Study. *Current HIV/AIDS Reports*,  
2 13, 194-201.

3 Simwanga, M., & Kabero, C. (2014). Community Engagement. In M. Krugger, P. Ndebele & L. Horn  
4 (Eds.), *Research Ethics in Africa: A Resource for Research Ethics Committees* (pp. 143-151). South  
5 Africa: Sun Press.

6 Slevin, K. W., Ukpong, M., & Heise, L. (2008). Community engagement in HIV prevention trials:  
7 evolution of the field and opportunities for growth. *Research Gate. January*.

8 Stoecker, R. (2013). *Research Methods for Community Change: A Project-Based Approach*. Los  
9 Angeles: Sage.

10 Strauss, R. P., Sengupta, S., Quinn, S. C., Goepfing, J., Spaulding, C., Kegeles, S. M., & Millett, G.  
11 (2001). The role of community advisory boards: involving communities in the informed consent  
12 process. *American Journal of Public Health*, 91, 1938-1943.

13 Tindana, P., De Vries, J., Campbell, M., Littler, K., Seeley, J., Marshall, P.,...Parker, M. (2015).  
14 Community engagement strategies for genomic studies in Africa: a review of the literature. *BMC*  
15 *Medical Ethics*, 16, 24.

16 Tindana, P. O., Singh, J. A., Tracy, C. S., Upshur, R. E., Daar, A. S., Singer, P. A.,...Lavery, J. V. (2007).  
17 Grand challenges in global health: community engagement in research in developing countries.  
18 *PLoS Med*, 4, e273.

19 Wakefield, S. (2005). Community Advisory Boards. In: KAHN, P. (ed.) *AIDS Vaccine Handbook: Global*  
20 *Perspectives*. New York: AIDS Vaccine Advocacy Coalition.

21 Woolf, S.H., Zimmerman, E., Haley, A., & Krist, A.H (2016). Authentic Engagement Of Patients And  
22 Communities Can Transform Research, Practice, And Policy. *Health affairs (Project Hope)*,  
23 35(4):590-4.

24  
25  
26