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

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Abstract

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

Key words: Accountability, Community Engagement, Community Advisory Boards (CABs), Power, Representation
Introduction

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

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

The ability of CABs to represent community interests and to reduce exploitation depends to a large extent on the accountability mechanisms between researchers, CABs and the people they represent. Accountability can be understood as a ‘referee of the dynamics in two-way relationships’ (George,
often between entities, organisations or individuals who may not have equal power or influence. Accountability can also be understood in terms of answerability, meaning that (research) organisations are obliged to answer to partners, provide them with information and justify their actions (Brinkerhoff, 2004). A small number of studies have suggested that, in practice, CABs often have very limited powers and ability to demand and enforce accountability. CABs have been described as ‘paper councils’ or ‘window dressers’ (Cox, Rouff, Svendsen, Markowitz, & Abrams 1998; Strauss et al., 2001), lacking the power to influence the research agenda and to reduce the potential for exploitation (Slevin, Ukpong, & Heise; Pratt et al., 2013). CABs can in this regard be viewed as appendages to research with the specific interest of enrolling the world’s most poor and vulnerable into clinical trials (Petryna, 2009; Rottenburg, 2009; Nguyen, 2015). Yet, we still have very few sustained accounts of how CABs perceive their roles, how they balance their allegiances between researchers and community members and how they strive to demand and enforce accountability.

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

Study Setting and Methods

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

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

The case study approach (Green & Thorogood, 2009) helps to illuminate cases in great depth and detail (Murray & Beglar, 2009) by using different data collection methods. Accordingly, a mix of methods was used to triangulate the findings from the CABs in the two studies. In-depth interviews (n=25) with CAB members and researchers were conducted, and, to assess individuals’ experiences, key informant interviews (n= nine) were done with purposely selected residents who had knowledge of the community (opinion leaders) (Richards, 2009). Secondly, focus group discussions (n= nine) with members of the community were used to understand collective narratives. For a year and half, observations of research activities (n=33) were conducted to enable a deeper understanding of behaviour and interactions (Silverman, 2011). Finally, participatory research appraisal techniques were employed to gather background information for both communities. These included asking residents (n=eight) who had knowledge of and who had lived in the community for at least 10 years, to draw social maps and to construct historical timelines of the two communities. Selection of information rich residents for in-depth interviews and participatory appraisal research activities was carried out with the help of a local Community Based Organisation, and the Neighbourhood Health Committee which works with health facility management to identify and mitigate health challenges in communities. A Neighbourhood Health Committee was present in both communities. In addition, document analysis (n=35) was conducted to gain insight into unobservable interactions. This included documents of: CAB meeting minutes, community meetings and sensitization reports, CAB guidelines or constitution, correspondence between researchers and the CABs, study instruments and any form of records that were kept by the studies and CABs on CAB activities. All focus group discussions, participatory research appraisal and document analysis were conducted by the first author with some observations and interviews carried out by the research assistant. Interview guides and observation checklists were developed and piloted.
All interviews were recorded, while observations and data from participatory research appraisal activities were written up as field notes using a guide which divided the observations into two broad categories; field activities and meetings and or forums in which researchers interacted with the CABs and the community. Interviews conducted in the local language (Nyanja and Bemba) were first transcribed and then translated into English and were then imported into NVivo. A code book (thematic framework) was developed by the first author, with assistance from the supervisors and research assistant, consisting of both preconceived themes from the study’s conceptual framework and themes which emerged from the field data. This was followed by coding of the data by the first author. Data were then charted into different matrices and tables bearing themes or variables for interpretation of the data across participants, themes and communities.

Findings

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

CAB Formation, Composition and Selection of members

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

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

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

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

Another criterion for researchers’ selection of CAB members was people’s knowledge of health-related issues. Understandably, the researchers considered knowledge of HIV and TB to be important
given the nature of the respective studies. Some CAB members themselves said that members must
wield influence in the community for people to listen and respect them, and one factor contributing
to their influence was their health-related knowledge. However, concerns were raised by residents
about the bias and favouritism in the selection of CAB members, with some people alleging that
volunteers in good standing with health facility management and Neighbourhood Health Committees
were often picked.

The nature of CAB-community-researcher interactions

Interactions with community members

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

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

Despite CAB involvement in sensitization (information giving and education) activities, findings from
interviews with key informants showed that there was low awareness among residents of the
existence of CABs. However, some people knew the CAB members from their other pre-existing roles
in the community. This low awareness was in part because CAB members and their representative
role was never explained during research specific community sensitization meetings.
Both CABs said that the researchers told them not to directly contact study participants. The main reason was not to compromise participants’ privacy and confidentiality. A further reason was that this could constitute a conflict of interest and expose the CAB members to risk of violence in the event of a backlash against the studies. The CAB members expressed reservations about this guiding rule that were both pragmatic and ethical. Regarding the former, they felt that the ability to visit study participants would improve retention substantially. Regarding the latter, they felt that contact would enable them to understand the challenges participants experience so that they were in a better position to speak on their behalf. In any case, it was impossible to prevent some degree of contact between CAB members and study participants because they were familiar to each other through the CAB members’ membership of other Community Based Organisations. Moreover, in the HIV study, when it became clear that they were not going to meet their recruitment targets in time, researchers authorised direct contact with potential participants by asking the CAB to conduct sensitization activities among patients at the Anti-retroviral Therapy (ART) and Tuberculosis (TB) departments, some of whom they later met at the study recruitment offices.

Interacting with Researchers

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

CAB members felt that protocol development and review ought to be one of their most important responsibilities. However, the TB study CAB participated in neither because it was created once the study was already underway, while the HIV study CAB’s involvement was limited to responding to a set of predetermined questions. However, both CABS were involved in reviewing Information Education Communications materials. The HIV study CAB also reviewed the Audio Computer Assisted Interview and suggested shortening the programme as well as including captions in local language.
CAB members also identified scientific language in study documents that would be a barrier to communication and meaningful CAB involvement.

Power dynamics

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

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

Additionally, proximity to researchers and health facilities was seen by CAB members as giving them an advantage over other community members. Being volunteers and being found within the health facility meant that CAB members were always in the communication loop regarding forthcoming projects, studies and other opportunities. They were not shy to enquire from researchers for such opportunities. Some of them even asked for work. Therefore, some CAB members used the CAB as a conduit for other opportunities. As one CAB member indicated, even though the initial motivation for joining the CAB might be altruism, some CAB members soon began to ask for incentives, partly driven by the demands put upon them as members.
CAB members also said ‘they had potential power over researchers and they could wield it if prompted to’. According to them, an important source of their power was being resident in the area and their membership of social networks within the communities. They claimed they could use this power to influence community opinion about research if they were unsure about the benefit of the study to the community and were concerned about the safety of participants: ‘If the worse comes to the worst, we can influence people not to participate in that research because we have all the information, but we do not do that because it is for the good of society’ (Female, CAB member, HIV study). Researchers, aware of these close-knit social networks believed that a rumour started by a discontented CAB member could damage the image and reputation of a study.

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

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

Researchers also wielded structural power. Power asymmetry was written into the CAB guidelines (although only the HIV study CAB had such guidelines). The guidelines stipulated the roles and responsibilities for the CAB and its members. Yet, the guidelines were almost exclusively targeted at
the organisational arrangement of the CAB and the conduct of its members for the purpose of sensitizing and communicating study related information. Nothing about the conduct of researchers or how the CAB could deal with misconduct by researchers was mentioned in the document. These guidelines reflected the concern that CAB members would use their considerable influence (discussed above) to disrupt research and jeopardise a systematic approach to data collection. For instance, in addition to the guidelines, HIV CAB members were made to sign a confidentiality note which asked them to make a strong commitment to research. There was no corresponding document for the researchers to sign that could enable them to be held accountable beyond the protocol and the ethical review process. In one CAB meeting, HIV CAB members accused researchers of only ‘recognising’ them (in the more general sense of engaging with them) only when they needed help. Perhaps the most flagrant disrespect encountered was when researchers failed to forewarn the TB study CAB members about the suspension of the study.

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

Discussion

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

The CAB and community accountability relationship

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

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

The CAB and researchers’ accountability relationship

The CAB and researchers interacted in several forums including CAB meetings, training, and community sensitization meetings. However, this interaction and relationship was imbalanced in favour of researchers who were more knowledgeable, more skilful and better resourced. This allowed the researchers to define the relationship with the CAB at the expense of the latter. For instance, they justified the decision to deny CAB members access to study participants using the ethical argument
for privacy and confidentiality even though this presented the best opportunity to CAB members to be more answerable to the community. They also ensured that the CAB guidelines required the CAB members to be more accountable to research, without a corresponding requirement for researchers towards the CAB and the community.

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

Reflecting on implications on the researcher and community accountability relationship

The community was not consulted during protocol development for both the TB study and the HIV study. This limited community involvement at the protocol development stage affected the ensuing researcher-community accountability relationship in three main ways. Firstly, researchers were able to retain their traditional powers over the community which usually come with ethical and regulatory approval of the protocol: the power to decide which communities to work in, which population groups to intervene in, and what recruitment and retention strategies to use without meaningful consultation of community based stakeholders. Secondly, and relatedly, the lack of and/or limited formative research in the studies missed an opportunity to build a stronger voice for the community. Such consultation would have helped researchers build strong community representation by identifying key community stakeholders eligible for election on the CABs (Simwinga & Kabero, 2014). Thirdly, ongoing
updates about study progress were not sufficient and hindered a successful and transparent relationship between researchers and the community. While it was not expected of researchers to hold regular community meetings to provide ongoing feedback, a higher degree of transparency in CAB meetings could have been achieved, and more information beyond recruitment and retention data could have been provided. Sharing information from sources such as the Data Safety and Monitoring Board (DSMB) reports could have been important in this regard. This could have had the additional benefit of preparing CAB members for possible participation in the interpretation and dissemination of final study results (see also Mott et al., 2008).

Conclusion

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

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