

The Challenge of Community Representation: Lessons From Six HIV Clinical Research Community Advisory Boards in Uganda

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Abstract

Although community advisory boards (CABs) are widely used in clinical research, there is limited data regarding their composition and structure, especially in Africa. Our research provides the first qualitative study of the membership practices, selection methods, and qualifications of the six major HIV research centers that comprise the Ugandan National CAB Network (UNCN). Researchers conducted interviews ($n = 45$) with CAB members and research liaisons at each of the sites. While selection practices and demographics varied between the sites, all six CABs exclusively followed a broad community membership model. Results suggest successful CABs are context dependent and thus distinct guidelines may be needed based on variables including CAB funding level, representation model, and research focus.

Keywords

community advisory boards, CABs, Uganda, Africa, research ethics, HIV/AIDS, clinical trials, broad community versus population-specific membership model

Introduction

Community advisory boards (CABs) are standard in many types of clinical research both in the United States and abroad. Despite this, empirical research on HIV-related CABs is limited, leading to a recent call from Delaney et al. in 2012 for further empirical inquiry into the topic. The influence of location, resource availability, and research topic on CAB function and composition is not well understood. The literature gap is especially evident in Africa, despite the fact that over 70% of the world's HIV cases and 14% of HIV clinical trials occur on the continent (The Joint United Nations Programme on HIV and AIDS [UNAIDS], 2011; U.S. National Institutes of Health, 2015b). A 2015 literature review of community engagement strategies in biomedical research in Africa found only eight articles that focused on CABs, thereby highlighting the need for a deeper look at the continent's HIV clinical research ethics groups (Tindana et al., 2015).

This study provides the first published overview of membership practices, selection criteria, qualifications, and challenges of CABs at six Ugandan HIV clinical research institutions. HIV research began in Uganda as early as 1987 and in 1998 the Joint Clinical Research Centre (JCRC) initiated the country's first CAB ("Biomedical HIV/AIDS Prevention," 2009; Uganda Virus Research Institute, 2014). According to the U.S. National Institutes of Health, 19% of

all African HIV-related clinical trials occur in Uganda (U.S. National Institutes of Health, 2015b). Thus, the nation is an exemplary location for a study of resource-limited HIV CABs.

Previously published CAB studies describe two major models for community representation: (a) population specific and (b) broad community (Delaney et al., 2012; Morin, Maiorana, Koester, Sheon, & Richards, 2003). Population-specific CABs focus on the subsection of the community directly affected by the proposed study topic (Campbell et al., 2015; Silvestre, Quinn, & Rinaldo, 2010). Each study protocol determines CAB composition and then ensures that all members belong to the subpopulation of interest. In contrast, broad community CABs select for a cross-section of the community and often include religious, political, and media leaders. These board members then facilitate outreach to various subpopulations of interest. The two models for representation each have their own strengths and weaknesses and the differences cannot be ignored during CAB analyses. For instance, while the broad community model

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Table 1. Roles of Community Advisory Boards.

Serving researchers	Serving community
Inform research priorities based on local needs	Dispel myths and raise awareness of HIV vaccine research
Advise on community norms and expectations	Convey information about research opportunities
Assist with disseminating results	Voice community concerns to researchers
Review informed consent and protocols	Gather ideas for future beneficial research projects
Facilitate recruitment	Help ensure ethical treatment of community and research participants

may be used to monitor multiple studies and thus is cheaper, its members are not required to have firsthand experience with each study topic (Silvestre et al., 2010). Population-specific CABs garner firsthand opinions from members themselves but tend to be more expensive to create and maintain (Campbell et al., 2015).

Our research provides the first qualitative study of the membership practices, selection methods, and qualifications of the six major HIV research centers in Uganda. Limited resources and logistical barriers necessitated the use of the broad community model at all six Ugandan research institutions. Our findings highlight how these broad CABs could more effectively provide voice to the community and ensure ethical research. The objectives and demographics of CABs often vary based largely on the research they oversee. For instance, CAB membership depends on whether the HIV research is focused on prevention, detection, treatment, or some combination of the three. Thus, we argue that distinct guidelines may be needed for CABs based on funding level, representation model, and research focus to appropriately account for their often-distinct roles in the research process. This study uses lessons from Uganda to inform how other institutions may determine appropriate and localized guidelines.

Brief History of CABs

As early as 1971, "CAB" describes an emerging type of research committee, defined as a group of community members tasked with ensuring the ethical rights of research participants (Brieland, 1971). The publication of the Belmont Report in the Federal Register in 1979 solidified ethical practice as a central tenet in all U.S.-based research studies (U.S. Department of Health, Education and Welfare, 1979). This led to an increase of CABs, specifically within educational and psychological research (Ahmed & Harm, 1979; Cox, Rouff, Svendsen, Markowitz, & Abrams, 1998; Rabiner, 1972). The unprecedented activism of the HIV community in the mid-1980s brought with it a new wave of community participation in biomedical research that demanded both an active and central role for the community in the research process (Harrington, 2009). Community protests brought about the formation of the first National Institutes of Health (NIH)-mandated CAB in 1989 and the

establishment of the Community Constituency Group at the National Institute of Allergy and Infectious Disease in 1990 (Cox et al., 1998; Morin et al., 2003). In 1993, the HIV Network for Prevention Trials (HIVNET) introduced CABs at their international research centers (Strauss et al., 2001).

The global expansion of HIV research in the late 1990s and 2000s standardized CAB use in ethical clinical research worldwide (Menezes, Hannah, & Yassky, 2012). In the past decade, CABs have become commonplace in many research institutions both in the United States and abroad. However, despite their widespread use, many questions still exist surrounding their role in clinical research (Bonner et al., 2001; Reddy, Buchanan, Sifunda, James, & Naidoo, 2010; Silvestre et al., 2010). The first major HIV-related CAB study, published by Cox et al. in 1998, interviewed 267 CAB members affiliated with the National Institute of Allergy and Infectious Disease. The study explored the history, formal mission statement, and demographics of the organizations and concluded that CABs are valuable elements of the HIV research process. Past studies make little distinction between CABs in high-income versus low-income countries, despite significant differences in both capacity and membership (Ahn, Grimwood, Schwarzwald, & Herman, 2003; Lo & Bayer, 2003). No standardized CAB selection or formation methodology exists for establishing CABs, and past studies show wide variation in such processes (Manda-Taylor, 2014; Ntshanga, Ngcobo, & Mabaso, 2010; Shubis, Juma, Sharifu, Burgess, & Abdulla, 2009). In addition, the practical impact of CABs, especially in resource-limited settings, is not well understood (Lwin et al., 2014; Simon, Newbury, & Heureux, 2011). Previous studies outline a number of potential roles for CABs, summarized in Table 1, though little is known regarding the relative weight of each role. The table is based on previous studies of CAB roles and separated into those that primarily serve researchers versus those that primarily serve the community, another recurring dichotomy within CAB scholarship (Cox et al., 1998; Menezes et al., 2012; Quinn, 2004; Pratt, 2015; Strauss, 2001). Table 1 provides a frame of reference for understanding the fundamental purpose of a CAB, that is, to bridge the gap between the community and researchers. When analyzing CABs, we must consider how characteristics such as membership practices, selection methods, and qualifications may shift CAB priority between these various roles.

Not enough is known regarding which of the above roles take precedence across different research settings. This study aims to address these points, primarily by analyzing how the broad community model used across the six resource-limited Ugandan CABs affected various CAB functions. Table 1 was also used to inform our interview questions and guide our analysis in regard to the Ugandan CAB roles.

Determining Community Representation

A review by Morin et al. (2003) of six domestic and international CABs identified two models for board membership: broad community and population specific. The former describes a CAB composed of a range of leaders such as politicians, educators, religious leaders, and members of the potential study population (e.g., HIV-positive representatives for HIV clinical trials). The broad community model is employed as generally representative of the community and members remain for terms that often span for years. The population-specific model employs a particular demographic of people, such as solely HIV-positive members, to target this certain group within the larger community. Every member on this board has personal experience with the study illness or demographic, in contrast to the broad community boards. Quinn (2004) writes that the literature tends to explore population-specific CABs, which also are typically found in more resource-rich locations. The deficit of empirical studies in resource-limited settings is problematic as it may lead to a falsely homogenous understanding of CAB priorities.

When creating a broad community CAB, research institutions attempt to select board members who, as an aggregate, will accurately represent a cross-section of the wider population. However, methods for selecting community representatives are neither straightforward nor universal. For example, MacQueen et al. (2001) write that every community contains five common elements: locus, sharing, joint action, social ties, and diversity. MacQueen's model provides a framework for better understanding group and individual interactions, a key feature when considering CAB effectiveness. The challenge in representing these communities lies in selecting members who accurately account for these five characteristics. MacQueen warns that there is no one method for determining community representation but that selection should be local and specific.

Specific research sites may rely on a number of academic, institutional, and governmental approaches in their CAB formation process. For instance, the International AIDS Vaccine Initiative, one of the Ugandan research institutions in this study, states that organizations should take the following five criteria into account when selecting members: representation, cultural insight, technical expertise, access to constituencies, and leadership in local setting

(Menezes et al., 2012). These criteria overlap but are not identical to MacQueen's five core elements of community. The Uganda National Council for Science and Technology's (2007) guidelines for clinical research state that CAB membership may include but is not limited to (a) religious leaders, (b) peer leaders, (c) representatives of the study population, (d) media, (e) professionals who understand research and/or science issues, (f) community leaders, and (g) those with understanding of local culture and laws. Thus, within Uganda, there are no universally accepted guidelines for accurate community representation. Research institutions instead rely on a patchwork of guidelines that fit their needs. When expanded worldwide, it becomes clear that community representation techniques are inconsistent across research settings (Cargo et al., 2008; Conway, Hu, & Harrington, 1997; Koné et al., 2000; Slevin, Ukpong, & Heise, 2008).

The selection process for CAB members is also wide ranging, with no one method appearing consistently across the literature. Newman et al. (2011) writes that CABs in resource-rich settings often take a detailed iterative approach for selecting their CAB members, requiring input from all members of the research team. Though no systematic review of the CAB selection process in low-resourced settings could be found, our results point to a much more scattered selection process that varies not only between institutions but also often within the organizations themselves.

HIV-related CABs oversee studies on the prevention, detection, or treatment of HIV (U.S. National Institutes of Health, 2015a). Little is known regarding how HIV study type influences CAB function. Prevention trials often involve a wide and diverse spectrum of participants and thus necessitate a more diverse CAB (Slevin et al., 2008). All community members are potential study participants for prevention trials, as opposed to treatment trials in which participants must be HIV positive. Research institutions often conduct a combination of prevention, detection, and treatment trials. For instance, research at the six Ugandan HIV research sites often fell somewhere between treatment and prevention, depending on the specific study protocol. However, due to resource and logistical limitations, each Ugandan institution used one CAB irrespective of trial type. The implications of broad community CAB use across all trial types must be further explored.

Methods

Our study sought to better understand the CABs of Uganda's six major research institutions. Between 2011 and 2013, researchers interviewed 45 CAB informants from the six major HIV clinical research centers in Uganda: Makerere University Walter Reed Project (MUWRP), Makerere University–Johns Hopkins University Research Collaboration (MUJHU), Rakai Health Sciences Program

Table 2. Summary of Key Characteristics of Six Ugandan Community Advisory Boards.

Research institution	Year of inception	Number of members	Term limits
JCRC	1998	15	No limit, reelect leadership every 2 years
MRC–Masaka	2005	12-20	2 year terms, maximum 4 years
Rakai	2000	14	4 year terms, maximum 8 years total
UVRI-IAVI	2002	12	5 years terms, maximum 10 years total
MUJHU	1998	12	2 year terms, maximum 4 years
MUWRP	2011	8-9	3 year terms, unknown if maximum
Uganda Cross CAB Network	2005	72-82	N/A

Note. JCRC = Joint Clinical Research Center; MRC = Medical Research Council; UVRI-IAVI = Uganda Virus Research Institute-International AIDS Vaccine Initiative; MUJHU = Makerere University–Johns Hopkins University Research Collaboration; MUWRP = Makerere University Walter Reed Project; CABs = community advisory boards.

(RHSP), Uganda Virus Research Institute-International AIDS Vaccine Initiative (UVRI-IAVI), Medical Research Council/Uganda Virus Research Institute of Masaka (MRC/UVRI-Masaka), and the JCRC. Together these organizations make up the Uganda National CAB Network (UNCN), a network established in 2005 to facilitate information exchange and increase CAB effectiveness within the country's leading research institutions. The questions explored the history, demographics, selection methods, roles, and challenges of each CAB. Interviews and focus group discussions lasted approximately 1 to 2 hr and were recorded with digital voice recorders and later transcribed. The data were entered into the qualitative research software NVivo and the demographic information for each informant was linked to each transcript. The data were initially coded based on the research questions and further refined using common themes, novel insights, and connections to literature queries. The nodes were then synthesized into "trees" within NVivo to allow for insightful and effective analysis. Makerere University in Kampala, Uganda, as well as Northwestern University and Duke University in the United States provided institutional review board approval for the project.

Researchers interviewed 45 participants for the study, 37 during in depth key informant interviews and eight in a single focus group discussion. Thirty-five of these informants were CAB members, representing an estimated 46% of the total number of CAB members in the Ugandan National Cross CAB network (based on membership data in Table 2). The group, which brings together the six Ugandan CABs annually, provides a vital venue for information sharing between the different boards. In addition to the 35 CAB members, at least one liaison officer from each of the six institutions was interviewed, along with a representative from the Uganda National Council for Science and Technology and two clinical trial managers. Each participant took part in an interview that lasted between 1 and 2 hr. Questions focused on the demographics, roles, challenges, and successes of the respective Ugandan CABs.

Demographic categories recorded for each informant include gender, age, and highest level of education. The

gender distribution was 39% female (15/38) and 61% male (23/38). The age of informants ranged from 24 to 72 years (average = 45). Thirty-nine percent of interviewees completed postgraduate education (15/38), with 32% completing undergraduate (12/38), 21% secondary, and 29% unknown.

Results

Overview of Ugandan CABs in Cross CAB Network

Over the past years, knowledge has increased in terms of participation, willingness, and support. The community is changing and interested in answers. HIV is very known to them and there are many unanswered questions. (CAB 5 Liaison)

Each of the six Ugandan research institutions employs slightly different methodology for the formation and structure of their CAB. Table 2 provides an overview of the inception date, the number of members on the CAB at any one time, and the term limits for each of these members. Despite variation, the boards typically range from 10 to 20 members and reelect members every 2 to 5 years.

The demographics of the six CABs in Uganda vary slightly but maintain certain commonalities across all sites. For example, every site uses a broad community model of representation. Informants cited financial viability and the practical restrictions of repeating the selection process for every study as the main reasons for the cross-sectional approach. Table 3 outlines various qualities of the two CAB methodologies.

Membership

There is no blueprint for the mix, but the selection of CABs may be determined by the prevailing needs of the research organization. (CAB 1 Liaison)

Membership practices were not universal across the six sites. However, informants cited a number of common

Table 3. Methods for Determining Community Representation.

	Broad community	Population specific
Membership	Samples larger community outside HIV-affected groups (Morin, Maiorana, Koester, Sheon, & Richards, 2003) May include representatives such as government employees, religious leaders, and journalists	Limited to subsection of HIV-affected community (Morin et al., 2003) Example: drug users, women, sex workers
Distribution	Tends to be implemented at resource-limited sites	Tends to be implemented at resource-rich sites
Selection methods	<ul style="list-style-type: none"> • Researcher guided • Community guided • CAB guided 	Iterative and guided by researchers
Qualifications	Broad and subjective both between and within research institutions	Specific but vary based on study population
Role of cross CAB	Network between various populations	Network within specific population
Implications for CAB roles	<ul style="list-style-type: none"> • Width in perspective • Less financially burdensome 	<ul style="list-style-type: none"> • Depth in perspective • More financially burdensome

Note. CAB = community advisory boards.

elements as important in determining board composition. Gender, employment, and age were typical responses, with a focus on the increased need for youth involvement on the CAB. The ability to reach those in rural areas was also critical, as many of those infected with HIV were in rural communities or within vulnerable populations outside typical community spaces. Due to the HIV-focused research priorities of the sites, it was important for at least one member to be HIV positive. Religious, political, and media leaders often had large constituencies to which they could disseminate information and listen to concerns without much financial assistance. Other less common representatives included police officers, physicians, lawyers, and health counselors. The wide range of representativeness also has unintended benefits, as one informant stated,

One thing we have in our CAB is to learn from each other because we are coming from different communities, different backgrounds so, we decided to teach ourselves to learn from each other. (CAB 3 Member)

The diverse nature of broad community CABs provides a unique space for conversation and growth between members of the community who may otherwise not often interact socially. There are few other instances in Uganda where such a diverse group of individuals is given the opportunity to discuss issues facing their community as peers.

Barriers to adequate representation. The challenge in selecting for a broad community CAB is that 10 to 20 members cannot possibly represent or reach all members of the community. Thus, interviewees reported that many in the community were not aware of the CABs existence. This is due, according to

informants, to a lack of opportunity for communication between CAB members and various subpopulations. CAB outreach often occurs through methods convenient and unique to each CAB member. For instance, a member priest may communicate during a mass whereas a journalist may use his or her media outlet as an information outlet. These individualized methods serve those they reach well but leave others consistently without a voice. Also troubling is that those failed by the process are often those most affected or involved in HIV research. Vulnerable populations such as female sex workers (FSWs), men having sex with men (MSMs), the disabled, and youth were often cited as underrepresented groups by the boards. Legislation and stigma punishes homosexuality and sex work in Uganda and makes direct participation by these groups impossible and indirect consultation difficult at best (Article 31 of Constitutional (Amendment) Act, 2005; Human Rights Watch, 2009; Johnson, 2015; Chapter 120 of Uganda Penal Code Act, 1950; Wanyenze et al., 2016). This is particularly disturbing due to the elevated HIV infection rates of these groups, estimated at 37% for FSWs and 13.5% for MSMs (compared with an estimated 7.4% of adults nationwide; Hladik et al., 2012; Pettifor, Rosenberg, & Behets, 2011; UNAIDS, 2014). Logistical and regulatory barriers also inhibit disabled persons' and youth participation. Increased effort must be made to facilitate incorporation of these groups into the research process.

Geographical barriers to representation also pose an issue for CAB communication and representation. Lack of access to rural and isolated areas such as fishing villages makes CAB membership and outreach difficult. HIV infection rates in these communities can reach three times the population average, making them attractive candidates for HIV clinical research trials (Kiwanuka et al., 2014). However, their increased recruitment must be accompanied with increased representation on CABs.

Most people, especially these professionals, usually fear living in rural areas where we mostly do our research. (CAB 2 Liaison)

Although some representatives were chosen based on HIV status, age, or gender, many were chosen based on their professional connections. The focus on professional and well-educated members in Ugandan CABs limits the geographical outreach of the board. Those with wide networks were said to typically come from urban town centers and not from the isolated rural areas. Travel and financial restraints also limit feasibility of rural CAB membership. Thus, rural residents are underrepresented on CABs.

Religious dynamics on the CAB

Religion and the sciences normally are not one; they do not normally agree . . . The Muslims and Catholics are very opposed to condom use and yet these are the people that the researchers are using to spread the gospel of prevention through condoms. (CAB 2 Member)

One major challenge especially relevant to HIV research is the conflict between religious doctrine and research agendas. For example, religious CAB members often struggle with promoting condom use as an HIV prevention method. Individual CAB members reconciled the issue differently, with some deciding to excuse themselves from any outreach that involved promoting condom use and others choosing to advocate for the research programs despite their conflicting personal religious views. Other conflicts also arise when dealing with the intersection of religion and medical treatment. One JCRC member said their CAB included a religious leader who advised a local community to substitute prayer for HIV drugs. Other CABs followed similar paths, bringing on religious leaders after hearing of local sermons condemning HIV trials and interventions. Challenges remain, for instance, surrounding the refusal of some Muslim members to advocate for monogamy, an element of many HIV prevention education programs. Localized issues also often arise, such as the conflict for practicing Seventh Day Adventists to conduct education outreach days on their Saturday Sabbath. Incorporation and communication with religious leaders has helped mitigate these issues and further collaboration may improve relationship between religion and HIV research.

Qualifications

Our main role in CAB is to take the information to the community and from the community back to the researchers and anybody, even though s/he is not educated, can do that. (CAB 3 Member)

Determining qualifications for the Ugandan CABs is a challenging task due to fears of misrepresenting or failing to represent many vital yet vulnerable populations. This is especially challenging with non-English speakers or those who may be illiterate. Although many in the community fall into these categories, the logistical aspects of CAB meetings and obligations make it difficult to include them on the boards. Most CABs require proficiency in English and some level of secondary education. Without proficiency in English, CAB members are unable to understand the research protocols and cannot adequately convey important information to the communities they represent. Informants also stated that competence in English was necessary to ensure productive meetings, accurate material translation, and adequate understanding of terminology used by researchers. To reconcile this issue, many CABs use outreach and local health teams to reach illiterate populations. By translating information between the researchers and community, the CAB is able to better fulfill its role as ethical monitors of research and also communicate study opportunities and updates to those who may otherwise not have access to the information.

What I have observed in [X] CAB is there are members who have never uttered a word during our interactions . . . Many of our colleagues are nervous which is regrettable. (CAB 2 Member)

Despite these qualifications, inequality can persist within meetings between CABs and researchers as well as within the CABs themselves. Members must feel comfortable and prepared during meetings to adequately fulfill their roles and represent their constituencies. Though most participants felt prepared and welcomed during meetings with researchers, others cited fluency in English and incomplete understanding of scientific jargon as barriers to meeting efficiency. This again highlights the tension between complete community representation and ensuring an appropriate level of scientific literacy on the CAB. CAB liaisons at each center serve to reduce some of this barrier by maintaining communication with both members and researchers at all times. These liaisons are the primary contact for CAB members with questions, concerns, or information for researchers between meetings. This helps mitigate confusion and preempt any misunderstandings between the groups.

Connected to the issue of qualification is access to proper and complete CAB training. Nearly a quarter (24%) of respondents stated that training could be improved at their CAB. Members typically undergo an orientation upon selection for the CAB with some sort of continuing education throughout. Meetings are often months apart and the activities of the research organization can change substantially

between meetings. Members sometimes struggle to maintain understanding of the research and their responsibilities. Some cited a lack of scientific and organizational knowledge as the greatest barriers whereas others listed a lack of advocacy training as a major concern.

Selection

The selection of CABs is not straightforward. I have had personal experiences where CAB members are handpicked by the research institution or the research institution asks the current members serving on the board to identify people who can best represent the members they are replacing. (CAB 1 Liaison)

Although the selection process for CAB members was often inconsistent and varied both within and between institutions, our data identified three approaches. The three methods are not exclusive, and often some combination of two or more are used to identify and select potential members. The outline is meant to serve as a guide to understand the consequence of each approach and determine how each affects the composition and roles of a CAB.

Researcher-guided. In this approach, it is the researchers and employees of the institution who create a list of qualities they seek in a CAB and then search for community members who fit this description. This method often relies on researchers seeking out members who will best fit the organization's research agenda. The researcher-guided selection is most common with newly created CABs that lack relationships with community organizations and leaders.

Community guided. This process requires substantial input from community leaders and the local population. Often it is the CAB liaison who approaches the community and asks for input on possible membership openings. In this case, the community leaders reach out to their constituencies via public meetings, word of mouth, religious services, and other methods, and then bring their suggestions back to the researchers.

CAB guided. This approach requires a CAB to already be in existence at the institution and involves discussion with an exiting CAB member and identification of possible replacements.

Although these methods serve as guides, the actual selection method often involves contributions from CAB members, the community, and researchers. The value given to each group's input is where organizations differ. Examining how CAB selection processes affect membership characteristics may explain why certain CABs function and perform differently. Each selecting group, whether it is the researchers, the community, or the CAB, has unique

priorities and reasons for selecting members that will shape the demographics and roles of the future board. The ambiguity of the selection method for CABs led not only to confusion within the CAB but also within the community. Community members had no clear method for proposing possible incoming members and in many cases the existing CAB members or the researchers identified potential board members. Using the same persons and channels to recruit CAB members may contribute to a continuation of representation of certain groups over others.

Ugandan National CAB Network (UNCN)

In 2005, Uganda initiated the UNCN and in 2015 celebrated a decade of collaboration between its members. The UNCN brings together CAB members from each of the country's six major HIV clinical research institutions annually for a forum. Sigirenda, Bassajja, and Mutengu (2008) state that the UNCN serves to promote learning, integration, and support between the CABs. They report the UNCN is instrumental in optimizing use of resources and increasing effectiveness of community collaboration and engagement in the research process.

One out of five of our interview participants cited the Ugandan National CAB Network as a main success of Ugandan CABs. Interviewees stated the UNCN provides the ability to share perspectives, challenges, successes, and skills among six CABs across Uganda. It also builds capacity through mutual training and consolidates and harmonizes community mobilization in areas where participant communities overlap. Networking between CABs increases representativeness, thwarts challenges, and encourages communication between board members (Sigirenda et al., 2008). The model should be built upon and expanded to other resource-limited research settings.

Discussion

This study examines the demographics of six CABs affiliated with HIV clinical research institutions in Uganda. The results highlight the great variety in CAB membership and structure. Unlike population-specific boards, the CABs in the Ugandan Cross CAB Network exclusively use a broad community approach. The use of the broad community model directly affects CAB activities. The members are mostly, with the exception of the HIV representative, thought to be HIV negative. The boards instead consist of community leaders tasked with conveying opinions of constituents to the researchers. Thus, the members themselves act as liaisons for the views of their subpopulation, for example, parishioners, students, media consumers, and so on. They may not personally identify with the concerns they advocate. One participant addressed this issue saying, "CABs [in Uganda] are passive unlike those in developed

countries which question and demand to know.” We must take into account how the demographics of the CAB may relate to this potential passivity in Ugandan CABs.

Broad community CABs provide a wide range of perspective in the research process but lack the experience of a population-specific board. Having a single HIV representative inherently limits the diversity of personal input the researchers receive from the HIV-positive community. In studies involving small populations such as fishing communities or sex workers, input is limited to those who have contact with these small subpopulations. Further investigation into the distinctions between broad community and population-specific CAB functions is necessary.

Mwinga and Moodley’s study of broad community model CABs in Zambia contains novel and slightly different insights into the implications of demographics and selection methods. They argue that study-specific CABs may compromise CAB independence due to the direct funding of the boards by the research partner (Mwinga & Moodley, 2015). The study states that community-based CAB member selection, when possible, is the best method. The community-initiated processes increase trust in and awareness of the CAB within the community. This approach may also combat the lack of community awareness of the CAB while potentially opening up membership opportunities to otherwise silent subpopulations. CABs should explore the idea of garnering selection input from vulnerable populations, especially those that cannot legally and openly serve on the board such as FSWs, children, and MSMs. Involving the disabled, youth, and fishing communities would also help break the cycle of underrepresentation for these groups. CAB function and efficacy may also improve over time, as Pratt et al. (2015) argue in a recent publication. The authors contend that CAB ability to combat exploitation increases the longer a CAB has existed. This is yet another factor, in addition to those presented in this article, that should be considered when comparing efficacy of CABs across settings.

The broad community CAB model provides a more financially stable, reusable source for community input in HIV trials compared with the population-specific approach. The community leaders on these CABs are able to reach larger constituencies than population-specific groups. They facilitate large-scale sessions for information sharing, recruitment, and dissemination. However, using the same representatives for all studies also has drawbacks. As participants cited, certain groups often go underrepresented, and this underrepresentation is likely to continue if CAB-based selection dominates member nomination processes. The qualifications and selection methods for these CABs are obscure and often decided on a case-by-case basis.

A separate implication of the broad community model is that it can be used for multiple studies, avoiding the costly and time-consuming process of selecting members for each

new research project. Their stability over time makes them more attractive to resource-limited research institutions than the temporary population-specific alternative. Geography also plays an important role in the feasibility of the broad community membership approach. For instance, it is often financially and practically infeasible in Uganda to establish a new board for every clinical trial or research study conducted at each site. The logistics involved are too complex and costly. This makes broad community models a more viable option in many resource-limited settings and thus it is essential we understand how to ensure they are as effective and ethical as possible.

Best Practices

CABs and their affiliated organizations should make clear the CAB’s role, qualification standards, and selection process to the community. If committing to the broad community model, CABs and their affiliated institutions must consistently assess the subpopulations that are underrepresented on the board. This will require community input, particularly from vulnerable populations. The selection and evaluation processes should incorporate underrepresented study populations (e.g., MSMs, FSWs, youth, and the disabled). These groups are often study participants but rarely receive a voice in the research process due to legal and logistical barriers. This process will also facilitate awareness of the CAB within these communities. Community forums and health outreach sessions designed specifically for these groups could help foster communication and awareness of the CAB. CABs and researchers must not fall into the practice of selecting members from the same social circles. This creates a cycle of underrepresentation for those outside the groups. A protocol should be developed to determine the responsibilities of CAB members with personal or religious objections to research agendas. Structure meetings to allow and ensure that all CAB members are given a chance to voice their concerns and an environment of equity is fostered, whether it be between researchers and the CAB or CAB members themselves. Regular continuing education sessions on CAB responsibilities and competencies should be incorporated either into existing meetings or added to the CAB agenda. These meetings should involve scientific presentations as well as opportunity for CAB members to openly address any areas of uncertainty. This will help alleviate the feeling of underpreparedness expressed by nearly a quarter of Ugandan CAB members. The UNCN is a powerful tool for information sharing between research institutions and increased collaboration must be encouraged between Ugandan CABs. Networking sessions should also bring together those of similar demographics from the six CABs (e.g., religious, political, HIV-positive representatives) to share their strategies, successes, and challenges.

Given Uganda's global role over the past two decades in groundbreaking HIV/AIDS clinical research, it is essential we understand the practices of these six CABs. The study's findings regarding selection practices, board demographics, and representation models have significant relevance in other resource-limited settings and beyond. We have shown that CABs are context dependent, and it is now imperative that research focuses on the factors that shape a CAB's role in the research process.

Research Agenda

Further research is necessary to understand how demographics influence CAB efficacy in practice. While Newman et al. (2011) provide a review of best CAB practices in the United States, no such review exists for low-resource settings. Though Table 2 provides a review of CAB roles, future research should explore the weight of each role across various research settings. Potential study questions include the following: How does CAB membership affect CAB member relationships with the community and researchers? Is there, as one informant asserted, a passivity in resource-limited broad community CABs? If so, why? What factors determine whether a research institution employs broad community or population-specific CABs? How does increasing community input in CAB selection affect CAB function and public awareness of CAB? How can we incorporate populations that legally or logistically cannot serve on CABs into the research review process? What are the differences between resource-rich and resource-limited broad community CABs? What are the practical effects of the Uganda National CAB Network on research oversight? How does HIV study type (i.e., prevention, detection, treatment) affect CAB composition and function?

Educational Implications

Training of researchers, CAB members, and the community must incorporate the distinctions between various CABs. CABs should not be viewed as uniform across funding levels, research type, or membership model. Researchers should be briefed on the characteristics of broad community versus population-specific CABs before deciding which to implement. If HIV is the research focus, study type (e.g., treatment, prevention, detection) may influence CAB demographic selection. Training should stress the value in seeking clarification of any confusing terms and members must feel comfortable voicing opinions during meetings. Joint training sessions with researchers and CAB members may lessen the communication barrier between the groups and facilitate information sharing. The importance of CAB networking, community input in the selection process, and member preparedness must be incorporated into member

and researcher training. Training could potentially include contact information for other members of the UNCN that could offer support and input for new demographically similar members. CABs must be seen as dynamic and context-specific, with training and education focusing on how the setting may influence CAB function and the broader research process.

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