

“Why Don’t You Go Into Suburbs? Why Are You Targeting Us?”: Trust and Mistrust in HIV Vaccine Trials in South Africa

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Abstract

Trust is a key element of high-quality stakeholder relations, which are themselves essential for the success of HIV vaccine trials. Where trust is absent, community stakeholders might not volunteer to become involved in key trial activities, and potential participants might not volunteer for enrollment. We explored site staff and Community Advisory Board (CAB) members' experiences of trust/mistrust among community members and potential participants. We analyzed 10 focus group discussions with site staff and CAB members at two active South African HIV vaccine trial sites. We report on key characteristics perceived to contribute to the trustworthiness of communicators, as well as factors associated with mistrust. Attributes associated with trustworthy communicators included shared racial identity, competence, and independence (not being “captured”). Key foci for mistrust included explanations about site selection, stored samples, vaccination, and Vaccine Induced Sero-Positivity (VISP). Our findings suggest that community members' trust is not necessarily global, in which trials are trusted or not; rather, it appears fairly nuanced and is impacted by various perceived attributes of communicators and the information they provide. We make recommendations for clinical trial site stakeholders invested in building trust and for future research into trust at these sites.

Keywords

trust, mistrust, informed consent, stakeholder engagement, HIV vaccine trials, South Africa, research ethics

Introduction

HIV vaccine trials (HVTs) are lengthy, sensitive, and complex endeavors with invasive procedures, targeted against a highly stigmatized condition and enrolling potentially vulnerable participants often drawn from marginalized communities. As such, they require the engagement of multiple stakeholders for their successful execution (Joint United Nations Programme on HIV/AIDS [UNAIDS] & AIDS Vaccine Advocacy Coalition [AVAC], 2011; Slack et al., 2016). Two stakeholders whose engagement is indispensable to such trials are representatives of the local community and potential participants. Trust has long been recognized as a key ingredient of sound relations with community stakeholders and potential participants (UNAIDS & AVAC, 2011; UNAIDS & World Health Organization [WHO], 2007).

If community representatives do not trust the research, sites, or site staff, then community members may be less willing to volunteer their own time and contributions to research processes, and could be less willing to encourage others to do the same. Among community members who

might enroll as participants, trust in research, sites, or site staff is essential for their on-going co-operation (Mastroianni, 2008) and for genuine informed consent (Kass, Sugarman, Faden & Schoch-Spana, 1996; Miller & Weijer, 2006). Some have argued that trust by community members and participants might be implicated in increased participation in research processes, decreased controversy about trials, and better retention by eligible participants (MacQueen, Bhan, Frohlich, Holzer, & Sugarman, 2015). HVTs sites typically

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establish formal mechanisms called Community Advisory Boards (CABs) comprised of diverse representatives to provide inputs about needs, concerns, views, and perspectives of community stakeholders, and represent the interests of recruited participants as recommended by ethics guidelines (UNAIDS & AVAC, 2011).

The presence of trust in HVTs cannot be taken for granted. Community members' and potential participants' trust in HVTs could be influenced by public mistrust of scientific research, mistrust of vaccines, and controversies about HIV, its causes, and treatment. Several scholars have reported on empirical investigations of trust/mistrust in HIV prevention trials specifically (Andrasik et al., 2013; Newman et al., 2011; Saethre & Stadler, 2013). Such studies join a long, rich scholarship on public trust/mistrust in scientific research generally (Crocker & Cooper, 2011; Kennedy, 2008). There has also been much work—in many settings—exploring trust/mistrust by members of the public in available vaccines (Forster et al., 2016; Freed, Clark, Butchart, Singer, & Davis, 2010; Mcbrien et al., 2003; Obadare, 2005; Renne, 2006; Speers & Lewis, 2004). Scholars in various settings have also explored community members' trust/mistrust in conventional explanations of HIV (Bogart et al., 2008; Kalichman, 2014; McKnight & Chervany, 2006) and HIV vaccine research (Roberts et al., 2005).

Trust has been defined as a complex, multidimensional construct that is difficult to operationalize and measure (Simpson, 2007). According to dictionary definitions, trust is confidence or a belief in some quality or attribute of a person or thing, including goodness, honesty, reliability, safety, and effectiveness (Procter, 1995; Stevenson, 2010; “Merriam-Webster’s Collegiate Dictionary,” 2003). According to certain scholars, trust is held to refer to the psychological state of an actor (“the truster”) toward a specific party (“the trustee”) with whom the actor is in some way interdependent (Simpson, 2007), and is viewed as comprising a “self,” a “partner,” and a specific goal in a current situation (Hardin, 2003, in Simpson, 2007). Experiences of trust are informed by perceptions that the trustee has favorable attributes, for example, competence and benevolence (McKnight et al., 1998, in McKnight & Chervany, 2006).

Empirical studies have explored participants' trust in investigators to follow approved research procedures (Lind, Mose, & Knudsen, 2007), to mitigate research related harms (Hall et al., 2006), to respect their confidentiality (Neidich, Joseph, Ober, & Ross, 2008), to act professionally (McDonald, Townsend, Cox, Paterson, & Lafrenière, 2008), to manage financial conflicts of interest (Weinfurt et al., 2008), not to disclose sensitive research information (Hall et al., 2006), and to follow the conditions of ethics approval (Lind et al., 2007). It has been noted that participants might express *concrete* trust in specific researchers and research

organizations, as well as *abstract* trust in the profession of scientific research (Lind et al., 2007; McDonald et al., 2008; Weinfurt et al., 2008). Leading ethical guidelines for HVTs suggest that researchers should attend carefully to the issue of building trusting relations among key stakeholders (UNAIDS & AVAC, 2011). However, there has been little detailed exploration of trust in South African HVTs specifically, despite the country having the highest HIV prevalence in the world and hosting many HIV vaccine and other biomedical HIV prevention trials.

Method

In this analysis, we aimed to explore site staff and CAB members' experiences of trust/mistrust from community members and potential participants at two active urban HIV vaccine trial sites in South Africa. After site leadership gave permission for site entry, face-to-face meetings with site stakeholders were held to describe the study. Then, CAB members, educators, and counselors at these sites were invited individually via email to take part in Focus Group Discussions (FGDs) and provided with opportunities to ask questions, make inputs, and express concerns. Written informed consent was obtained for participation in FGDs.

The data set for this analysis was comprised of 10 FGDs across two HIV vaccine trial sites. FGDs were conducted by four researchers from the HIV AIDS Vaccines Ethics Group (HAVEG) (who worked in pairs), and took place between late 2013 and early 2017. During FGDs, participants were asked to discuss their roles and experiences, how they communicated key concepts to community members or potential participants, challenges or difficulties they experienced, and strategies that were implemented in response to the challenges. Semi-structured interview schedules with probes guided the FGDs (cf. Kvale, 1996).

The sample ($N = 59$) for the FGDs is outlined in Table 1. At *Site 1*, the data set included two FGDs with 10 CAB members each (i.e., 20 CAB-enrollees), one FGD with eight educators (i.e., eight educator-enrollees), three FGDs with consent counselors (comprising 10 counselor-enrollees, with eight participating in more than one FGD). At *Site 2*, the data set included two FGDs with a mixed group of site staff that consisted of counselors, and educators also involved in recruitment (seven site staff enrollees, with five participating in more than one FGD) as well as two FGDs with CAB members (14 CAB enrollees).

The guiding questions for data analysis were as follows: What are the key attributes that render a “communicator” of trial information more or less trustworthy? And, what is the informational component that is the focus of mistrust, and therefore key to trust-building interventions? The coding of text from transcripts was “keyed” to these study questions (Miles & Huberman, 1994). Text was coded for the party being referred to (e.g., site staff member) and the attribute

Table 1. Sample of FGD Participants by Group.

Site	FGD No.	No. of participants in FGD	Total number enrolled participants
Site 1	1, 2	10, 10	20 (CAB members)
	3	8	8 (Educators)
	4, 5, 6	7, 6, 8	10 (Consent counselors)
Site 2	7, 8	7, 5	7 (Mixed staff)
	9, 10	7, 7	14 (CAB members)
	Total 10		Total 59

Note. FGD = Focus Group Discussions; CAB = Community Advisory Board.

being referred to (e.g., “independence” or “competence”). Text was also assigned a code depending on the informational component being referred to (such as “site selection” or “stored samples”). The research team was sensitized to certain components of trust from the academic literature, especially models of trust that highlight that trust generally involves two (or more) parties (the “truster” and the “trustee”) interacting in a current situation (Hardin, 2003, in Simpson, 2007). Codes were identified at a semantic level, that is, within the superficial meanings of the data and staying close to participants’ own words (Braun & Clarke, 2006), so affected stakeholders would find them accessible (Patton, 1990) and able to be pragmatically applied in context (Durrheim, 2006). Text was also coded to identify at which participating site it emerged, to allow the team to make observations across sites. To establish “consistency of judgment” among observers (Boyatzis, 1998), a sample of interviews was coded by two independent coders, and coding differences were resolved by “reconciliation discussions” (Boyatzis, 1998, p. 152).

This analysis forms part of a broader study which aimed to explore representations of key research concepts in clinical trials, and to explore important interpersonal processes in engagement and consent encounters. Earlier study findings about “competing versions” of key concepts in HVTs have already been published. Those findings suggested that trust was a likely factor in resolving “competing versions” or competing interpretations of HVTs concepts (Rautenbach et al., 2015). Other study findings about important interpersonal strategies implemented in trials were also published, where it was identified that site staff implement various techniques to build trust (Slack et al., 2016). It became clear from these analyses that trust was a critically important concern for HVTs and deserved dedicated, in-depth exploration and analysis.

The study was approved by all Research Ethics Committees affiliated to the research team, the site, and the funders, including University of Toronto Institutional Review Board (IRB) (#28859), and University of KwaZulu-Natal, Humanities and Social Sciences Research Ethics Committee (HSS 1332/012).

Results

The results are organized into two sections. In the first section, “(mis)trusted communicators,” we describe attributes or qualities perceived to be associated with trustworthy persons providing information about trials. In the second section, “(mis)trusted information,” we describe informational components that were reportedly mistrusted by community members or potential participants, and features of the information that rendered it more or less trustworthy. These accounts come from counselors, educators, and CAB members themselves, and reflect their experiences of working with community members and potential trial participants.

(Mis)Trusted Communicators

In the context of trial education initiatives, in which site staff and CAB members presented information about the site or about research, community members at both sites were reported to have more trust in such information when it was provided by persons with whom they were familiar or with whom community members could identify:

... it is very hard to come up with Siya [SBT; researcher’s name] in the place of (X), and the people of (X) will never trust you. They will never listen to you *because you are the foreigner*, that is the truth, that is the truth ... [laughter]. (FGD 9, CAB, Site 2, P7, emphasis added)

It was also suggested at both sites that community members may be more trusting of persons perceived to be unaffiliated to the site, than those perceived to be working for the site. Therefore, the importance of information-provision by community leaders and community stakeholders was underscored, because these stakeholders were perceived to have some independence from the site or the research team conducting the trial:

We still need to engage people who are gatekeepers because ... people rely on things that come through imbizo¹ from a king² rather than a health worker, who they believe is captured by the Bill Gates in order to vaccinate people for death ... [laughter] (FGD 9, CAB, Site 2, P7)

At Site 2, it was suggested that community members may have cause to mistrust site representatives when they gave information that contradicted information heard at service-delivery centers:

... what is happening is that there are service providers that are there at the clinic and research site ... The information that nurses have at the research site and the information that nurses are giving at the local clinics and hospitals is not the same, so

you find that sometimes people who are working for the Department of Health, let's say health workers, they spread a lot of misinformation because they do not understand what is happening . . . because people they believe on the DOH (Department of Health). "I won't go to the research because they keep on feeding us the wrong information." (FGD 10, CAB, Site 2, P6)

In the context of consent counseling, counselors at Site 1 also indicated that shared racial identity with potential participants may help increase trust or mitigate mistrust. A FGD participant said,

I think the participants trust that the people that . . . are here are the same as them, like I'm black, and then they are black. They trust that they are gonna give them the correct information when we explain the informed consent. (FGD 4, Counselors, Site 1, P35)

In the context of counseling participants to start antiretroviral treatment (ART) (because participants have acquired HIV infection despite risk reduction), counselors at Site 1 believed that participants trusted medical doctors (study clinicians) rather than counselors to initiate ART. Study clinicians were reportedly viewed as having more competence even though they may provide the same information as counselors:

A few months ago we had this seroconvert, and I had to counsel this participant on starting the highly active antiretroviral treatment . . . she said . . . "at the moment I'm not ready to take the treatment" . . . had mixed feelings, is waiting for the mother who is away, not at home, the mother will be at home in 2 weeks' time, she needs to digest this, and then . . . she went to the doctor, the English doctor, of course [laughter] ja, and I'm black like him, like her, I'm black like her, and now, I don't know . . . maybe she looks at me and thinks that I don't have enough information to convince her . . . when she went to the doctor, the doctor told her the same information that I'd given her because I read the doctor's notes. And then, same day she was started ARVs. (FGD 5, Counselors, Site 1, P27)

(Mis)Trusted Information

Site selection. At both sites, some potential participants were described as mistrustful of researchers and sites because of the perception that participants are drawn from predominantly poor Black communities. Consent counselors recounted that community members raised questions, such as "why don't you take this study, and do it in upmarket white areas, go do it in that white area?" (FGD 5, Counselors, Site 1, P30) and "is it because of we are poor, we don't have money, we don't have food?" (FGD 5, Counselors, Site 1, P30). Community members described the view that

sites were located in predominately poor Black communities because "researchers . . . know they are going to get their results there" (FGD 1, CAB, Site 1, P4). This view was also described at Site 2 where community members reportedly said "why don't you go into suburbs? And why are you targeting us . . . because we are poor that they come to us?" (FGD 9, CAB, Site 2, P4).

Site staff and CAB members in our FGDs described informing community members that sites are chosen based on risk of HIV infection and HIV sero-prevalence, and not based on their vulnerability. However, at both sites, it was reported that community members and potential participants distrusted such explanations because they claimed to see evidence that contradicts the explanations offered. As one community member reportedly stated, "why's the black community targeted? . . .; go to the colored community, they also have a high rate of HIV. But there is no study or something that is connected on them, so there's a lot of questions" (FGD 2, CAB, Site 1, P13). Another view reported was ". . . there are *still* people who are getting HIV in white suburb so, *why* don't you go there?" (FGD 4, Counselors, Site 1, P40). At Site 2, similar findings were reported in which community members expressed suspicion for explanations of site selection, as one FGD participant reportedly said, "every time there is a research they go to black townships. They don't go to the Indian areas and everywhere, so why you come to us, why you always come to us?" (FGD 10, CAB, Site 2, P11). Here, evidence that HIV infections occur in White and Colored communities was invoked as the reason for rejecting explanations for site selection based on science as trustworthy. This reason for trust/mistrust appeared to remain even when the explanation was offered by persons from the same racial background, or with similar characteristics.

In the context of explanations about site selection, it appeared that the most influential attribute was whether the explanations were congruent with everyday observed experiences, rather than whether the explanations were offered by persons with particular characteristics, such as their familiarity, their competence, or their independence.

Vaccination. Certain community members at both sites reportedly did not trust site staff explanations regarding "vaccination," or the act of injecting participants with an experimental vaccine. Reasons for suspicion or mistrust ranged from an assumption that the experimental HIV vaccine could contain HIV which might cause infection, to assumptions that site staff deliberately inject participants with the actual virus. Here, historical exploitation was sometimes cited to justify suspicion.

With the background we are coming from and the legacy of . . . there is a Zulu saying that people are always saying, there used to be a car called phungukani Mazulu,³ which will go, and

people are vaccinated and injected so that they die in order to reduce the number. So when you explain the concept of vaccine, the concept of immunisation for the lay man's person, you really, it's hard for them to grasp that concept without having fears and those phobias that maybe now they are the ones who are injecting us. (FGD 9, CAB, Site 2, P3)

Some of them, they think that the researchers add or put the virus in them. So if we are trying to educate them, some still find it difficult to understand. We need to explain. Still they say "no no no, I can't go there, because they do 1, 2, 3 and going to get infected, bla, bla, bla." So it's very, very challenging. (FGD 10, CAB, Site 2, P10)

At Site 1, similar mistrustful views were described—as one community member reportedly remarked, "but if I go there, they'll inject me with HIV" (FGD 3, Educators, Site 2, P10)—suggesting that the act of vaccination may be feared because of concerns about possible inadvertent or deliberate infection with the HI virus.

Vaccine induced sero-positivity. Closely related to the concerns indicated about vaccination, and reported at both sites, were suspicious responses by certain community members and potential participants to explanations about VISIP, the phenomenon whereby vaccinated participants may test HIV positive on certain standard HIV tests even if they are not HIV infected. This suspicion reportedly arose during educational sessions with participating-community members in response to site staff explanations about VISIP. It was implied that in some instances, the explanation of VISIP itself was viewed incredulously because of existing suspicions that the site infects people with HIV.

Another myth is that we infect people with HIV. That [centre] infects people with HIV. We can't go there because when they get those vaccines, then, it is about this concept, the VISIP. So that's the other myth that we find a challenge. . . . Because most of the people in our area, they stigmatised the place to a place for HIV positive people. So they think if you come into the centre you might be HIV positive, or, when you come out, you can get HIV positive. (FGD 3, Educators, Site 1, P35)

I think, more especially with VISIP, maybe it's the way that it has been communicated . . . the community you'll find that they have misconceptions about vaccines and how they work. Cos you'll get others saying, "you guys are giving people HIV." So, I think it's, maybe it's the way maybe it's been communicated by our participants, or not our participants but those participants who maybe, I don't know, were not eligible, and then they will spread wrong information, or who had a bad experience. (FGD 7, Mixed site staff, Site 2, P9)

A counselor at Site 1 also suggested that VISIP creates uncertainty among some participants about their HIV status. It was suggested that despite reporting understanding of VISIP, some participants were uncertain about site staff explanations about VISIP:

And on that, sero-positivity is that, when we explaining these terms, are very difficult. Because really these participants would say, "yes I understand it." Now when they sero-convert, this is when we struggle, all of us. Because now, the question would be, but (name) "you told me, I can turn out, HIV positive." You know what I mean? So now where we always get stuck, is that, you know, "how do you know? How do you separate that it's because of my sexual behaviour, or you're still seeing a vaccine?" (FGD 4, Counselors, Site 1, P19)

Use of stored samples. One of the responsibilities of site staff was described as providing information about stored samples (specimens) for future research. However, at both sites, certain community members and participants were noted to be suspicious of site staff explanations because they contradicted community-level discourse about the trial site, as seen in the following extracts.

. . . they are people who are talking some bad things about the site. Like people here are being given things, that's not even known what it's going to do to them. And they are donating blood, they are *selling blood* actually. (FGD 4, Counselors, Site 1, P11)

I think, . . . they think we sell the blood and get the money, without knowing them. (FGD 7, Mixed site staff, Site 2, P13)

The issue of stored samples appeared not only important at the community level during educational sessions where perceptions about the sites selling blood are encountered, but this issue was also described as arising among some potential participants during the consent process. One site even reported an approach whereby participants and community members are invited to witness samples being destroyed as evidence of the validity of their explanations.

Discussion

This qualitative investigation of multiple constituencies—CAB members, consent counselors, and educators—associated with two geographically and culturally diverse HVTs sites in South Africa revealed key findings regarding the perceived attributes of trusted "communicators," as well as the informational components perceived to be mistrusted by potential trial participants and community members. Engagement of these communities, in addition to potential trial participants, in high HIV prevalence areas in ongoing

clinical trials is foundational to the development and testing of future HIV vaccines—the best hope for controlling the global AIDS epidemic.

Trusted Communicators

Attributes perceived to be associated with trusted “communicators” in various contexts included competence, shared racial identity, familiarity, and independence. This highlights the significant role that perceived characteristics of the informational source play in determining the trustworthiness of information (Hall et al., 2006). FGD participants invoked the notion of “capture” to emphasize how a perceived lack of independence can undermine trust in “communicators.” The term “capture” has become widely used in South Africa to allege that powerful members of the state have been “taken over” by groups attempting to exploit the South African treasury and economy for their own gain at the expense of the population as a whole. The term is commonly associated with corruption (Brosio, 2000; Manning, 2001). The term illustrates how important it is, in the context of educating community members, for communicators to be perceived as not having the interests of powerful hidden groups at heart. This suggests that experiences of mistrust in the research context are informed by experiences of the broader South African sociopolitical context. Scholars in various settings have observed that public trust in research is indexed to concerns about independence from commercial interest groups (Kamuya, 2013), and private companies (Critchley, 2008), and to concerns about researcher motives (Andrasik et al., 2013). Even for participants enrolled in health research, mistrust is linked to concerns that pharmaceutical companies have interests that do not coincide with the interests of participants (Andrasik et al., 2013). The preference for receiving information about trials from community stakeholders was observed by Andrasik et al. (2013) who reported that members of the transgender community would trust the information given at trial sites more if it was provided by community stakeholders rather than medical practitioners. Chakrapani, Newman, Singhal, Jerajani, and Shunmugam (2012) also observed that the recruitment of participants was perceived by community members to be more reliable if it was conducted by trusted community-based organizations rather than other groups (Chakrapani et al., 2012).

These findings also suggest that community members and potential participants are involved in a complex weighing up of various attributes depending on the context (Good, 2008; McKnight, Chervany, & Cummings, 1996; Mechanic & Meyer, 2000; Miller, 2004). For example, in the context of counseling participants to initiate ART, it appeared that the attribute most valued was competence, which appeared more important than site-affiliation, or even shared racial identity.

(Mis)Trusted Information

Site selection. Site staff and CAB members described experiencing some mistrust from community members regarding explanations for how sites were chosen. Certain community members reportedly had views that sites are selected because community members are vulnerable and unable to protect their core interests. This perspective has been reported in other trials as well. Newman et al. (2011) described concerns that emerged across several key populations about being unfairly targeted for HVTs recruitment and used as “guinea pigs” because of the vulnerability of their community. Chakrapani et al. (2012) reported perceptions that men who have sex with men (MSM) are targeted for enrollment in HVTs because they are vulnerable, adding to the burden of stigma already experienced by this population. Furthermore, both Haire (2011) and Syvertsen et al. (2014) reported that sex workers expressed mistrust toward Pre-Exposure Prophylaxis (PrEP) researchers because they perceived they were being targeted by researchers to exploit their vulnerability as sex workers. Kamuya (2013) has observed that the legacy of historically exploitative relationships under colonialism and post-colonial influence continue to influence people’s engagement with contemporary health initiatives. In South Africa, knowledge of or direct experiences of exploitation and discrimination under Apartheid informs perceptions of site selection. The current context of exclusion from social and economic opportunity experienced by many South Africans is also relevant. Also, certain community members reportedly mistrusted sound epidemiological explanations for site selection because these explanations were inconsistent with their everyday observations—namely, that there is sero-prevalence in all racial groups in South Africa. It has been observed that persons might well be suspicious of scientific claims when these claims appear to contradict their direct experiences (Hardin, 1992; Rubincam, 2017).

Vaccination. Site staff and CAB members experienced suspicion from some community members about the activity of vaccinating participants and how it could best be interpreted. Some community members had suspicions that vaccinating participants was a front for infecting them with HIV. Such views about deliberate infection with HIV resonate with several AIDS conspiracy beliefs that position HIV as an attempt by White foreigners to cause genocide in Black Africans (Bogart et al., 2008; Kalichman, 2014). Such mistrustful views are possibly rooted in historical experiences of exploitation and discrimination experienced by Black South Africans. These views may be linked to an awareness of clandestine efforts of the Apartheid operative and medical doctor Wouter Basson (publicized in the Truth and Reconciliation Committee hearings) to develop vaccines designed to curb fertility in Black South Africans

(Singh, 2008). Concerns about possibly contracting HIV from a candidate vaccine might also be linked to poor understanding of vaccine development (Fincham, Kagee, & Swartz, 2010; Leach & Fairhead, 2007). Those involved in educating community members and potential participants about experimental HIV vaccines are required to explain that the vaccine contains a small amount of genetically engineered virus. This may easily be misconstrued. Several empirical studies outside of South Africa have linked mistrust in research(ers) to legacies of past abuses by previously marginalized citizens (Braunstein, Sherber, Schulman, Ding, & Powe, 2008; Corbie-Smith, 1999).

Vaccine induced sero-positivity. Site staff and CAB members experienced suspicion from some community members regarding explanations about VISIP, where acceptance of such explanations appeared difficult in light of suspicions that the site might be responsible for infecting participants. Similar findings have been observed in previous research (Chakrapani, Newman, Singhal, Nelson, & Shunmugam, 2013; Newman et al., 2015). Newman et al. (2015) observed that poor research literacy and exploitative experiences under colonial powers might explain the perception that VISIP is a cover for sites infecting participants with HIV. Chakrapani et al. (2013) found that many MSM community members held the belief that VISIP indicated actual HIV infection, which fostered fear regarding participation in HVTs. Awareness of VISIP needs to be enhanced among multiple stakeholders (Newman, Woodford, & Logie, 2012; VISR Working Group of the Global HIV Vaccine Enterprise, 2015).

Another concern expressed in this study regarding VISIP is that it creates uncertainty about one's HIV status. Other studies have reported similar findings and suggested that language and cultural barriers can enhance confusion regarding one's HIV status and VISIP (Newman et al., 2015; Newman et al., 2012). Newman et al. (2012) found that Canadian Aboriginal peer educators and service providers feared that the potential introduction of HIV vaccines in to their communities would foster uncertainty about actual HIV status. Educators faced challenges explaining the notion of false-positives that arise because of VISIP, because there are no specific words in the Aboriginal languages to describe the phenomenon (Newman et al., 2012).

Use of stored samples. Site staff and CAB members experienced suspicion from some community members regarding stored samples. Some community members reportedly did not trust that stored samples would be managed appropriately but rather would be sold to generate profits for the site. Several empirical studies have reported on mistrustful views by community members regarding the storage of tissue or blood samples, including concerns that stored blood is used in occult practices. For example, Gikonyo, Bejon, Marsh, and Molyneux (2008) found views in malaria vaccine trials

that stored bloods were used for devil worship. Saethre and Stadler (2013) also reported that participants in HIV prevention trials believed that blood would be sold. In Coetzee, Kagee, Tomlinson, Warnich, and Ikediobi (2012), participants expressed fears that their samples would be used in witchcraft and some said that blood may be sold by *sangomas*⁴ in traditional medicines. Boahen et al. (2013) found that some trial participants expressed concerns that their blood would be used for rituals. Stadler and Saethre (2010) documented rumors among participants that blood specimens would be exchanged for cash during microbicide gel trials, and observed that perceived exploitation of vulnerable groups was a likely explanatory factor. More broadly, Baik et al. (2016) found that community members had trust concerns regarding the stakeholders directly involved in regulating and using stored bio-specimens in research. Murphy et al. (2009) found participants' trust/mistrust of researchers was linked to concerns about potential exploitation of research subjects for profit.

These findings suggest that site staff and CAB members observe that particular concepts (e.g., site selection) attract mistrust from community members, rather than their experiencing global mistrust of trials. That is, trust by community members and potential participants appeared fairly nuanced (Mechanic & Meyer, 2000; Miller, 2004).

Study limitations. This study explored CAB member's and various site staff experiences of trust and mistrust among community members and potential participants with whom they interact. This study did not enroll community members and potential trial participants in FGDs, as accessing such persons can be disruptive for active trial sites. However, in the future, such representatives should be sampled for a fuller picture regarding perceived trustworthiness of communicators and communicated information. As a qualitative study, we cannot (and did not seek to) quantify levels of trust or mistrust; rather, we successfully analyzed the elements and contexts of trust and mistrust in two different HVTs sites. In addition, we explored trust and mistrust by triangulating accounts from several different site constituencies (CAB, educators, and consent counselors) and the themes were further corroborated across two different clinical trial sites, which increases the validity of the findings. Our findings show subtle differences across sites regarding which issues were spontaneously volunteered. For example, at Site 2, the issue of the competence/credibility of doctors was not spontaneously raised. However, it is possible that, with specific questioning along the lines of a structured interview or questionnaire, similar concerns would have been uncovered at both sites.

Conclusion

Successful HVTs depend not only on sophisticated science but also on the willing co-operation of participating

communities, and potential participants. Trust is a critical component of engagement with community members and potential participants that should not be over-looked in preparations for trials. These findings suggest that site staff and CABs are constantly being evaluated for their perceived trustworthiness as informational sources (such as their competence or independence), and as such, community members are not merely passive recipients of information. These findings also suggest that site staff and CAB members experience particular informational components (such as site selection) as “foci of mistrust”—so these components should be included (or continue to be included) in trust-building initiatives. These findings do not suggest that mistrust was rooted in any direct negative experiences with vaccine sites. Rather, mistrust appeared linked to experiences of the broader socio-political context (Newman et al., 2015) of racial discrimination under Apartheid, and continued marginalization of certain groups in post-Apartheid South Africa.

Best Practices

Site staff and CAB members should draw on strategies such as two-sided messaging, which is an advertising strategy that includes both positive and discounted, negative or refuted negative information about a product (Lally et al., 2014). This may involve acknowledging alternative explanations of trial-related information, so that potential participants may be less influenced by contradictory information from competing sources and may experience heightened trust (Lally et al., 2014). Also, acknowledging possible negative information may minimize beliefs that sites have a hidden agenda (Crowley & Hoyer, 1994; Hagen, 2005). It may be of value if site staff and CAB members help potential participants to be more “critical” receivers of information which might reduce the acceptance of contradictory information in the future (Weir, 2017, p. 28). Site staff should be aware that some skepticism from community members may be appropriate, and that blind trust is not desirable (Gikonyo et al., 2008; Kamuya et al., 2013; Rubincam, 2017). Kamuya (2013) reported that skepticism may help questions to be voiced, and explanations demanded. A certain level of skepticism from community members may also encourage researchers to develop better strategies for engagement (Jagosh et al., 2015).

Research Agenda

These findings suggest that sites should conduct their own formative research with community members (UNAIDS & AVAC, 2011) to identify for themselves those attributes of communicators most likely to build trust, and the information most likely to be mistrusted. This is because it may not always be straightforward or

warranted to import findings about trust from other community locales. Also, there needs to be more research with community members about the process by which community members come to trust information they are given (cf. Rubincam, 2017). It may help to explore the issue of trust and mistrust at different stages of HVTs, to assess whether there are qualitative differences across phases such as engagement, recruitment, or results dissemination. It may further be of value to explore how explanations of VISPs are received in a context where suspicions of deliberate infection exist. It may be of value to explore how tensions and trade-offs between valued attributes are made depending on the context, such as when “familiarity” is valued more highly than “competence” or vice versa. The findings further suggest that it may be of value for research sites to explore the trustworthiness of health care staff and site staff when providing competing information, as the data suggest that competing versions of important information may further contribute to mistrust among community members.

Educational Implications

CAB members and site staff should be aware of the attributes reportedly valued in educational encounters, such as familiarity (not being “foreign” to a community) and independence (not being “captured”), while recognizing that these may be context-specific. However, they should also be aware that such attributes may not be sufficient to ensure that explanations about contentious issues (such as site selection or VISPs) will be uncritically trusted. Site staff should try to enhance the trustworthiness of their explanations (Gikonyo et al., 2008). Marketing strategies have been shown to improve trust in the medical and research sectors (Balls-Berry et al., 2016; Cox, Cox, Cyrier, Graham-Dotson, & Zimet, 2012; Evangeli, Kafaar, Kagee, Swartz, & Bullemor-Day, 2013; Igartua, Cheng, & Lopes, 2003; Keys, Morant, & Stroman, 2009; Lally et al., 2014). More specifically, two-sided messaging may resonate “with the receiver’s attitudinal schema and may thus encounter less resistance” (Crowley & Hoyer, 1994, p. 566). It minimizes the chance that competitors’ counterattacks will affect consumer attitudes (Crowley & Hoyer, 1994; Eisend, 2007). If information that potential participants have in their existing schemas is included along with more accurate information, then it is suggested that the accurate information would less likely be rejected in favor of alternatives (Kahan et al., 2015; Lally et al., 2014; Weir, 2017) or “competing versions” (Rautenbach et al., 2015). Individuals may be more likely to accept information if it aligns with their existing beliefs (Ditto & Lopez, 1992; Kahan, 2015; Kahan et al., 2015; Weir, 2017) and mental models (Chakrapani et al., 2013; Newman, Seiden, et al., 2009). Hagen (2005) also suggested that acknowledging participants’ fears and

misconceptions may help “create the atmosphere of mutual trust” crucial to effective trials (p. 40). Community members’ experiences of mistrust might be the grist for critical reflection by CABs and site staff (Heller, 2015; Mezirow, 1991).

Authors’ Note

The views expressed are those of the authors and do not represent the position or policy of CIHR. These views do not represent the position of any council or committee with which the authors may be affiliated.

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Notes

1. A community gathering.
2. A King in this context refers to a traditional or community leader who has authority within the community.
3. Decrease Zulus.
4. Traditional healer.

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