

Caveats and pitfalls associated with researching community engagement in the context of HIV vaccine trials

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Abstract

HIV vaccine efficacy trials require the enrolment of large numbers of HIV-negative individuals and thus it is necessary to engage with communities where HIV incidence is high. We identify some of the caveats and pitfalls associated with researching community engagement in the context of HIV vaccine trials. These are as follows: the lack of consensus of what community engagement is and how it is practiced, the sometimes paradoxical role of community advisory boards as community representatives and challenges associated with information dissemination in communities. We identify a set of considerations for community engagement practitioners, trial investigators and social scientists when conducting community engagement.

Keywords

community health psychology, health education, HIV, South Africa, vaccines

Background

In the context of the global effort to develop an effective and safe HIV vaccine, clinical trial investigators are faced with the question of how best to enrol large number of HIV-negative individuals in studies of vaccine efficacy. Of considerable importance in recruiting participants for clinical trials is how persons who form part of communities where HIV prevalence is highest – such as low-income and marginalised communities in the global south, men who have sex with men (MSM) and intravenous drug users (IDUs) – are best informed of and recruited into future HIV vaccine trials. Engaging with these communities has become an important and necessary endeavour to maximise the effectiveness of recruitment strategies and thus yield large enough sample sizes to test vaccine products.

The concept of community engagement (CE) is controversial as there is little consensus regarding what the term means and how it may be adequately operationalised. Measurement of a construct is only possible when it has been adequately operationalised. Indeed, in the absence of an operational definition, any attempt at measurement is inherently compromised. In emphasising the importance of CE in

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research in the context of global health, CE has been described as working collaboratively with relevant community partners who have shared goals and interests (Tindana et al., 2007). To this extent, CE is a process that involves building partnerships based on respect and active and inclusive participation, sharing power and deriving mutual benefit from collaboration (Tindana et al., 2007). Engaging stakeholders from vulnerable communities in medical trials may be difficult to study with the traditional rules of empirical science (Newman, 2006). Yet, its importance in ensuring that high scientific standards are met cannot be underestimated, which brings into focus the need to design and initiate strategies directed at understanding CE.

There have been a few key examples of efforts to engage communities around specific issues. For example, a participatory action research project that emerged collaboratively between academic researchers and community health workers in the aftermath of Hurricane Katrina in New Orleans developed a unique cross-cultural awareness and a set of skills that facilitated critical analyses and ways of responding to structural inequalities (Scheib and Lykes, 2013).

The results of a component of a programme of evaluation of the impact of an urban generation scheme in the United Kingdom indicated that a social model was implicit in much of what how health behaviour was thought about, including health as individual and family lifestyle; the local environment and health; and the nature of life is a struggle (Dalton et al., 2008).

In an indigenous community project in the Philippines that adopted an empowerment education model in health literacy, community members were engaged in critical reflection to gain a better understanding of how health is conceptualised within their socioeconomic and political environment (Estacio, 2013). The study findings called attention to unbalanced power relations and unfair structures that act as barriers to positive social change.

In a study identifying links between physical health and community participation among

individuals with a serious mental illness, it was found that physical health played an important role in community participation, both causally and consequentially (Patel et al., 2016). The authors documented the ways in which mobility was a barrier to physical community involvement and showed how multi-directional interactions occurred between social relationships, community involvement and physical health. They also found that identity was a mechanism linking physical health problems and CE.

Rigorous qualitative approaches such as conducting focus groups, key informant interviews and ethnographic investigations to inform theory-based interventions and social marketing strategies have been advocated to support fieldwork and preparation of communities for biomedical HIV prevention trials (Newman, 2006). Furthermore, the lack of consensus concerning an operational definition of CE is highlighted in a review that juxtaposed principles outlined in UNAIDS/AVAC Good Participatory Practice (2007), such as respect, mutual understanding, integrity, transparency, accountability and community stakeholder autonomy with existing empirical research.

A number of gaps have been identified as requiring further research (Newman & Rubincam, 2014). Despite the lack of consensus about the definition of CE, specific goals of CE that have been identified are (1) ensuring the relevance of research, (2) assessing whether the relevant research is culturally and practically acceptable in its context, (3) ensuring that disruptions in the community as a consequence of the research is kept to a minimum and (4) ensuring that the benefits of the research is distributed fairly (Tindana et al., 2007). The aim of the study was to call attention to the caveats and pitfalls associated with researching CE in the context of HIV vaccine trials.

Method

Data collection and analysis

We searched the following bibliographic databases for the years 1990 to April 2016 using the

search terms in Web of Science, Scopus, PubMed, Academic Search Premier and PsycARTICLES. We did not include conference proceedings or unpublished articles in our search. The keywords we searched for were 'community engagement', participant engagement, empowerment, decision-making and 'HIV prevention trial'.

Selection of studies

The initial search yielded 893 titles and abstracts, which were independently reviewed by members of our research team. We then obtained full-text articles for all studies that both team members recorded as potentially relevant for the review. If the two team members did not agree initially, we obtained the full-text article and arrived at consensus about whether or not the article should be included. We did not specify a range of years for the article search and did not have an a priori template for reviewing the literature. The variables that were analysed emerged organically through our reading and review of the articles that we selected. Most of the abstracts did not directly address the terms of interest, that is, CE related to HIV prevention trials.

Our abstract review resulted in 64 articles being included in the next stage of the study. These were read specifically to determine the ways in which the authors defined and used the concept of CE. Of the 64 articles, we identified 18 that directly addressed the concepts of interest for this study. Two team members independently extracted data on the ways in which authors used the term CE in the context of HIV vaccine trials.

Findings of the review

We found a diversity of ways in which CE has been operationalised and utilised, thus making comparisons of definitions across studies difficult. Because of this diversity, we concluded that the literature on CE in the context of HIV prevention was not amenable to identifying overarching lessons learned. A common feature

of the literature was that CE was discussed without being specifically defined or operationalised. CE is commonly mentioned as part of trial practice (in line with Good Participatory Practice guidelines) (UNAIDS-AVAC, 2007), but there is often no detail given about what practices have been conducted. An exception to this trend is a detailed four-country case study, which identifies three cross-cutting themes as central to CE. These are trial literacy, mistrust of researchers due to historical exploitation and the importance of engaging in participatory processes (Newman & Rubincam, 2014). An important contribution of this study is that the authors emphasised the interrelationships between what may be termed the cognitive aspects of CE activities (i.e. the trial processes and concepts that trial participants need to understand) and the participatory aspects (e.g. involving as wide a group of stakeholders in processes designed to increase trust between researchers and community members). An implication of these interrelationships is that in contexts where there are high levels of mistrust between researchers and community members, it is possible that communicating trial-related concepts such as randomisation and the placebo arm of the trial may be more difficult to achieve in low-trust environments than in contexts where trust is greater (Newman & Rubincam, 2014). The question of context, then, is key, and we turn now to examining the contexts in which HIV vaccine research is conducted.

Communities of interest

Of interest to us are the communities of potential HIV vaccine trial participants where HIV incidence is high. The individuals who constitute these communities differ across contexts. In the United States, for example, the community of potential HIV vaccine trial participants is generally either MSM, people who inject drugs or sex workers (Buchbinder et al., 2004; Hays and Kegeles, 1999; Strauss et al., 2001). In the South African context, the communities of potential HIV vaccine trial participants are mainly heterosexual men and women who

reside in informal settlements, although the MSM community (Lane et al., 2011) and to a lesser extent people who inject drugs also constitute groups at elevated risk for HIV infection. In the context of vaccine trials, the term ‘community’ in the South African context of high HIV prevalence pertains to a specific geographical catchment area populated by Black Africans who are economically marginalised and who live in peri-urban areas, that is, poor Black townships where there may not be formal housing. Studies show that incidence and prevalence of HIV in South Africa are concentrated among Black women who live in peri-urban communities (Shisana et al., 2014). HIV prevalence among Black African females aged 20–34 years has been reported to be 31.6 per cent, while among male and female urban informal dwellers’ HIV prevalence it is 19.9 per cent, which is substantially higher than the South African national prevalence rate of 12.2 per cent (Shisana et al., 2014). The incidence in Black African females aged 20–34 years is 4.5 per cent per year, while incidence of both male and female urban informal dwellers’ incidence has been reported at 2.46 per cent per year, substantially higher than the national 1.1 per cent incidence for individuals 2 years and older (Shisana et al., 2014).

The stated core purpose of most CE activities is to facilitate community members to make informed decisions about whether to participate in a future vaccine trial or not. How this translates into action changes from one context to another, but a few common elements may be observed. A common feature of CE activities is the establishment of a community advisory board (CAB) that comprises community members who form part of the community. In geographically delineated areas, CABs consist of individuals who reside in these locations. When engaging with communities of interest (sex workers, MSM and people who inject drugs (PWID)), CAB members are not necessarily limited to a specific geographic location. In most instances, trial site staff engage with CAB members with the expectation that information that is shared via the CAB and other influential

community leaders will be disseminated to the community members via a trickledown effect, that is, where information is passed from CAB members and/or community leaders to the general community. Alternative approaches to CE include vaccine discussion groups with community members who have indicated that they are interested in volunteering to be part of a potential HIV vaccine trial, linking activities to public holidays or days of special relevance to the research (e.g. World AIDS Day).

It is within the context of these communities and practices that the core task of CE activities must take place, that is, to facilitate informed decisions about whether or not to participate in a future vaccine trial. An informed decision needs to include knowledge about specific aspects of a vaccine trial, for example, what a clinical trial is, what the placebo condition is, what prophylaxis is and what the risks and benefits to the individual and society might be. In certain contexts, the knowledge base regarding HIV and AIDS is so low that trial researchers need to start with more basic knowledge such as what HIV and AIDS is and how one might contract it and then proceed to methods of prevention.

As has been noted, being informed about HIV vaccine trials does not necessarily equate to being willing to participate in such a trial. A truly informed potential trial participant may choose to either participate in an HIV vaccine trial or not to participate (Swartz and Kagee, 2006). Similarly, potential participants who are not informed or poorly informed are also likely to choose to either enrol or not, on the basis of their limited knowledge. Ensuring that potential participants have sufficient knowledge to make an informed decision regarding participation in an HIV vaccine trial is an ethical requirement. Yet, information alone is unlikely to lead to potential participants being willing to participate in an HIV vaccine trial. In a study of CAB members, educators and consent counsellors on the communication of complex research concepts to prospective HIV vaccine trial participants, the question of enhancing comprehension emerged as a salient theme (Slack et al., 2016).

Also important as themes were building trust, respecting culture and preserving free choice among potential trial participants.

We were unable to find evidence that being better informed about trial-related concepts in itself increased the likelihood of trial participation. In fact, an inverse association was observed between increasing knowledge of vaccine trial concepts and willingness to participate (Koblin et al., 2000). In particular, increased knowledge from baseline to 18 months about vaccine safety was associated with a decreased likelihood of willingness to participate. It may be that willingness to participate is influenced more directly by an appraisal of the potential benefits associated with community programmes (Chakrapani et al., 2013), including the perception of access to enhanced health care as a result of being a trial participant (Lesch et al., 2006; Newman et al., 2015). In a study conducted with low income MSM in India, post-trial availability of an efficacious vaccine, free medical treatment post-trial, and life insurance were the highest rated trial characteristics in overall importance (Newman et al., 2014). In the context of poverty, any material benefit is likely to be accepted. Thus, if material benefits accompany trial participation, this may increase the likelihood of enrolment. Such a scenario brings into focus the ethics of creating undue inducements for people to participate in activities that they may not have enough knowledge about, including knowledge about potential risks and adverse events, and the challenges of balancing fair benefits with exploitation (Molyneux et al., 2012; Slack, 2014).

With whom do trial investigators engage?

It is logistically and practically not feasible for trial investigators to engage with all members of a community. For this reason, CE depends centrally on working with community representatives rather than with community members as a whole. In qualitative studies of civil society and stakeholder perspectives on engagement in HIV prevention trials, representatives of civil society

and activist groups were asked about their views on trial decision-making, including the cessation of a clinical trial due to unforeseen harms (Koen et al., 2013; Newman et al., 2011). Several participants stated that there was a divide between the scientists and the advocates themselves, even though this divide may have narrowed over time. Community advocates stated that they played an important role in enhancing awareness among community members about the decisions of the scientists to stop the trial. Even though the notion of ‘political correctness’ as a reason to engage community stakeholders was noted among some advocates, they also emphasised the importance and necessity of engaging communities even at the stage of protocol formulation so that their perceptions of the social value of the research could be considered (Koen et al., 2013). Beyond maintaining community awareness and engagement throughout the trial itself, sound engagement practices emerged as crucial to maintaining ongoing community support for the longer-term HIV vaccine research endeavour (Newman et al., 2011).

Two key issues emerge from this reality. First is the question of who is assumed to represent the community, and second is the question of how community representatives themselves engage with the community they are said to represent. We discuss the issues briefly in turn.

Who are the community representatives? CE in HIV prevention trials, including didactic and social programming, has been conducted with representatives of the community, such as youth, church and community organisation leaders (Koen et al., 2013; Newman & Rubincam, 2014). Ideas about community and community cohesion are in fact highly contested, as in the broader field of biomedical research in resource limited settings (Marsh et al., 2008). Furthermore, people who through their ascribed positions (such as being church leaders) or through their own agency (such as community activists) make claims, explicit or implicit, that they represent the community. Yet, such individuals may not in fact be widely viewed as doing so. In some cases, community representatives may

even act against the interests or wishes of the majority in order to achieve their own personal goals. The question of how representative CABs are of communities they purport to represent is of considerable concern (Marsh et al., 2008; Newman & Rubincam, 2014). Specifically, as one becomes a CAB member, one may become less representative of the community by virtue of having direct access to researchers and the resources they may bring. These resources may be material (such as access to refreshments at CAB meetings) or in the nature of social capital resources, such as where CAB members meet with CABs from other communities and may access opportunities to travel nationally and internationally as experts who have experience and privileged knowledge on CE.

An unintended consequence of CE programmes that intervenes with community representatives therefore is that representatives may become part of an elite in the very community they purport to represent. People who attend workshops, earn credentials, gain experience and develop contacts outside of the community may be inclined to leave their communities, if these are characterised by conditions of poverty, inadequate housing, the absence of basic amenities and unsafe living circumstances. To this extent, community interaction activities may have the opposite effect they are intended to have, with credentialed representatives leaving to find employment and better living conditions elsewhere. The complexity of the fundamental question of 'who speaks for whom' in CE in HIV prevention trials has not received sufficient attention in the literature. This may be a key question affecting the dissemination of information in communities, as we now discuss.

How do community representatives communicate with the broader community? In the literature on CE, it is commonly assumed that community leaders and representatives (and this includes CABs) will then inform those whom they are thought to represent about what they need to know regarding potential future vaccine trials, including about issues of trial literacy. There are

two key underlying assumptions at work here. The first assumption is that community representatives, even those whose credibility is high and whose status as representatives is uncontested, will actively and consistently engage in vaccine awareness activities with the community at large. Relatedly, it is also assumed that processes and procedures exist for such educational activities to occur. Unless these are well-resourced, highly organised, carefully implemented and properly evaluated, the likelihood that community representatives will necessarily implement such educational programmes in communities of their own volition and on an ongoing basis is low. We have not been able to find literature on HIV vaccine preparation that has studied this question systematically.

The second assumption is that community representatives will maintain fidelity to what we have earlier termed the 'cognitive' aspects of CE. To this extent, it is unclear whether community representatives will accurately impart the fund of information that community members need in order to make properly informed decisions about trial participation. The technical details of a vaccine trial, that is, a treatment and placebo condition, the nature of the placebo effect, the concept of prophylaxis and the specific risks that may accrue to participants require detailed and specific knowledge and understanding. Not only must community representatives understand these concepts but they must also have the skills to communicate them to others. Communicating these issues is very difficult, as is assessing whether concepts have been communicated (Lindegger et al., 2006). The potential for misinformation if educational awareness tasks are carried out by newly trained community representatives may be substantial. Needless to say, misinformation may have severe implications for trial participation, as it violates the ethical principle of informed consent. Specific strategies to enhance comprehension among potential trial participants have been identified by CAB members, educators and consent counsellors (Slack et al., 2016). These strategies included the use of analogies;

familiar examples; the use of teaching aids such as PowerPoint presentations and pamphlets; question and answer sessions; and encouraging interaction between prospective trial participants and consent counsellors and educators.

Those who agree to participate in a trial on the basis of insufficient or incorrect information are likely to do so without a full understanding of the risks they face. Even though opportunities to correct misinformation exist at the point of informed consent, this is by no means a certainty. Conversely, if potential participants decline participation on the basis of incorrect information, this will have a negative effect on the recruitment of adequate numbers of trial participants.

Implications of the study

Despite the complexity of the dynamics of CE in resource-constrained communities, the importance and urgency of developing an effective and safe HIV vaccine bring into focus the need for careful consideration of how CE may proceed. We now identify some considerations for CE practitioners, trial investigators and social scientists to keep in mind in efforts to understand the role of CE in recruiting large numbers of trial participants.

First, basic and applied research on the practice of CE is required to elucidate the dynamics of how and under what conditions CE is optimally executed in the service of trial participant recruitment. Second, there is no consensus in the literature, nor among practitioners, of a universally applicable definition of CE. The absence of a clear operational definition of CE as a circumscribed construct creates difficulties in efforts to conduct empirical research in this area. While efforts to develop a definition may be appropriate, it is also necessary to understand and document the existing practice of community workers who are actively involved in CE activities. There may be tension between the requirements of researchers on one hand and practitioners on the other. Researchers seek to formulate and define CE in a systematic way, while practitioners engage in CE activities as

they see fit and on the basis of local, specific and sometimes idiosyncratic conditions that characterise various communities. If CE defies any operational definition as a theoretical construct, then fine-grained anthropological research into its praxis may be appropriate to understanding how its implementation occurs, what its effects are and how, if at all, it contributes to creating awareness of HIV vaccine trials among non-elite members of local communities. Yet, despite inherent challenges with the construct of CE, we believe that a concerted effort needs to be made to arrive at a working definition of CE, so that the concept can be researched, monitored and evaluated. To this extent, we argue for the identification of key indicators of CE that are context-specific and which would enable researchers to assess the effectiveness of CE in the context of HIV prevention research.

Third, it is necessary to acknowledge the reality that CE would not occur in the absence of vaccine or other clinical trials. CE efforts operate in the service of scientific research whose ultimate objective is to reduce HIV incidence in society. Trial investigators have a vested interest in being able to recruit large numbers of participants, which they would not be able to do without the efforts of CE practitioners. CE practitioners, however, usually wish to create conditions under which potential participants are able to make the best decision for themselves about whether or not to accept enrolment. These competing interests are an inevitable consequence of the reality of the HIV vaccine research field. Acknowledgement of both these narratives is necessary for greater understanding and cooperation between these two sets of players.

Fourth, the notion of undue inducements has been raised as a caveat in the context of trial enrolment (Lesch et al., 2006). While indeed undue inducements are a valid concern in the context of resource-constrained communities, actual data on what constitutes a threshold incentive that would activate trial enrolment are sparse. For example, anecdotal evidence from interviews with community representatives of

Thai female sex workers indicated that they felt insulted and disrespected by unduly low incentives for HIV prevention research, which were considered insufficient to ensure their enrolment or compromise their underlying intentions (Newman et al., 2012). It is a matter of some importance to understand the dynamics of decision-making of individuals living in poverty who are confronted with the opportunity to generate an income by participating in medical research, in this case an HIV vaccine trial. Research of this nature would assist in understanding how CE efforts need to be dovetailed with individuals' cognitive appraisal and consequent decision-making about trial participation. At this point in our knowledge, it is unclear that poor individuals will participate in a study that, in their perception, may introduce health hazards in the future. Hypothetical scenarios in which incentives of increasing magnitude are presented to the participant may elucidate our understanding of the role of incentives so that CE efforts may be tailored accordingly. To this extent, the ethical imperative for CE is to circumvent perverse incentives so that individuals may make a truly volitional decision about trial participation.

Fifth, CE is to some extent an invisible practice as trial investigators infuse awareness-raising, social and cultural activities and the provision of health services within their scientific activities. The challenge for social scientists then is to remain attuned to these informal CE activities so as to document and understand their impact in communities. It appears at this point in our understanding of the dynamics of CE that a survey of current practices is necessary among HIV vaccine trial investigators in various contexts around the world where such trials are being conducted or planned. Such a survey will elucidate how trial investigators think about CE, what their current CE practices are and whether they believe that their efforts have any effects in communities insofar as awareness-raising and willingness to participate are concerned. Relatedly, actual programme evaluation of CE efforts in terms of knowledge, understanding and awareness of key concepts pertaining to HIV vaccine trials is

also indicated (MacQueen et al., 2015). The method of knowledge transmission, trajectories of communication and the effectiveness of these in terms of knowledge enhancement of ordinary community members, that is, those who are potential trial participants, awaits investigation. Such studies will enhance the effectiveness of HIV prevention efforts, ostensibly leading to a reduction in HIV incidence.

Action guidelines to improve CE in the context of HIV vaccine trials

From our experience, it would seem that support to staff who implement CE programmes in communities is crucial. The interpretation of Good Participatory Practice guidelines may vary depending on the context, staff rotations and funders involved. Supervision and support to staff on the coalface of interacting with the community to ensure consistent practice in terms of CE is therefore worth considering.

Furthermore, the meaning of CE in a specific context requires exploration and consensus by stakeholders at the start of the process of vaccine trials, that is, upon entering the community. This may contribute to a better understanding and management of diverse expectations later on in the CE process, as well as reducing the likelihood of unmet expectations on the part of community stakeholders in terms of what they do and do not gain from the process.

It is important that researchers engage with a broad range of community stakeholders, not only CAB members and research participants in their CE efforts. Examples of other stakeholders include other community organisations, civil society and non-governmental organisations (NGOs), representatives from government organisations and religious groups. Such an approach may ensure that the research is grounded within the local community context, tailored towards and sensitive to the local context, and that information about the research, the activities of research centres, and benefits of participating in the research are disseminated throughout the community that is being targeted for their participation in the research.

A limitation of the study is that it was not possible to conduct a systematic review and apply the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria to the literature. Given the disparate nature of the literature in CE and its varied definitions, such a systematic approach to the review was not possible, which reflects a lack of readiness of the field for such study. It may be that in the future, when universally acceptable definitions of engagement and empowerment are developed, such a systematic approach may be possible. At present, however, the use of these terms are better suited to localised and context-specific usage.

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Ethical approval and informed consent

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References

- Buchbinder SP, Metch B, Holte SE, et al. (2004) Determinants of enrolment in a preventive HIV vaccine trial: Hypothetical versus actual willingness and barriers to participation. *JAIDS: Journal of Acquired Immune Deficiency Syndromes* 36: 604–612.
- Chakrapani V, Newman PA, Singhal N, et al. (2013) ‘If It’s Not Working, Why Would They Be Testing It?’: Mental models of HIV vaccine trials and preventive misconception among men who have sex with men in India. *BMC Public Health* 13: 731.
- Dalton S, Orford J, Parry J, et al. (2008) Three ways of talking about health in communities targeted for regeneration: Interviews with community professionals. *Journal of Health Psychology* 13(1): 65–78.
- Estacio EV (2013) Health literacy and community empowerment: It is more than just reading, writing and counting. *Journal of Health Psychology* 18(8): 1056–1068.
- Hays RB and Kegeles SM (1999) Factors related to the willingness of young gay men to participate in preventive HIV vaccine trials. *JAIDS: Journal of Acquired Immune Deficiency Syndromes* 20: 164–171.
- Koblin BA, Holte S, Lenderking B, et al. (2000) Readiness for HIV vaccine trials: Changes in willingness and knowledge among high-risk populations in the HIV network for prevention trials. *JAIDS: Journal of Acquired Immune Deficiency Syndromes* 24: 451–457.
- Koen J, Essack Z, Slack C, et al. (2013) ‘It looks like you just want them when things get rough’: Civil society perspectives on negative trial results and stakeholder engagement in HIV prevention trials. *Developing World Bioethics* 13: 138–148.
- Lane T, Raymond HF, Dladla S, et al. (2011) High HIV prevalence among men who have sex with men in Soweto, South Africa: Results from the Soweto Men’s Study. *AIDS and Behavior* 15: 626–634.
- Lesch A, Kafaar Z, Kagee A, et al. (2006) Community members’ perceptions of enablers and inhibitors to participation in HIV vaccine trials: Health psychology. *South African Journal of Psychology* 36: 734–761.
- Lindegger G, Milford C, Slack C, et al. (2006) Beyond the checklist: Assessing understanding for HIV vaccine trial participation in South Africa. *JAIDS: Journal of Acquired Immune Deficiency Syndromes* 43: 560–566.
- MacQueen KM, Bhan A, Frohlich J, et al. (2015) Evaluating community engagement in global health research: The need for metrics. *BMC Medical Ethics* 16: 44.
- Marsh V, Kamuya D, Rowa Y, et al. (2008) Beginning community engagement at a busy

- biomedical research programme: Experiences from the KEMRI CGMRC-Wellcome Trust Research Programme, Kilifi, Kenya. *Social Science & Medicine* 67: 721–733.
- Molyneux S, Mulupi S, Mbaabu L, et al. (2012) Benefits and payments for research participants: Experiences and views from a research centre on the Kenyan coast. *BMC Medical Ethics* 13: 13.
- Newman PA (2006) Towards a science of community engagement. *The Lancet* 367: 302.
- Newman PA (2010) VOICES-Thailand (unpublished study).
- Newman PA, Chakrapani V, Weaver J, et al. (2014) Willingness to participate in HIV vaccine trials among men who have sex with men in Chennai and Mumbai, India. *Vaccine* 32(4): 5854–5861.
- Newman PA and Rubincam C (2014) Advancing community stakeholder engagement in biomedical HIV prevention trials: Principles, practices and evidence. *Expert Review of Vaccines* 13: 1553–1562.
- Newman PA, Logie C, James L, et al. (2011) ‘Speaking the dialect’: Understanding public discourse in the aftermath of an HIV vaccine trial shutdown. *American Journal of Public Health* 101: 1749–1758.
- Newman PA, Roungrakphon S, Tepjan, et al. (2012) A social vaccine? Social and structural contexts of HIV vaccine acceptability among most-at-risk populations in Thailand. *Global Public Health* 7(9): 1009–1024.
- Newman PA, Rubincam C, Slack C, et al. (2015) Towards a science of community stakeholder engagement in biomedical HIV prevention trials: An embedded four-country case study. *PLoS One* 10(8): e0135937.
- Patel P, Frederick T and Kidd SA (2016) Physical health, community participation and schizophrenia. *Journal of Health Psychology*. Epub ahead of print 13 September. DOI: 10.1177/1359105316666654.
- Scheib HA and Lykes MB (2013) African American and Latina community health workers engage PhotoPAR as a resource in a post-disaster context: Katrina at 5 years. *Journal of Health Psychology* 18(8): 1069–1084.
- Shisana O, Rehle T, Simbayi LC, et al. (2014) *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012*. Available at: <http://www.hsrc.ac.za/uploads/pageContent/4565/SABSSM%20IV%20LEO%20final.pdf>
- Slack CM (2014) Ancillary care in South African HIV vaccine trials: Addressing needs, drafting protocols, and engaging community. *Journal of Empirical Research on Human Research Ethics* 9: 83–95.
- Slack CM, Thabethe S, Lindegger G, et al. (2016) ‘... I’ve gone through this my own self, so I practice what I preach...’: Strategies to enhance understanding and other valued outcomes in HIV vaccine trials in South Africa. *Journal of Empirical Research on Human Research Ethics* 11: 322–333.
- Strauss RP, Sengupta S, Kegeles S, et al. (2001) Willingness to volunteer in future preventive HIV vaccine trials: Issues and perspectives from three US communities. *JAIDS: Journal of Acquired Immune Deficiency Syndromes* 26: 63–71.
- Swartz L and Kagee A (2006) Community participation in AIDS vaccine trials: Empowerment or science? *Social Science & Medicine* 63: 1143–1146.
- Tindana PO, Singh JA, Tracy CS, et al. (2007) Grand challenges in global health: Community engagement in research in developing countries. *PLoS Medicine* 4: e273.
- UNAIDS-AVAC (2007) *Good Participatory Practice: Guidelines for Biomedical HIV Prevention Trials*. Geneva, Switzerland: UNAIDS.