Why We Need Community Engagement in Medical Research

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Abstract

Background—The medical research enterprise depends on public recognition of its societal value. In light of evidence indicating public mistrust, especially among minorities, inadequate enrollment and diversity of research participants, and poor uptake of findings, medical research appears to fall short of sufficient public regard. Community engagement in medical research, with special attention to minority communities, may help to remedy this shortfall by demonstrating respect for communities in practical ways.

Approach—We provide three case examples that illustrate how specific approaches to community-engaged research can build trust between researchers and communities, encourage participation among under-represented groups, and enhance the relevance and uptake of research findings.

Discussion—A common attribute of the specific approaches discussed here is that they enable researchers to demonstrate respect by recognizing community values and interests. The demonstration of respect for communities has intrinsic ethical importance.

Conclusion—Two potential outgrowths of demonstrating respect specifically through community engagement are (1) the production of research that is more relevant to the community and (2) the mitigation of asymmetry in the researcher-community relationship. We summarize practical resources available to researchers who seek to incorporate community engagement in their research.

Introduction

The effective functioning of the medical research enterprise depends on public perceptions of research as socially beneficial. We as medical researchers expect the public to value our

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research. Yet medical research evidently falls short of gaining public regard in some communities in the United States in at least 3 ways: first, communities in some cases actively mistrust the research enterprise;[1–3] second, researchers sometimes struggle to enroll study participants in sufficient numbers;[4,5] and third, research findings are often not translated to, disseminated among, or adopted by their intended beneficiary communities.[6]

Community engagement in research is "a process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership" of people affiliated by geographic location, shared interest, or similar circumstances to address issues affecting community wellbeing.[7] Our aim in this paper is to illustrate how community engagement can help to remedy shortfalls of community trust, participant enrollment, and uptake of research findings. After briefly describing these shortfalls, we consider 3 case examples that demonstrate the potential of community engagement to address each. We then discuss a salient feature of community engagement common to all 3 cases -- namely, the demonstration of respect for the community. Researchers' respect for communities is not only ethically important *per se* but may also help specifically to build trust, encourage participation, and promote uptake of findings.

Three Shortfalls in the US Public's Regard for Medical Research

Mistrust in Research

Mistrust in research can impede communities from recognizing the social benefits of research. Mistrust of the health care system (including hospitals, health insurance companies, and medical research) has been found to be common in the general US population and is associated with poorer self-reported health.[8] When asked about medical research specifically, over 1/3 of respondents agreed or strongly agreed that it would be possible for medical experiments to be done on them without their knowledge, indicating misunderstanding of and mistrust in the medical research enterprise.[8] The NIH has identified mistrust and lack of understanding as critical barriers to participation.[2] Mistrust is particularly present among ethnic minorities.[1] Studies show that ethnic-minority respondents, as compared with ethnically white counterparts, anticipate greater risk from research participation and are consequently less willing to participate in medical research.[3,9]

Research Participation in the US

Only 15% of people in the United States report participating in clinical research.[10] Reasons for non-participation in research may include not having been recruited, having been deemed ineligible, or having refused to participate. Regardless of reason, low participation is also evident in the length of time researchers take to recruit participants to trials. A review of 114 trials found that fewer than 1/3 were able to complete their recruitment in the timeframe originally specified.[4] Difficulty with recruitment makes studies longer and more costly, delaying the development of new knowledge in clinical science and reducing funds available for future work.[4,5]

A general lack of participation in research, with consequent hindrance of advances in clinical science, is exacerbated by population-specific disparities in participation.[11,12] Without the involvement of diverse populations, research findings have questionable

generalizability.[12] Moreover, for populations with little research involvement, diseases and conditions disproportionately affecting them will tend to be studied less, with the result that less evidence-based knowledge will exist to guide care and prevention.[13,14]

Insufficient Uptake of Research Findings

It is widely recognized and often lamented that medical research findings take years, even decades – in fact, 17 years on average – to translate into practice change.[6,15–17] Even when new research findings are presented in a user-friendly clinical guideline format, clinicians struggle to follow them.[18] A 2013 review paper on management of back pain, for example, found that despite numerous national treatment guidelines, clinical practice remains discordant with evidence-based guidelines.[19] Beyond clinical practice change, non-clinical standards may also take years to realize changes long indicated by the evidence base. For instance, even as we know that smoke detectors significantly reduce deaths from house fires, many houses still lack functioning smoke detectors.[20] While implementation of evidence-based measures is a complex process often involving behavior change in clinical practice and communities, researchers have some responsibility to ensure that their findings reach intended users, clinical practitioners and communities alike. Inadequate uptake of research findings diminishes the utility of research for improving the health and wellbeing of our communities.

Community Engagement as a Pathway to Building Trust, Encouraging Participation, and Promoting Uptake of Findings: Three Case Examples

Building trust

Because the inclusion of ethnic minority populations in medical research is paramount to addressing health disparities and improving health, the federally funded Resource Centers for Minority Aging Research (RCMAR) were established in 1997 to increase research participation of ethnic minorities.[21] Moreno-John and colleagues have described the trust-building community engagement activities of 3 RCMAR sites: the Center for Aging in Diverse Communities in California, which engaged African-American, Latino, and Asian communities; the Center for Minority Aging located in North Carolina, which engaged African-American communities; and the Native Elder Research Center in Colorado, which engaged American Indians and Alaska Natives across the United States.[21]

Over several years, each RCMAR site employed its own set of locally appropriate trust-building activities such as hiring community members, working with community leaders and community-based organizations, considering the research participants' practical needs, inquiring about factors affecting recruitment and retention, incorporating cultural practices into research protocols, and sharing results with community members.

At all 3 centers, community engagement improved community-university relations and community trust in the institution. At the Center for Minority Aging in North Carolina, after a hurricane hit the area, existing relationships were leveraged to provide "service through research".[21] There were also gains in recruitment and retention of African-American research participants. The other two centers reported similar successes.

Encouraging participation

In the Women's Health Initiative (WHI), which was a large nationwide prevention study of cardiovascular disease, cancer, and osteoporosis in postmenopausal women,[22] Larkey and colleagues observed differences in the rates of enrollment of Hispanic study participants across study sites. Specifically, the Tucson, AZ study site frequently enrolled Hispanic women referred by Hispanic study participants, but the Phoenix, AZ study site did not and had much lower enrollment. The researchers hypothesized that Hispanic lay advocates might encourage other Hispanic women to participate.[23]

In order to test their hypothesis, the researchers selected 56 Hispanic WHI participants who appreciated the study and had a certain number of social contacts, and randomized them into two groups: a lay health advocacy group called *Embajadoras* (Ambassadors) (n=28) and a Hispanic control group (n=28). The researchers also selected 42 ethnically white women through a similar mechanism to form an Anglo control group. The 28 *Embajadoras* received 6 hours of training about communication, the societal benefits of WHI for Hispanic women their daughters and granddaughters, and personal storytelling. All women in the *Embajadoras*, Hispanic control, and Anglo control groups were provided brochures with response cards that interested women could use to contact the study.

The *Embajadoras* were more effective than the Hispanic and Anglo control groups. They accrued a greater total number of referrals and a greater total number of women who actually enrolled and continued at least to the randomization stage of WHI. While the *Embajadoras* study is only a single case, it is consistent with findings from a 2012 systematic review of similar community engagement approaches.[24]

Promoting uptake of findings

In 1985, the prevalence of Type 2 diabetes among adults aged 45–64 among the Kahnawake, a Native Mohawk community located near Montreal, was twice that of the general population in Canada.[25] The community also noticed a troubling prevalence of child obesity. Concerned about the health of the community's children, Kahnawake elders approached academic researchers for help in developing a school-based intervention to address diabetes prevention and healthy eating. Established in 1994 and continuing today, the Kahnawake Schools Diabetes Prevention Project (KSDPP) includes education for grades 1–6 and nutrition policy changes at local schools.[26]

Throughout the project, the community has been involved in project governance through a community advisory board (CAB), which established an innovative code of research ethics for CABs.[27] Evidence published in 2003 showed that the program had developed culturally appropriate educational modules, changed the environment to incentivize healthy lifestyle choices, and funded itself for 10 years.[28]

The Kahnawake community was unusual in approaching researchers with a problem rather than being approached by researchers with ideas. Nonetheless, the KSDPP experience shows that community engagement in research can lead to striking changes in policies and community behavior, even around problems as complex as diabetes in Native communities. While the successes of the Kahnawake and the researchers who work with them are not

universally applicable to other communities with different health concerns, researchers engaging with other aboriginal communities in Canada have benefited from lessons learned in the KSDPP.[28]

Discussion

In this paper, we claim that efforts to engage with communities and thereby to demonstrate respect for them can result in increased community trust, higher participation, and improved uptake of research findings. Community engagement demonstrates respect to communities by recognizing community values and interests that matter to community members *as people*. Two logical outgrowths are the production of research that is relevant to the community and the mitigation of asymmetries in the researcher-community relationship.

In all 3 case examples, researchers demonstrated respect for the community by engaging community members in research, which resulted in pragmatic benefits addressing each of the shortfalls identified above. It is well-established in the research ethics literature that the demonstration of respect for research participants has intrinsic moral importance.[29–31] The principle of respect for research participants is traditionally understood to require the protection of autonomous individual choice through informed consent processes.[32] Some bioethicists have argued that we ought to extend the principle of respect so as to include the communities in which research takes place, in order to ensure that communities are protected and that their interests are taken seriously.[33,34] According to this view, engaging community members demonstrates respect by acknowledging the interests of the community and what is important to community members as *people* rather than treating community members as only research participants.[35] From this standpoint, community engagement activities can function as a means of demonstrating respect for the community, aiming to build inclusive collaborations in order to address issues that communities value.[7]

An outgrowth of the demonstration of respect entailed by community engagement is the production of research that is relevant to the community. The case examples illustrate how the engaged community members created opportunities to make research more responsive to important issues that their communities faced, thereby increasing the relevance of the research to each community. In the case of the Kahnawake, community elders set the agenda and oversaw programs to address a critical public health problem plaguing their community —namely, the high prevalence of diabetes among adults and obesity among children. The resulting diabetes prevention program initiated in Kahnawake schools was of the utmost relevance to the community, as it was created to respond to the community's self-identified need. Community engagement can increase research relevance even when the community itself does not influence the agenda to the extent that the Kahnawake were able to do. In the *Embajadoras* case, Hispanic women engaged as lay health advocates appreciated the study's societal benefits for their daughters and granddaughters, and shared their understanding of the relevance of the research with other community members, which helped increase recruitment. This result highlights the potential effect on participation of showing how research is relevant to the community. The review of 114 clinical trials mentioned above found that the trials most successful at enrollment were those that were clinically relevant to participants and which physicians felt would have measurable benefit for their patients.[4]

Communities are often their own best spokespeople when delineating the issues affecting and concerning their members, so it makes sense that the relevance of the research can be enhanced when researchers engage communities.

Another outgrowth of a respectful stance toward the community is the mitigation of asymmetry in the relationship between researchers and communities. Communities, particularly those of historically marginalized or underserved groups, may perceive a power differential between them and researchers.[2] Researchers have money and knowledge not available to the lay public, and their interests largely drive the research agenda. In the community engagement activities of the 3 RCMAR sites described above, the researchers proactively sought to build trust in and empower minority communities, which brought symmetry to the researcher-community relationship. Similarly, in the case of the Kahnawake, the establishment of a CAB with representation from diverse community sectors and an open-door policy regarding membership helped researchers to acknowledge the community as an equal partner in the planning and implementation of the research.

In each case recounted in this paper, the researchers developed their own unique set of approaches to community engagement, underscoring the variety of ways in which researchers can demonstrate respect for communities. Table 1 describes in summary form the main approaches that the researchers in each case used to engage their respective communities. This is by no means a complete list of all approaches to community engagement; the approaches described in Table 1, however, are consistent with guidelines that have been designed to be comprehensive.[36–38] These guidelines are excellent contributions to the science of community engagement and serve as resources for researchers who seek to engage their communities. Researchers interested in a deeper understanding of community engagement principles and practices can consult sources such as Community-Campus Partnerships for Health;[39] the Centers for Disease Control and Prevention Principles of Community Engagement, created in concert with the National Institutes of Health's Clinical and Translational Science Award Community Engagement Key Function Committee;[40] and work by Israel, Minkler, Wallerstein, and colleagues.[37,41,42] Additional resources are available from the University of Maryland's project aimed at helping researchers build trust with communities.[43] The principles of community engagement may seem very demanding, however, for researchers who have not previously considered engaging communities. Such researchers might feel overwhelmed at first by the number of changes necessary to shift their manner of working with community members in their research (perhaps regarding them simply as participants) to a more engaged approach guided by these principles and frameworks. Aspiring to undertake community engagement that aligns with leading principles and frameworks is a laudable goal. Although engaging communities in research requires planning and dedication, simply adopting a new standpoint on research and the role of communities in research is a readily attainable step in working toward the goal of meaningful engagement.

A limitation of this paper is that the case examples are context-specific and thus not generalizable to all research projects. Despite this limitation, we have identified key approaches and illustrated salient features that clarify the value of community engagement from both ethical and pragmatic standpoints. Furthermore, examples of engagement can be

seen in national programs such as NIH-funded Centers for AIDS Research (CFARs),[44] which can deliberately consider how to engage communities in order to enhance research success, and the NIH Clinical & Translational Science Award Institutions (CTSAs), which include community engagement as a core component.[45,46] Provided that researchers maintain context-specific situational awareness, the understanding of the value of community engagement we provide is potentially applicable to any kind of medical research with communities.

Conclusion

Demonstrating respect for communities requires acknowledging that they have valid reasons for being wary of the medical research enterprise, and that those reasons demand responses from researchers to bridge the gap between communities and researchers. To respect communities properly and to remedy deficits impeding the advancement of medical research and the improvement of health and wellbeing in our communities, researchers should consider the needs and interests of communities in which they conduct research.

Acknowledgments

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Table 1
Specific Approaches to Community Engagement

This table summarizes the community engagement approaches adopted in each case. It is important to recognize that in each case, the researchers designed a unique set of activities to achieve their project goals (building trust, encouraging participation, and promoting uptake of findings). In any given case, depending on the circumstances, a few targeted activities may be all that is needed to meet successfully the needs and interests of the community.

Approach to Community Engagement reported	CASE 1: Building Trust [21]	CASE 2: Encouraging Participation [23]	CASE 3: Promoting Uptake of Findings[26–28]
Developed culturally appropriate health promotion and/or research materials with input from community	X	X	X
Provided training and/or technical assistance to community members	X	X	X
Inquired about factors affecting recruitment and retention	X	X	
Hired community members as research staff and/or community health workers	X		X
Considered practical needs of community	X		X
Established a community advisory board (CAB) involved in all stages of research	X		X
Included community-based organizations on research advisory boards	X		X
Partnered with local organizations including faith-based organizations and/or schools	X		X
Collaborated with community leaders	X		X
Conducted qualitative focus groups with community members to inform research approach			X
Attended community events			X
Shared research results with community	X		X
Involved the community in efforts to secure funding			X
Trained community members as volunteer health advocates		X	
Developed ethical guidelines for community engaged research with input from community			X
Established a partnership with the community			X