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Relationships Hold the Key to Trustworthy and Productive Translational Science: Recommendations for Expanding Community Engagement in Biomedical Research

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Abstract

Good relationships between research institutions and communities are an essential, but often neglected, part of the infrastructure of translational science. In an effort to create greater interest among translational science researchers in cultivating relationships with community members, we report the results of a workshop we convened to learn how relationships vital to research are best created and sustained. We highlight common barriers and challenges that hinder relationships. We also provide recommendations that individual research institutions and teams can use to expand and strengthen their relationships with community members. The improved relationships between universities and communities that could result from their implementation should build greater public trust in biomedical research, lead to a stronger commitment to see it succeed, and engender shared values and commitments that will give rise to new rewards, recognition and admonishment to sustain those values and commitments over time, all of which would facilitate translational science.

Keywords

ethics; editorial; translational research

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Introduction

Translational science promises greater health benefits by moving new treatments and preventive health insights up the translational pathway from discovery to delivery.¹ To bring these benefits to communities, however, one needs to know what benefits are most needed, as well as the manner in which they are best pursued. Essential aspects of this knowledge reside in the community, highlighting the value of mechanisms for conveying it. Good relationships are the best conduits for that knowledge flow so it behooves research institutions to have a plethora of relationships that will permit them to be engaged in multiple ways with their communities. Yet many relationships are in a state of disrepair. Witness news accounts of misunderstanding and miscommunications, such as occurred between researchers and the Havasupai tribe² and public reaction to the Henrietta Lacks story.³ We have seen first hand, through our involvement with research projects involving community engagement in genetics research and biobanking, the poor state of relationships that exists between some communities and research institutions as well. Alongside this state of disrepair is a dearth of relationships between the research community and the broader constituencies it seeks to serve. In order to redress these limitations, researchers need to know how to build and sustain good relationships with communities.

Researchers can learn much from the many researchers and organizations who work in a community based participatory research (CBPR) tradition.⁴⁻⁶ The central programmatic role granted to community engagement at the launch of the US National Institutes of Health Clinical and Translational Science Awards (CTSA) program⁷ should also prove helpful. However, as respected as the CBPR tradition is and as central as community engagement is within many CTSA network members, we worry that relationships with the broader community remains outside the scope of interest of too many in the mainstream of research.⁸

Reports from a Workshop

To learn more about how researchers can create and sustain the relationships that can help translational science, we convened a workshop to review mechanisms for relationship repair and building that others have successfully used in settings outside of academic medicine. We invited experts in community relations and partnership building, representatives from rural, African American, American Indian, Hispanic, and Asian American/Pacific Islander communities with experience partnering with university researchers, and researchers. There were two plenary sessions that addressed strategies for establishing and sustaining relationships, a panel discussion with members of under-represented communities who spoke about their experiences in partnerships with academic institutions on biomedical research projects, and extended discussion about case studies focused on cancer genetics and biobank research.

The first plenary session recounted lessons, found in List 1, learned by a leading communications expert about the value that respectful relationships had in a decades long project to turn a superfund waste site into a US National Wildlife Refuge. This transition required building trust among the numerous neighborhood communities surrounding the superfund site in the various government agencies and private corporations responsible for

the clean-up and transfer. The address highlighted multiple instances in which the establishment of relationships characterized by honest, ongoing communication helped buffer the inevitable challenges that arose at the superfund site during the transition. It also described keys to maintaining those relationships, which proved essential to the eventual accolades the site's transition received and the public benefits it continues to bestow.⁹ The main theme of the address was that building relationships and enjoying the trust that eventually arises from them take time, patience, and great effort.

The second plenary session recounted many lessons about relationships, found in List 2, from the leader of a community-based health organization. It explained why a commitment to cultivating relationships is fundamental for organizations that require collaboration for success and why efforts to develop the relationships themselves must occur prior to efforts to collaborate on specific projects. As was stated in the address, "people need to see how much you care before they will care how much you know." The address drew from the ancient creation myth about how the earth is supported on the back of a giant tortoise, supported by another tortoise underneath, and so on, to illustrate the fundamental importance of good relationships. When it comes to seeking productive partnerships, the leader reported, "it is relationships, all the way down."

The panelists' commentaries, as well as the workshop participants' discussion of the case studies, provided the opportunity to explore the relevance of the plenary sessions' key points to research relationships. Two of the authors of this commentary made extensive notes of the discussions. All but one of the authors met later to analyze the notes. That analysis, the results of which are found in Table 1, identified key barriers to productive relationships between communities and researchers, such as how communities can feel used at times by the research process or observe an uneven playing field when it comes to research. Such barriers are major impediments to creating the sustainable relationships that will help contribute to the success of translational science. The analysis also produced strategies, listed in Table 1 as well, for overcoming those barriers. We next developed recommendations, set forth below, that are offered as ways to implement the strategies. Before discussing our recommendations, however, we need to acknowledge the challenging landscape within which efforts to implement those recommendations must operate.

Challenges

Our experience has shown there is often a tendency to minimize or ignore the asymmetries in power that are intrinsic to relationships among researchers and community constituents. While communities certainly can and do exercise power and influence over various aspects of research, the science expertise and access to funding enjoyed by the research community creates entrenched imbalances. We have learned that it is a mistake to downplay them. Researchers need to acknowledge the difficulties asymmetries pose to respectful and productive relationships and collaboration. When they are made transparent, they can be navigated. Transparency invites the dialogue and negotiation that can strengthen relationships and the research partnerships that emerge from them.

The overall historical legacy of biomedical research can prove to be an even more difficult challenge to relationships, especially in marginalized communities. Many in these communities have limited access to the health care system and thus limited opportunities to enjoy the benefits of research. These communities are also more likely to have been impacted by dark episodes in research of controversy, exploitation, and abuse. Further, individual communities have their own history with local research institutions that can influence relationships just as much as the overall historical legacy does. This local history encompasses all of that institution's activities, not just its research. We have witnessed, for example, how local community perceptions of discrimination in a university's undergraduate admissions practices and hospitals turning away uninsured patients frame a community's response to researchers' invitations to enter into relationship.

Part of the challenge history poses to relationships is found in the mindsets some have about it. Some researchers, for example, are impatient when listening to community members recount episodes when trust was violated or indifference shown. Statements such as "I have no control over admissions policies," or "My lab wasn't involved in that" reflect this impatience. On the other hand, there are some in the community who refuse to let anything other than dark chapters of the past define the present relationship between research institutions and communities. One will likely encounter such mindsets in efforts to build relationships because relationships never start with a blank slate. Thus one must work to insure that history is the starting rather than the stopping point in the effort to build sustainable relationships.

Recommendations for Building Good Relationships

Against this backdrop of challenges, we offer two recommendations for promoting good relationships in biomedical research that incorporate three of the four strategies contained in Table 1. Others have already addressed how to change complex research reward structures, the remaining strategy in Table 1.^{10, 11} Our recommendations are ones that individual institutions and investigators can implement themselves and they are designed to overcome the barriers to sustainable relationships listed in Table 1.

1. Recruit community advisors to each research team

The plethora of relationships that translational science requires will never be established in the absence of a conscious effort to create them. Accordingly, research institutions should nourish the expectation that each research team will invite a small group (4--8) of community members to join them as advisors and colleagues. When possible, groups should include members who enjoy trust in their community and who can provide portals to communities for accurate and timely communication. The parties will need to meet on a regular basis and engage in a variety of activities, from observing research teams at work to participating in strategic planning and all matters in between.

A host of sustainable relationships and communication channels will quickly be built from this. In a very short time frame, dozens, hundreds or thousands of community members, depending on the size of the institution, will grow more knowledgeable about research, how it is conducted, the challenges it faces, and the community benefits it seeks. At the same

time, all participating researchers will be positioned to better understand the hopes and aspirations for research held by communities, as well as how they view multiple facets of the research endeavor.

The recommendation incorporates three of the five strategies from Table 1. It creates bi-directional communication channels. The ensuing communication should help make research institutions' core values and agendas more apparent. Perhaps most important, the relationships created by implementing this recommendation can break the current counter-productive cycle of researchers waiting until they need something specific from communities to reach out to them.

Our first recommendation is consistent with the growing practice of forming community-based advisory boards (CAB). A few words of caution are in order about CABs, however. Community advisors can contribute to the promotion of greater trust and support for research only when there is sincere engagement characterized by real exchange, dialogue, and give and take.¹² This cannot occur if researchers view community members as cheerleaders enlisted for fundraising or to help publicize researchers' accomplishments and good credentials. Instead, researchers must view community members as genuine colleagues. Recall the points from List 1 about listening. Institutional leaders and researchers must approach the formation and sustenance of community advisory groups with a sense of humility and openness, believing that they need help from people in the community to advance research in a trustworthy manner.

2. Implement meaningful sharing of the economic benefits of research

US universities are awarded almost 3,000 patents each year. They earn more than \$2 billion each year from patent royalties.¹³ Sharing a modest portion of these profits is a novel method for creating a greater sense of fairness in research relationships that, following Strategy 5 in Table 1, we think is worth exploring. So we propose implementing mechanisms that give communities a percentage, in the 5--10% range, of the profits from patents and other intellectual property rights that are generated by research. If institutions give back some of the benefits they enjoy, communities will enjoy the same kind of rewards from research that the research community itself enjoys. The transfer of money would acknowledge the contributions that local communities make in making research possible, whether through contributing financial donations or biological specimens, volunteering for clinical trials or other research, or permitting campuses to expand into local neighborhoods. It would also demonstrate that institutions are willing to give back to their communities, thereby balancing their continuous solicitations of community support and sacrifice.

Profit-sharing might be accomplished through a host of measures but it is important that communities are equal partners with research institutions in determining how profits are to be distributed and for what purposes. One way to do this is to create a non-profit grant making organization to expend the shared profits.¹⁴ Such a mechanism, or one comparable to it, could prove to be of tremendous value. It would invest much needed money in local communities, totaling millions of dollars over time at more successful research institutions.

There will be hurdles to implementing profit sharing. The profits to be shared will have to be reallocated from current uses; some institutions will have few profits to share; and all will likely need to revise technology transfer and other intellectual property policies, as well as renegotiate such policies with faculty. These will require long and arduous negotiations but they should prove worth the effort.

Repair of Internal Relationships

We close with an additional observation, taken from previous work of some of us to learn how to foster trustworthy research. The time and hard work that institution-based efforts to create or reform relationships with community constituents require will have diminished impact if they are not accompanied by equally time-consuming and difficult efforts to repair and build relationships within an institution itself.^{15,16}

Science--mission institutions are multi-faceted enterprises consisting of an interdependent web of relationships, some of which may be burdened by distrust. Broken bonds in an intra-institutional relationship can negatively impact the achievement of desired outcomes between investigative teams and their community partners.¹⁷ Recalling the point from List 2 that successful relationships require trust of an organization in addition to trust of individuals at the organizations, as long as trust within an organization is compromised, so is the ability to be a trustworthy partner in the community. Thus, in order for trust-building efforts to be authentic, institutions must “practice” internally what they “preach” externally.

Conclusion

The champions of translational science have staked its future on the promise to bring advances in health care to the public more quickly. If this promise is to be realized, research institutions will need to find ways to bring the broader public to the very heart of scientific research. That means the research community needs to embrace a far-reaching commitment to create respectful relationships across the spectrum of constituents and an infrastructure to sustain them. The recommendations we have set forth can help to create that infrastructure. The relationships between universities and communities that could result from their implementation should build greater public trust in the biomedical research enterprise, a stronger commitment to see it succeed, and engender shared values and commitments that will give rise to new rewards, recognition and admonishment to sustain those values and commitments over time, all of which would facilitate translational science.

List 1

- Sustainable relationships require communicating with those you want to establish relationships with, rather than communicating at them, calling for trusted channels of bidirectional information exchange.
- Genuine listening is a hallmark of lasting relationships. One must feel and be affected by what another person said, not just hear spoken words. Such affective listening demonstrates concern, intent and interest toward the speaker and what s/he is saying.

- One's reputation with community members results from what one does, not from what one says.
- Inclusivity is the key to building trusting relationships. Communities need to be kept apprised every step along the way of the decision-making process regarding matters of interest and concern to them.
- With respect to communication about the risks inherent to an enterprise or activity, it is essential that one understands the concerns the public has or may have regarding those risks and that one publicly acknowledges those concerns.

The keys to sustainable relationships, as presented by Jeff Julin, President and CEO, MGA Communications, at the workshop "Building and Sustaining the Relationships that Build and Sustain Trust in Biomedical Research."¹⁸

List 2

- Relationships lay the groundwork for and thus should precede specific collaborative projects.
- Institutions and their bureaucracies pose challenges to preserving relationships. One must find ways to keep missions and priorities at the forefront so that bureaucratic needs and procedures do not trump them.
- Relationships among individuals at different organizations or institutions are never just about individual personalities. Ultimately, successful relationships require trust of an organization in addition to trust of individuals at the organizations.
- Good relationships are matters of both the head and the heart. "People need to see how much you care before they will care how much you know."
- Researchers are usually less successful when they rely on others to be their bridge to the community to help recruit research participants. The best success is achieved when they invest their own time in establishing relationships.
- Relationships are always works in progress.

Highlights of the presentation by Grant Jones, Executive Director, Center for African American Health, presented at the workshop "Building and Sustaining the Relationships that Build and Sustain Trust in Biomedical Research."¹⁹

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Table 1

Research Relationships and Their Barriers.

Barriers to better relationships	Illustrations of the barriers	Strategies for overcoming the barriers
Research often makes communities feel like they are being used	i. Researcher outreach to communities is too frequently restricted to times when researchers need something from a community.	1. Encourage universities to seek relationships with local communities and their organizations <i>before</i> they seek their help with research projects.
	ii. "Helicopter research," when researchers come in and 'extract' what they need from communities but leave little or nothing behind and rarely, if ever, return, is a real occurrence.	2. Develop mechanisms for bidirectional communication.
Universities are too mysterious	i. Communities have a poor understanding of both the cultures and agendas of research institutions.	3. Promote transparency about a university's core values and agendas.
	ii. The "ivory tower" metaphor of universities is often still an apt one.	
Research incentives are often counterproductive to enduring relationships	i. Grants that fund research that involves community participation are time-limited.	4. Realign rewards for researchers so that they will have incentives to establish relationships with local communities.
	ii. Researchers are rewarded for publications for their peers, not communications with lay audiences.	
	iii. Federal funding has restrictions, such as limitations on food purchases that make funding community gatherings difficult.	
The research playing field is uneven (and often unfair)	i. Researchers receive immediate rewards from research, such as funding and career advancement. Research institutions benefit from research through indirect funds, prestige, intellectual property rights, and other tangible rewards.	5. Implement measures that will place researchers and communities on a more equal footing with one another.
	ii. Given the uncertain nature of scientific progress, communities must patiently wait for benefits.	
	iii. Communities must learn that "research takes a long time to pay off."	