HHS Public Access

Author manuscript

J Health Care Poor Underserved thor manuscript; available in PMC 2017 July 10.

Published in final edited form as:

J Health Care Poor Underserv**26**16; 27(2): 722€740. doi:10.1353/hpu.2016.0070.

Building a €Deep Fund of Good Will•: Reframing Research Engagement

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Abstract

Background, The engagement of underrepresented populations in health research has been an ongoing challenge. Yet, the participation of these groups is recognized as key to health equity.

Methods, Semi-structured interviews with 31 experienced investigators successful in the recruitment of underrepresented minorities were analyzed with reference to the concept of social capital to determine: 1) if it is actually in use by successful researchers although, yet unidentified as such; and 2) if the rubric could shed light on new directions especially for those who find it difficult to systematically implement community-engaged recruitment methods.

Results, Findings indicate that some aspects of the concept of social capital are being used successfully, but that there are also substantial barriers to its full implementation.

Conclusion, A lack of enforceable trust and associated institutional support for researchers is a detriment to research engagement. Efforts to remedy this would benefit large research projects, including clinical trials.

Keywords

Research participation; minority recruitment; mistrust; social capital; CBPR

The engagement of underrepresented minorities and low-income populations in health research has been an ongoing chall of the participation of these groups is recognized as key to the improvement of health outcome any researchers have explored this issue and find mistrust of health professionals and researchers tied to historical

inequality and mistreatment at the heart of the problem? Some researchers applying this knowledge to research engagement report success with the use of specific recruitment strategies for specific populations. Others have undertaken systematic reviews of the literature on the topic and point to the effectiveness of community-based strategies including building relationships with community organizations and maintaining community interaction either through community advisory boards or other means. Indeed, there is a well established literature on community-based approaches.

"the aggregation of the actual or potential resources which are linked to the possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition [49]

In the most general sense, social capital is thought of as a resource, like economic capital, that can be employed in the creation of more resources. Unlike economic capital, social capital is made up of networks of relationships, reciprocity, trust, and social norms that can be used to power human capital. There have now been decades of social capital based projects in economic development, education, health, and civic engagement. Many of the world•s leading agencies in social change have supported social capital approaches. For example, the World Bank started its Social Capital Initiative in 1996 and has since

The initial questions driving analysis included the impact of racial/ethnic identity on experience and recruitment strategies and what strategies were considered to be most successful. Emergent in the analysis were themes reflecting the sources of social capital as described by Portés in his review of scholarship on the topic. Following this realization, the qualitative data set was re-analyzed with reference to Portes categories of value introjection, bounded solidarity, reciprocal exchange and enforceable trust. The objective of this analysis was to determine the fit of participant statements into the sources of social capital to determine: 1) if the concept is actually in use by successful researchers in the field although yet unidentified as such; and 2) to discover if the social capital rubric could shed light on other directions specifically for those who find it difficult to systematically implement CBPR principles. The use of Portes model is strictly a heuristic, employed simply to afford deeper understanding. We do not intend to contribute to the discussion of the nuances of the concept of social capital, only to use this concept to illustrate the valuable findings that emerged in our analysis.

Results

A total of 31 investigators were interviewed for the study. While the largest number of the investigators (n=12;39%) self-identified as white, the sample was racially and ethnically diverse including African American researchers (n=10;32%), and those of Latino/Hispanic (n=6;19%) and Native American/American Indian (n=3;1%) descent. While there was an effort to include researchers working in other contexts, the majority were university-based (n=26;83%). All identified as either clinical or public health researchers. A majority further self-identified as community-engaged researchers (n=26;83%).

Social capital in research engagement: €Fertilizing the soil• or €building a fund of good will•

Through analysis it became apparent early on that while many...including our team at the onset of data collection...have a tendency to focus on key recruitment strategies, the researchers in our sample were working with a different model of engagement. When asked about their recruitment strategies, participants reported the use of techniques such as matching research staff to the study population on the basis of race or ethnicity; recruiting through community-based organizations (CBOs); and working with community advisory boards (CABs). Some, however, objected to the implication of what they saw as a one-size-fits-all approach.

- Yes, build a relationship, which is a lot of the give and take, so a real relationship, a two-way relationship. That s the single most important factor. There no magic strategy.
- Again, I don•t like that...I really do not like that [using the term ,strategyf]. But again, I•m going to say that it would be...do I have to just pick one?

Overall, when researchers responded to the question of recruitment ,strategies *f* they (#26) tended to speak more about relationship building than the presence or absence of a community advisory board or other strategies. As the second researcher quoted above

suggests, so too did several other participants note that researchers should use multiple approaches in the recruitment of research participants. For example,

- So from my experience, and that s why recruiting for minorities requires more time and more resources than the non-minorities because you re doing more than one thing and it s taking more time, and it s taking more steps to do it.
- You can to one thing; you ve got to do a lot of things, that the challenge.
- I have looked at recruitment strategies over the years on many of our different studies, and I think the thing that we•ve learned is that there•s no one strategy that works and that you really need to be approaching it from as many different avenues as possible, and they tend to play off of each other. So I think that somebody may see an ad somewhere that resonates with them and then they•re approached by somebody with the same material. It all, kind of, builds on each other.

The majority of researchers (n=29;94%) described not discrete strategies but ways of building relationships and with communities that bore a strikingly resemblance to the concept of social capital. A few researchers proposed terms to describe how multiple strategies work together to create a 'platform' or 'fund of good will among potential research participants, but the message was the same across our sample.

€Touching them:• unpacking the €deep fund of good will•

Each of Portes• sources is presented in Table 1 along with the expression in our data. In reference to Table 1, it is important to note that, for almost every concept, researchers also reported barriers or forces working against their ability to create social capital regarding each domain. Both the illustration on the source of the participant experience and their barriers are explored in more detail below. The reader should note that quotes included here in the illustration of specific concepts were chosen for clarity and do not represent the total number of quotes representative of the concept.

Values

Shared values and social norms (knowing the ,right thing f to do) are recognized as a fundamental aspect of social relationships in social the fig. The expression of these values is a challenge for new relationships. Indeed, researchers reported the importance of spending time with the communities in which they work to establish relationships. On one level, this discussion could be interpreted as recommendations for face-to-face interactions in community and communication about project goals. On a deeper level, researchers spoke of using this time to create a deeper social connection through ,relaxed time to interact. f Researchers also spoke about transparency both as a way to communicate shared values and a shared value in itself: honesty.

I think what we do is set certain principles about honesty, transparency, and hiring people, I did mention this earlier, but I think this is very important. When we bring in an African American person to the community, I think we go out of our way to bring a superb person that no one would even question is a token hire. When we bring in someone, it•s very clear that we went out and found the best for them. That has always been, I think, an underlying message that we found someone really good and this person is not a token hire, that this is a highly skilled person who we trust.

In this quotation, the researcher illustrates how the research team was able to communicate their position against tokenism which is another, presumably, shared value with the community.

In addition to honesty, respect was a frequently discussed component of a ,real *f* relationship. For some researchers, respect was construed as an alleviation of power differentials.

• "I think overall allowing them to shape the research and treating them with the assumption that we think they•re intelligent and not talking down to them, letting them discuss their research design and sharing data and not being paternalistic.

Researchers also expressed that being honest and transparent brought them beyond what they were trained to do as health researchers. For example, the researcher quoted below described himself as ,untraditional: *f*

• So there•s a lot of emphasis put on that understanding and being transparent about the research process. I should say, as a researcher, I think I•m untraditional in some ways. I share a lot about my background and other things with

communities. But I•m also pretty transparent to say to people that if it•s a new partnership, I promise them that I•ll be making mistakes along the way.

Other researchers noted that they were not trained to build relationships but learned ,on the job. f Still more researchers reported that time, money and lack of staff as a barrier to making connections in minority communities.

Solidarity

Beyond the transmission of shared values, interaction with research communities afforded researchers the ability to communicate or create mutual goals. Portes• notes that bounded solidarity as a ,identification with one•s own group, sect, or community can be a powerful motivational force^{!4 [8]} Here, the challenge for researchers is to bridge the gap of disparate identity and experience. On this point, they reported that they employed a range of activities that could be categorized as ways to create shared identity including working to help communities understand how research could serve their own goals (improved health), developing goals with community members, and joining community causes.

Yet, researchers also reported the limitations of a more traditional approach of recruitment in the building of solidarity:

• If we approach them as someone in a white coat with latex gloves that really doesn•t want to touch them, but will touch them if they have to and include them in the study, then sure, your responses are not going to be good. However, if

institution may work against them. This issue is expressed by an African American researcher quoted below.

• So some of the barriers have come with just the fact that we•re working in that particular context, and not everybody shares the same perspectives, opinions, values on the approach that we•re using or the goals that we might have. So the [Institution] might have a particular set of, a particular mission and vision and set of goals of what they are hoping to do that may or may not conflict with what we•re, actually, trying to do.

This tension was also described by another African American investigator whose team overcame the barrier with additional attention to mutual goals:

• "only two people turned us down because they had an issue with the medical center. They felt that the medical center where I worked was not supportive of them. And they said, ,You referred to the medical center. You people, I don•t want to see you. f That was the only challenge that we had, But people had a shared identity with us. They were happy to participate in something that would benefit the community at large and they were proud, really proud, to be involved in something bigger than themselves so that the whole community would benefit from their knowledge and their practices.

Reciprocity

While researchers often think of the use of incentives as a reciprocal exchange, the researchers in our sample spoke of reciprocity in a different way. Initially, our participants noted that the benefits of research are often unequally distributed and that this inequity is evident to both researchers and community members. For example, a white researcher noted,

• In other words, professors get promotions, they get pay raises, they get publicity because of the research. What do the subjects get? And what do the communities get? Generally, they don•t get very much.

Similarly, this sentiment was expressed by an African American researcher:

• That•s part of the problem with why recruitment may be, why we may be failing because we haven•t always been very sincere or deliberate in our efforts for recruitment that includes clear, informed consent, that people know what it is that they•re agreeing to, that they see some benefit of participating. We are the ones that often see the benefit, and we assume that they should see the benefit, as well. And I think that that is a huge assumption that we make, on our part.

When researchers in our sample spoke of reciprocity they discussed it, again, at a deeper level of exchange indicative of a closer, lasting relationship built on 4th lists a example, to

• The answer is very clear, having community champions who put their seal of approval on our program and say, ,This is a good program. These people are here to help you. They are doing research that will benefit the Black community, they are not here to take advantage of you or exploit you in any way. f

While third parties can increase the level of enforceable trust, they maintain it at an interpersonal level and thus do not have the power of formal, institutionalized support. Researchers reported the lack of institutional support of trust and many went on to describe how their formal affiliations created specific barriers to relationship building. Just as a lack of institutional support undercuts efforts to establish solidarity and mutual goals (as noted above), it also undercuts a potentially powerful source of more formalized enforceable trust.

• [I]t•s not just easy, the university has the power and the community doesn•t have the power, the university is all the White people and the community is all the people of color. It•s actually much more nuanced and complex than that.

The fact that no researchers noted the presence of or barriers to institutional enforceable trust in their work may relate to a total lack of expectation of this potentially powerful, enduring source of social capital.

Discussion

Our findings suggest that while many sources of social capital are being employed by researchers successful in the field, there are substantial limitations and barriers to its full application. Such an application would not suggest a substantial shift, but rather a reframing of existing knowledge and approaches. All of the points made by our participants have been made by public health researchers including the importance of shared values, solidarity, reciprocal exchange and enforceable or institutionally based **C3, 28, 30€31, 48€56.*

Through an explicit systematic focus on social capital and its components, researchers might be able to benefit from deep enduring connections to the community but each of the barriers described by our participants must first be addressed. Our participants suggest increased emphasis on relationship building processes in training and funding structures and enhanced relationships between researchers, institutions and underrepresented minority communities.

Why the social nuances of relationship building get somewhat short shrift in research implementation is complex. For some, interpersonal relationships may seem too time consuming, resource intensive and impractical. It may also relate to our predilection as researchers to prefer well definable research procedures over what some would call fuzzier ways of being and doing. Dependence on strategies feels right to many researchers especially as they enter unfamiliar terrain. It is essential to remember that race...both that of the researcher and that of the research participant...is often an undercurrent beneath this discussion of the engagement of minority communities in researchers.

The researcher is fallible and vulnerable within the research context. Of course we can try to cover up this vulnerability with the garb of our profession but this instantly diminishes us as experiential creatures sharing the understanding of our existence with other $\Re .184$]

Relationship-building might feel too personal or seem like undesignatifuscience to many.

While there is nothing wrong with establishing community advisory boards to facilitate community engagement, our participants specifically warn against a focus on strategies

objectivity as scientists. However, our findings indicate the value and success of, specifically,

professional organizations, universities, hospitals, and funding agencies may be suggested, one place to start, for universities, is Institutional Review Boards (IRBs) and University Offices of Community Engagement. While it would seem that each of these could lend support to community-engaged investigators, they do not appear to do so, on the basis of this research. More research should be done, in particular, to understand community perceptions of institutions and the institutional support of community-engaged research.

Acknowledgments

We would like to thank the investigators who willingly gave of their valued time to participate in this important work. This study was supported by Award Number RC2MD004766 (Sandra C. Quinn and Stephen B. Thomas, PIs) from the National Institute on Minority Health and Health Disparities and the Office of the Director, National Institutes of Health. Craig S. Fryer was supported in part, through his Mentored Research Scientist Development Award to Promote Diversity (K01CA148789; PI). James Butler III was supported in part, through his Mentored Career Development Award to Promote Diversity (K01CA134939). Mary A. Garza was supported in part, through her Mentored Research Scientist Development Award to Promote Diversity (K01CA140358). The funding agencies had no role in the study design, analysis or interpretation of the data, writing of the report, or in the decision to submit the article for publication. As a result, the content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute on Minority Health and Health Disparities nor the National Institutes of Health.

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Page 17

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Table 1

Sources of Social Capital and their Expression by Participants

		Pa	Participant Expressions	pressions	Partic	Participant Expressed Barriers	sed Barriers
Source (Portes)	Expression (Portes)	Concept, key words		Example:	Concept, key words		Example:
Value Introjection	Codes of ethics, shared beliefs, norms governing acceptable behavior	Transparency, honesty, n=29; 94% respect, humility, equity, facef time spent together = expression of values	n=29; 94%	I think what we do is set certain principles about honesty, transparency, and hiring people "I think this is very important."	lack of training; lack of \$\$ (staff); time	n=18; 58%	[A]cademic training, training in the classroom, is absolutely ineffective in teaching how to approach communities.
Bounded Solidarity	Bounded Solidarity Ethnic/social groups; political parties, class, groups put together for common goal or situation	Break down of .usf rand ,themf via shared ownership/mutual goals: shared value of researchand community objectives.	n=27; 87%	They just call me A. They just say this is good old A. They don't perceptions created call me Dr. S. They just call me through past part of them; interactions with When they hurt, I hurt. When institutions & they were celebrating, I would researchers celebrate with them and that sort of thing.	Negative t perceptions created through past interactions with institutions & researchers	n=19; 61%	Yeah, because I think because of sort of past behaviors of university researchers, there was a trust issue to start with, whether we were just going to come out and get our data, and not leave anything of value for the community.
Reciprocity	Exchange of goods, resources	Resource sharing rewithout immediate return (e.g. education, grant writing, jobs; doing taxes); leveraging of resources	n=23; 74%	kinds of ways. I remember in my *** study I would do "income tax. Yeah, people "needed somebody to help with income tax I served as a resource to the community in any way that I could.	lack of resources; limitations of grants/universities; perceived inequity	n=20; 65%	[P]rofessors get promotions, they get pay raises, they get publicity because of the research. What do the