

Summary of Research Findings: Community Perspectives on Supporting Clinical Research. July, 2016

Background: To support community organization participation in clinical research collaborations, we need to understand organizational concerns, strengths and challenges in this area. There's been a lot of research on individual decision making about clinical research participation and barriers to participation in clinical trials among diverse groups^{1,2} and some research on interventions to increase diverse participation in clinical research.³ However, we haven't found any research on how community organizations view partnering with research institutions for the purpose of educating community members about clinical research participation and/or partnering on the design and conduct of clinical research.

Purpose: Northwestern University's Alliance for Research in Chicagoland Communities (ARCC) conducted this study to learn more about community perspectives and inform efforts to engage community organizations as partners in clinical research. We asked about communities' experiences and concerns with clinical trials; their preferred methods for educating their communities about clinical research and research participation opportunities, and preferences regarding the role community organizations could/should play in educating communities about clinical research and giving input on clinical research design and conduct.

Methods: Three, 2 hour-long focus groups were held in fall 2015. Participants included organizational staff representing community-based, faith-based and patient advocacy organizations. Focus group participants were recruited from ARCC contacts. Focus groups began with sharing definitions and examples of clinical research to build shared understanding of the topic. Focus groups were recorded and transcribed verbatim. A team of three study team members analyzed the focus group transcripts.

The analysis focused on two questions.

- 1) How do community, faith and patient advocacy organizations want to support their communities' engagement in clinical research?
- 2) How do these organizations want Northwestern University to engage with communities regarding clinical research?

Initial findings were shared with focus group participants for feedback during two group conference calls. Findings were refined based on this feedback.

Results: A total of 24 individuals participated in the focus groups representing 15 community organizations, 4 faith-based organizations, and 3 patient advocacy organizations.

Key Findings:

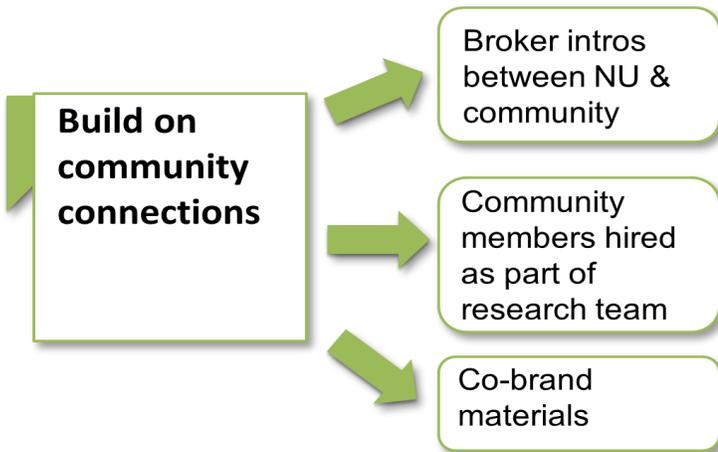
- ◆ Community organizations want to contribute their expertise, knowledge, and connections to inform the design and conduct of clinical research and facilitate diverse community participation. Most see this as a way to serve their communities.
- ◆ Communities want Northwestern University to engage with and contribute to communities as part of clinical research projects, as well as at non-project specific and institutional levels.
- ◆ Much of communities' willingness to support clinical research is dependent on the university's respect of and investment in communities.

Findings

How do community organizations want to support clinical research?

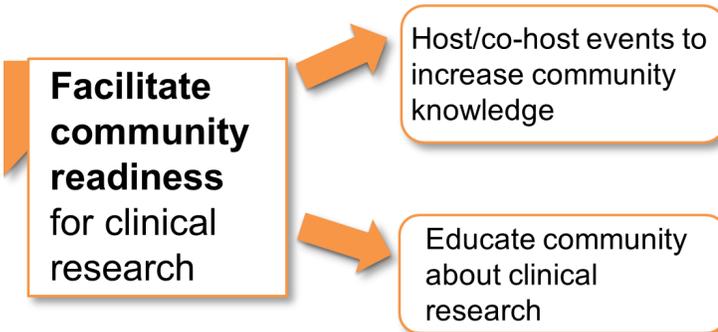


“We’ll educate you (Northwestern) about ‘this is what our makeup is, this is what we look like, these are our needs.’ I see that you are coming in because you think we need this, but maybe we don’t. But you need to know that.” (FG 1)



“..{We could} participate in the implementation of the research. This wasn’t a clinical trial, but one thing that {our organization} did was this health needs assessment. Two of our community health workers were given training to administer surveys, and they actually went out and did the surveys. I know that gets more difficult when you talk about medical research, but if there’s some way to get people in the community actually participating in the implementation of the clinical trial, I think that would get a lot of buy-in for participation.” (FG 2)

“(We could do) prescreening for the research that they want to come out with. So if you had your researchers write a two-pager about what they want to do- with the criteria that people can read through. Like a grant review but a research review ...We could tell you ‘yeah that won’t work, You shouldn’t even waste your time doing it’.” (FG 1)

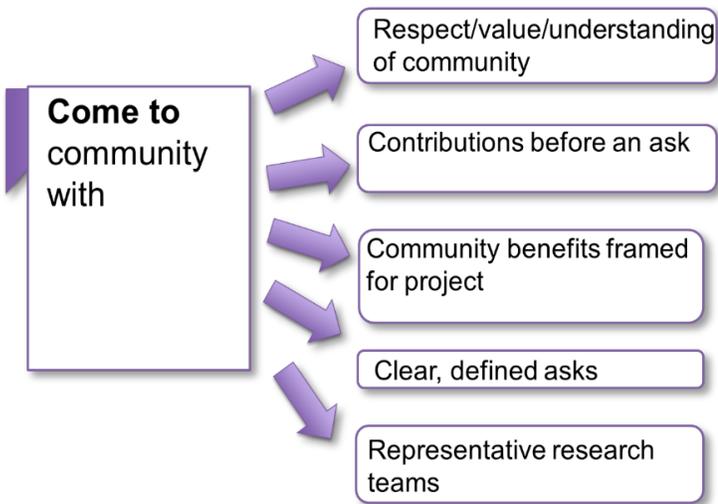


“I think it’s a lot about finding the right people too, because if you want to research a topic that I may not have any interest in, I’m less likely to take my own time to make that happen. But I would be likely to introduce you to somebody from the neighborhood who is that person. That’s their livelihood, that’s where they live, that’s their zone....Make sure you’re finding the right people, yeah.” (FG 3)

“Every opportunity I get I try to educate a group of people, letting them know that you might not need it now, but by you not participating in it, your community, your ethnic group, or whatever, is suffering because you’re not part of the sample that they’re testing.” (FG 3)

Findings

What do Community Organizations want Northwestern to do?



"{NU} Show up at a community before you need something. Try to make the first instance of a relationship be more than 'we would like to get this from you', but 'hey, we want to get to know your community.' Spend a little more time on the actual relationship building before you go in my pocket." (FG 1)

Show a presence. Before it's time for the actual study ...You know, when we have functions on the south side, like if it's the Africa Fest or old school picnic, just come..." (FG 1)

"I think all the organizations at the table have limited resources. So what do you {NU} actually bring to our community, from our terms, rather than on your terms?" (FG2)

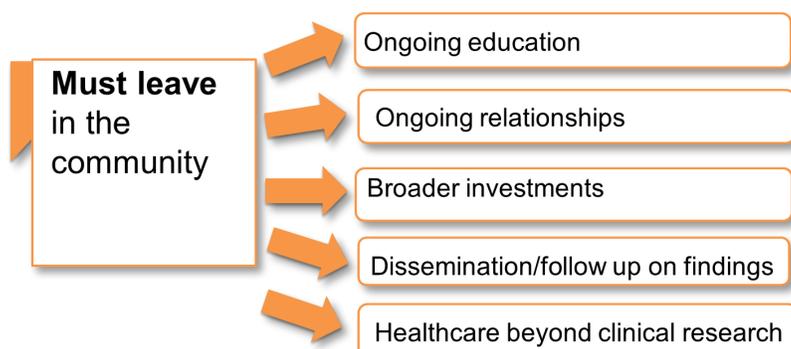


"...And showing up at their health fairs or whatever their things are, even if your purpose at that moment isn't to take names on a list for recruitment but just to kind of to get to know us, 'we care about your community more than just this study. We care about you. We're here at your health fair maybe giving free blood pressure checks or free whatever, for the day, just to get to know the community, and to get a feel for it.'" (FG 1)

"I think it goes back to that being part of the fabric of a community, because to just swoop in and offer something that's supposedly going to benefit you without being part of the community fabric is looked upon with suspicion, because it's just, 'who are you?'" (FG 2)

"The level of funding or other resources that might be provided have to be kind of commensurate with the level of participate and the work that's required." (FG2)

What do Community Organizations want Northwestern to do?

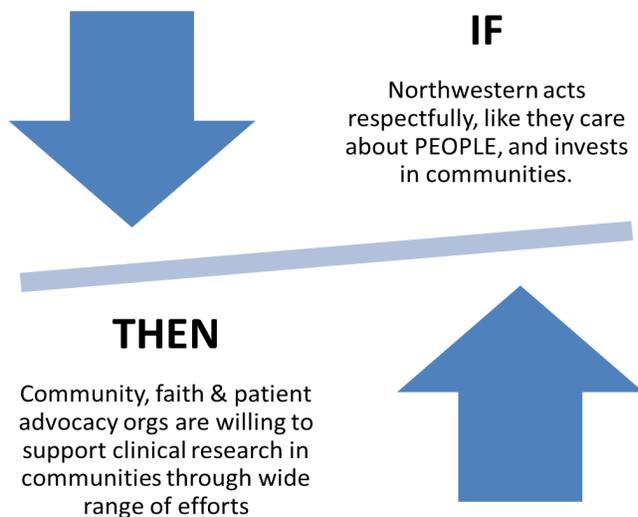


“Many of the community organizations I work with in my neighborhood- sometimes we have positive relationships with smaller healthcare providers. And that’s a permanent relationship we have, and so it might behoove Northwestern to come in and say, ‘these are the people who are actually on the ground providing clinical services.’ And so my organization and that organization together could partner with NU and some resources could be channeled.” (FG2)

“Having the research team come into the community and say ‘this is the research we want to conduct.’ Is there a way to reverse that and say ‘our community is really passionate about the fact that all of our kids are obese. Who’s doing research on obesity? Bring them in, we want to do it!” (FG 1)

“...if you strengthen the partners who are going to be here when you’re gone, when your research project is over, will the clinic down the street be a little stronger because you’ve been in the neighborhood?” (FG 2)

It’s a balance....



References

1. Ford JG, Howerton MW, Bolen S, et al. Summary, Evidence Report/Technology Assessment No. 122. AHRQ Publication No. 05-E019-1. Rockville: Agency for Healthcare Research and Quality; 2005. Knowledge and access to information on recruitment of underrepresented populations to cancer clinical trials.
2. Rivers D, August EM, Ivana S, Lee Green B, Quinn GP (2013) A systematic review of the factors influencing African Americans' participation in cancer clinical trials. Contemp Clin Trials 35(2):13– 32
3. Frew PM, Omer SB, Parker K, Bolton M, Schamel J, Shapiro E, Owens L, Saint-Victor D, Boggavarapu S, Braxton N, Archibald M, Kalokhe AS, Horton T, Root CM, Fenimore VL, Anderson AM. JMIR Res Protoc. 2015 Jun 2;4(2):e64. doi: 10.2196/resprot.4072. Deliv-

IMPLICATIONS/NEXT STEPS: This information will inform Northwestern University’s efforts to engage communities in clinical research. ARCC will be discussing these findings with community stakeholders, clinical researchers, and administrative leaders at Northwestern to inform directions Northwestern may take to improve its efforts to engage and benefit Chicago communities. If you have feedback, would like to be involved, or want more information, contact: ARCC@northwestern.edu, www.ARCCOnline.net