Recruitment Accelerator for Diversity in Aging Research - Cognitive Loss and Dementia (RADAR-CLD): Perspectives on Registry Recruitment

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BACKGROUND

The RADAR-CLD R-24 grant leverages an Accelerator model to assist in improving recruitment of diverse participants in aging research on cognition at two study sites. Unlike a Community Advisory Board (CAB), the Accelerator goes beyond collecting opinions and community project planning to promoting system-level changes needed to address the root causes of disparities in research participation. The Accelerator model brings together unique perspectives on research through a trans-disciplinary team of patients, advocates, clinicians, researchers, public health and industry leaders. The team discussions work to catalyze study operations by insuring communication between scientific and non-scientific stakeholders, improving the efficiency and effectiveness of research conduct. Over time, these collaborative teams become highly knowledgeable and effective in addressing needs of the community in cognition studies and understanding the unique skills and resources available in their communities to facilitate recruitment education and outreach. This report describes one of the Accelerator meetings at the Mount Sinai site.
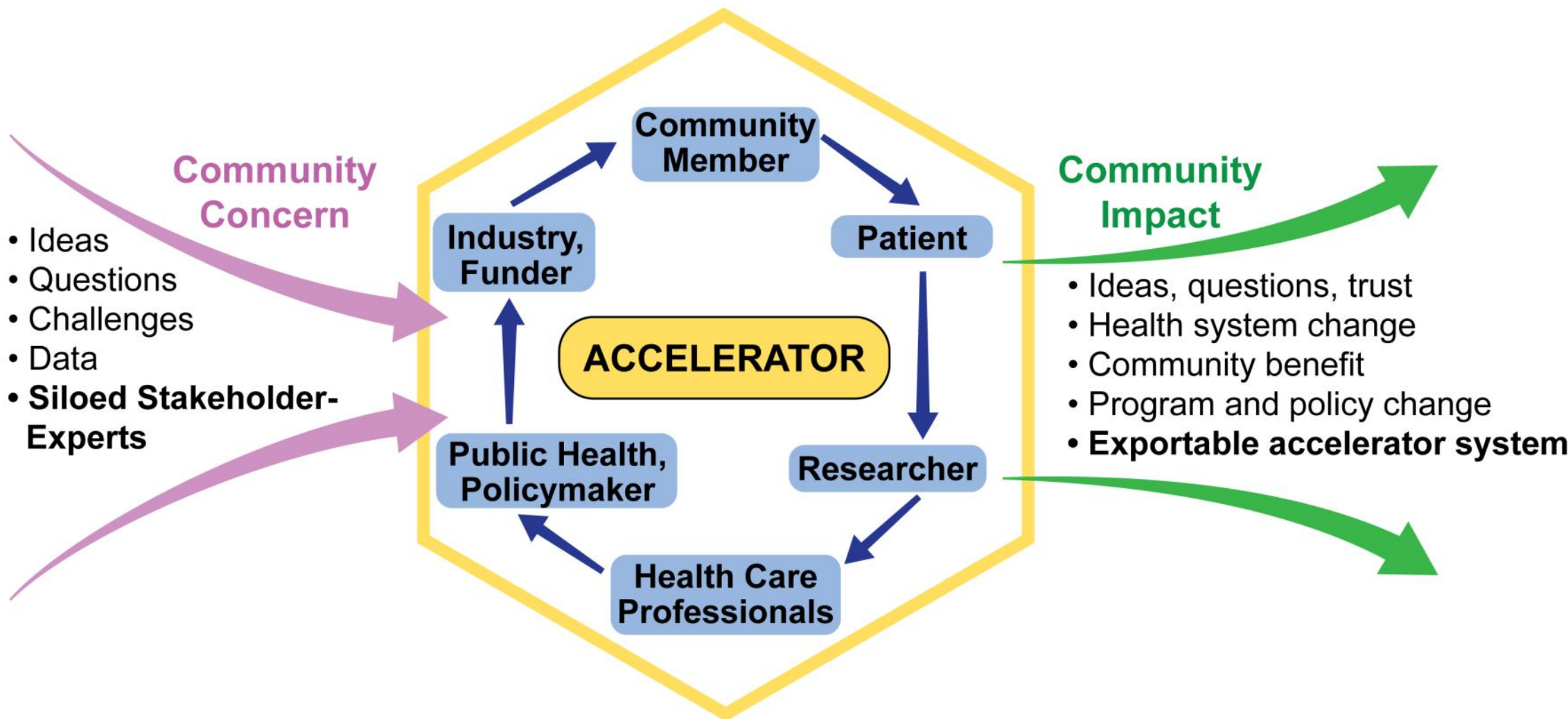

Image: Horowitz et al. (2017). Accelerators: Sparking Innovation and Transdisciplinary Team Science in Disparities Research. International Journal of Environmental Research and Public Health.

OBJECTIVES

The Sinai Accelerator group convened to engage in discussion regarding the role of registries in recruiting diverse older adults into research. The objectives of the meeting were to explore strategies to increase recruitment into research registries, identify the pros and cons of participating in a registry, and understand how to manage a research registry to maximize efficiency and recruitment success.

METHODS

Accelerator members of diverse backgrounds included (7) researchers, research staff and clinicians, (2) dementia caregivers, (2) community-based organization representatives, and (1) seniors from the local community. These stakeholders were chosen because they have a commitment to the aging population, have demonstrated skills required of collaborative team members, and offer unique perspectives to advance the science of aging research engagement, recruitment, and retention. Stakeholders virtually met with moderators independently prior to the meeting to orient them to the subject and meeting objectives, review meeting format, and set expectations of collaboration and mutual respect. An advance agenda and background reading was also supplied.

The 90-minute meeting was held over Zoom with a short question guide, designed to inspire open conversation. The moderators introduced a research registry as a database of research projects and personal information of potential research participants that can be used by researchers to identify individuals that fit their eligibility criteria, and as a tool for potential participants to find study opportunities of interest for themselves and those they care for. Researchers participating in the Accelerator highlighted their topics of interest regarding creating and improving registries, fielded questions from the accelerator members, and presented specific questions focused on collection of data at the time of a participant's registration to the registry, methods to update participant data, and frequency at which participants should be contacted to update their information.

Accelerator Stakeholder Representation

- Researchers/Clinicians
- Community Based Organizations
- Care Partners
- Seniors (non care partner)
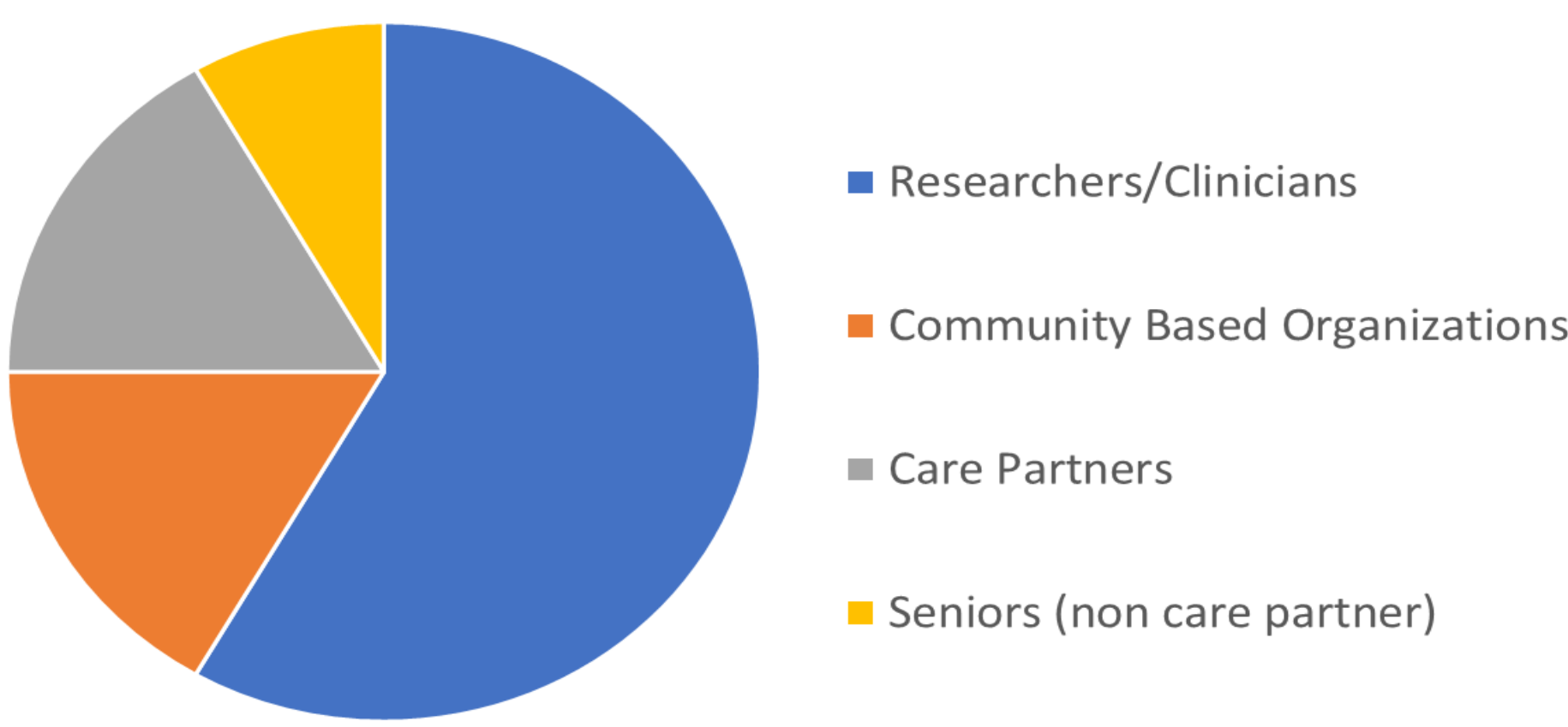
RESULTS

Seven major themes emerged from the Accelerator meeting, included building trust through relationship building and transparency. These themes are echoed in subsequent meetings that focus on actively enrolling studies at both sites. Additionally, stakeholders provided insight into the maintenance of registry data.

Relationship building. Accelerator members suggested researchers provide community presentations and attend informal community gatherings. An example included a weekly coffee group at the local senior center. Accelerator members also stressed that outreach would ideally be in-person and would be enhanced by inclusion of community partners. A community partner could be someone well-known and trusted within the community, or someone who is generally familiar with the community and culture. Finally, dissemination of study findings back to community helps solidify the relationship and allows community members to see firsthand the impact of their contribution. The theme of relationship building has been echoed in subsequent Accelerator meetings at both Sinai and Upstate.

> "You need to understand if you're sending people to work in the community, they have to do a little research and meet people and just know what it's like here before you come and start talking to people." (Senior Center Director)

Cultural Competency. Participants also noted that prior to soliciting research help, researchers need to have a level of 'cultural competency', a basic understanding of the community culture, and have had experiences and personal interactions with community members. At Upstate this concept is being successfully tested through community engagement by their Community Research Liaison and a team of Resident Health Advisors who are themselves residents of the community.

> "I really think it's helpful to have someone from within the community that you are looking to solicit to be there to help give the presentation...That really helps. It helps develop a sense of trust." (Senior Center Director)

Transparency of information security. The group stressed the importance of researchers explaining their plan to keep personal information safe. As one caregiver expressed, a drawback to participating in research is forfeiture of some privacy. Greater data security transparency could quell some fears, and potentially provide more comfort.

> "I think people should feel that the information is secure." (Researcher)

> "One thing about joining research, you're not going to have 100 percent privacy...I would consider that a con." (Alzheimer's Caregiver)

Transparency of Registry goals. Participants want to know why the research is important and how their participation will be beneficial. Additionally, researchers should convey to potential participants how entering a research registry will aid in efforts to increase diverse participation and why that is important.

> "What's the benefit? So, I think a clear goal to 'why is it that this would be important for you to participate' I think would be helpful to them. Because it builds back into the trust too." (Researcher)

Information Collection. Maximizing the information provided upfront when joining a research registry is mutually beneficial for both researchers and participants. Participants would be contacted directly for studies that they are eligible for. This is in contrast to the traditional recruitment process, whereby the individual carries the burden of finding the studies they could be eligible for and then reaching out to the study themselves.

> "Just having a name and a number and say I want to be in the study it doesn't help because you have no idea which study to put them in if you don't know anything about the person." (Alzheimer's Caregiver)

> "I'm probably willing to give a lot of information because I had one experience where someone was vetting people for a study, and I feel like I really wasted three hours of my life because what they were looking for was clearly not right." (Alzheimer's Caregiver)

> "...at that center there may be some flyers with some studies. It doesn't feel at all centralized. It's kind of random. So, I like the idea of it being centralized in one place if possible. It just seems helpful, win-win for everybody...I'm happy to participate, but anything that would make it more efficient would be a good thing from my point of view." (Alzheimer's Caregiver)

Frequency of Registry Updates. Suggestions for how often to update registry data varied considerably. Those that suggested more frequent updates explained that for older adults with ADRD, their health status and care situation is often rapidly evolving.

> "I mean things especially when dealing with patients' things are going to change very quickly for someone – we're talking about an older demographic. So, things are one week someone will be fine. The next week they're not going to be. Patients come and go. A lot of them will die." (Alzheimer's Caregiver).

Method of Registry Updates. Some suggested that there should be multiple methods of communication (phone, email, and mail) available for participants due to varied technological abilities. Each individual's communication preference should be listed in the registry, so that the research team knows how to best contact them. Similarly, if the participant wants to offer updated information, they should be able use whichever communication method they so choose.

> "I think having a diversity of ways to connect is going to be really important because people will be scared off if they think there's more technology they can't handle. It will just be too much." (Senior Center Director)

> "...one thought we had was you could reach out to the registry to update it any time you wanted. But to be bothered by the research team maybe once or twice a year." (Researcher)

CONCLUSION

The nature of the researcher-participant relationship can sometimes feel like a one-way transaction, in which the researcher's sole purpose is to collect information. However, by using principles of community-based participatory research (CBPR), the Accelerator model gives community members a voice in the research process, identifies research questions and approaches that are relevant to participants, addresses health equity, and engages a diverse spectrum of research participants, particularly those who may have traditionally been disenfranchised. The model has broad applications across a study life cycle, from early research planning and grant writing, as demonstrated in the Mount Sinai registry meeting, to adjusting recruitment and retentions strategies of an active study. Additionally, while an Accelerator will generate locally relevant knowledge and approaches, documentation of the Accelerator process will allow for replicable applications furthering the science of recruitment.

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Upstate MEDICAL UNIVERSITY

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