

Jill Harrison ([00:02](#)):

Hi, this is Jill Harrison, executive director of the National Institute on Aging Impact Collaboratory at Brown University. Welcome to the Impact Collaboratory Grand Rounds podcast. We're here to give you some extra time with our speakers and ask them the interesting questions that you want to hear most. If you haven't already, we hope you'll watch the full grand rounds webinar recording to learn more. All of the companion grand rounds content can be found impactcollaboratory.org. Thanks for joining.

Vince ([00:31](#)):

Good afternoon again. We're back after the wonderful presentation by Ellen Tambor and her colleagues from the Impact Collaboratory Stakeholder Engagement team. And Ellen, that was just terrific. And I was wondering for those of us who are researchers who are engaged in this kind of work, if you could just sort of comment on the level of contribution and how it is that stakeholders from the people living with dementia and their care partners, how are they engaged in this process of advising researchers in particularly the construction of methodological decisions around how to do a particular kind of pragmatic trial?

Ellen Tambor ([01:19](#)):

Sure. I think that the engagement of any stakeholder and that includes people living with dementia, comes before a trial has even begun in making sure that the research questions that are being studied are really important to people living with dementia and other stakeholders. And a lot of times they will contribute to, in addition to what's the most important study questions, what are the most important outcomes to measure in pragmatic trials? And then I think in terms of once a project is underway and advising, continuing to advise to the research team, it really varies across the scope of the project.

Ellen Tambor ([02:09](#)):

Early on, we usually have stakeholders doing things like reviewing study materials that are going to be used by participants, things like informed consent forms, commenting on the details of the study protocol and how people living with dementia are going to be involved in the study to make sure that what's being asked of them is not too burdensome or what's being asked of caregivers is not too burdensome. And then certainly once the study begins to have some results, stakeholders can contribute a lot to thinking about what's important from those research findings to people living with dementia? What sorts of messages are going to be important to disseminate? And I'll pause there and see if that answered your question.

Vince ([02:57](#)):

Gary, do you have anything you'd like to add?

Gary ([03:00](#)):

I would just emphasize the portions that Ellen said about feasibility and acceptability, particularly for the stakeholders who have cognitive impairment or our caregivers. They will want the research to be easy to participate in. Specifically regarding your methods question. And I didn't know if you were asking a separate methods question about the engagement itself, or if your question was about stakeholders contributing to the investigators methods.

Vince ([03:37](#)):

I was actually asking you about the latter since I'm a researcher. But I would love to hear your comments on the former.

Gary ([03:45](#)):

Ellen, that's a lot of what you presented. Do you want to kickoff that answer and then I'll join as well?

Ellen Tambor ([03:54](#)):

Sure. And would you rather that this answer be focused on methods for engaging people living with dementia? Or just engagement methods more broadly?

Vince ([04:03](#)):

I think for dementia, to the extent that the two of you can, you may want to talk more broadly, Ellen, and then Gary can speak to the specific issues around dementia.

Ellen Tambor ([04:14](#)):

Okay. That sounds good. In terms of approaches to engagement, I think it's obviously a rapidly evolving field, but I think we've learned a lot over the last decade or so about what works best and just some basic principles of effective engagement. Things like being sure to allow time to form relationships between members of the research team and stakeholders and making sure that stakeholders are really adequately prepared. That they have any sort of training and orientation they need to be able to contribute fully. And I could go into a lot of detail about different engagement methods, but I think it's very dependent on both the particular study, the phase of the research, what's being asked of the stakeholders. The type of engagement method you use at any given time is based on a lot of specific factors.

Vince ([05:15](#)):

Great Gary, how about, is there any specific things that are more complicated or difficult in the context of persons living with dementia, engaging them?

Gary ([05:24](#)):

Ellen addressed a lot of this in the grand rounds and addressed it really well, drawing from work that Lori Frank led reporting in the American Journal of Geriatric Psychiatry regarding a group of people living with cognitive symptoms who provided input to the 2017 NIA research summit on dementia care. And the best practices that grew from there were a lot of face validity. That people want to feel included, even though they have diverse capacities and not feel that there's excessive accommodation to them. It's sort of a person centered approach to supporting people by providing easy materials to go through, extra time when needed, opportunities for them to ask questions, but also an acceptance that for people with mild symptoms, they can function as independent people anywhere would want to respectfully be engaged in a dialogue. To not be patronizing or excessively accommodating.

Gary ([06:38](#)):

And for family members, there was a very nice comment today from Sue Borson about how caregivers have different perspectives over the natural progression of a disease of their loved one. I think investigators being sensitive to the multiple responsibilities that caregivers have and that participation

in a research project being on top of those and making adjustments over time would be particularly important for family caregivers.

Vince ([07:16](#)):

Great. Okay. Thank you. Related question from one of the people from the audience and asks, "When forming advisory committees for pragmatic trials, do you recommend offering compensation for their participation?" Some kind of honorarium. Ellen, what do you think?

Ellen Tambor ([07:36](#)):

I think it's become the accepted norm that when you're involving stakeholders, you compensate them in some way for their time and effort. I think for other types of stakeholders, clinicians and policymakers participating in things like advisory committees may just be part of their day to day job that they're compensated for anyway. But to involve patients and family members who have other responsibilities and are taking time out of their schedules to contribute to a project, it's really important to make sure that they're compensated.

Vince ([08:14](#)):

Great. Thank you. You talked a little bit in your presentation about work that you're going to be doing with the patient centered outcome group as one of our cores of the Impact Collaboratory and that you'll be working with the Alzheimer's Association in terms of identifying individuals living with dementia and their care partners who will be selected as part of a lived experience panel. How will those people be selected? And how long will they be engaged?

Ellen Tambor ([08:44](#)):

Well, I'll start off and then I'll let Gary add to this one because he's probably thought more about it. We're using a process that the Alzheimer's Association has used for previous stakeholder panels in the past where they accept applications or nominations from people that are interested in participating. And then there's a process of going through those and having a one on one conversations, phone conversations, with people that are interested. And so I'm not sure about more of the details what the criteria are going to be for identifying who will be included, other than the fact that they're really seeking a balance between earlier stage disease and then caregivers who are participating as proxy respondents for individuals with the later stages of disease. Gary, you might be able to add more detail to that.

Gary ([09:35](#)):

Sure. We're preparing the front material right now. Vince, you'll likely see it before it goes live on the Collaboratory website. And this will all be doubly branded and vetted with the Alzheimer's Association regarding their best practices for the early stage advisory group that they've run for many years. People with mild cognitive symptoms who provide input to the Alzheimer's Association. And there are other similar groups, but they really have the most experience. And when we send out the message, it will be to invite people with cognitive symptoms. And then also these other two categories, family caregivers who are representing their experience as a caregiver.

Gary ([10:22](#)):

And what's unique about this group is this work we'll be doing will be specifically asking and training family caregivers to function in a proxy role. Not representing themselves, but representing someone with later stages of illness who lacks the capacity to represent themselves. And when we make these selections, it will be four persons from each perspective and likely will be for one or two years that they will participate. And then there'll be a rotating process of including new people as members rotate off. The primary criteria will be what Ellen described of making sure that we have heterogeneity from all perspectives and that for people with cognitive symptoms and the caregivers who are doing proxy responding, that they understand the specific asks to them. And there likely will be an interview process that follows an online application.

Vince ([11:28](#)):

Great. One last question, the Alzheimer's Association, as well as presumably other projects that such as the ones that might emerge from the Collaboratory pilots, as they move into a broader, full scaled embedded pragmatic trial, let's assume they have a stakeholder group that they've recruited early on. How do they cope with and what are the best practices or the advice around managing to sustain the input of individuals as their intellectual capacity and ability to interact and engage deteriorates because of the advance of the disease? Ellen or Gary, whoever feels more comfortable.

Ellen Tambor ([12:11](#)):

Yeah, I think Gary, if you don't mind, I think you probably are in a better position to take that one.

Gary ([12:17](#)):

Sure. It'll be case by case for that investigator, Vince. And our team will provide guidance as requested for investigators. Them having set up a supportive arrangement, the person with cognitive symptoms will her or himself likely be aware that it's becoming additionally taxing. And there would be other people who have cognitive symptoms who are participating as stakeholders who will continue the efforts as there is a transition off. Something as simple as that.

Vince ([13:05](#)):

Okay. All right. That's great. Because these are all very subtle issues and it's not the kind of thing that investigators normally think about, but it is clearly an issue in this context. Ellen, you were going to say?

Ellen Tambor ([13:18](#)):

Oh yeah. I was going to just add more generally. I think it really points to the need for, we talked about the importance of establishing relationships with stakeholders and the research between stakeholders and the research team. I think in this situation of working with people living with dementia, it just points to the need for an even closer relationship between the research team and stakeholders. And certainly that's not the top skill of every investigator. I would think that just requires some self awareness on the part of investigators that if that is not really something they feel they're going to be strong with, that they bring somebody onto the team that really can focus on maintaining those relationships over time and checking in with people to see how they're doing and what their situation is and if they're struggling.

Vince ([14:12](#)):

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Sage advice. Thank you very much. Ellen and Gary, thank you very much for your time. We appreciate it. I'm hoping we'll do this again next year.

Jill Harrison ([14:24](#)):

Thank you for listening to today's Impact Collaboratory Grand Rounds podcast. Please be on the lookout for our next grand rounds and podcast next month.