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'd want to hear most.

Jill Harrison (00:17):

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 at impactcollaboratory.org. Thanks for joining.

Interviewer (00:29):

Good afternoon everyone. It's my pleasure, on the part of the IMPACT Collaboratory, to be recording this podcast. We had a fabulous Grand Rounds yesterday from our health equity team and today I'm talking to Ana Quiñones who leads our health equity team as an associate professor in department of family medicine at OHSU, and Jonathan Jackson, who is a instructor in medicine and neurology at mass general hospital where he directs the Community Access Recruitment and Engagement Research Center.

Interviewer (01:05):

So thank you both for being here. So Anna and Jonathan, there's been so much work done in the last eight to 10 years to advance the methodology of pragmatic trials. And at the same time there's been a lot of work done around health equity in the conduct of traditional randomized trials. But in fact, the intersection of the two, there's been almost no work done in terms of applying principles of health equity to the conduct of pragmatic trials. Jonathan, why do you think this is? Why do you think there's just been this gap?

Jonathan Jackson (01:38):

Goodness, that is a great question. I can't say for sure, but I think it's because health equity and trying to operationalize health equity is an ongoing challenge. It's one of those things where we hope we're doing the best we can, but in the absence of a really robust, rigorous methods or measures, it's too difficult. And given that pragmatic trials have really been coming into their own, I think that there were some people who assumed that pragmatic designs effectively solve the problem that might be addressed through health equity, and others may not just have had the tools.

Jonathan Jackson (02:29):

So I think it is probably felt like a bit of a challenge without a clear set of solutions. So I think both of those things probably played a big role.

Interviewer (02:40):

Yeah, it's an interesting point you make. When I once brought this topic up, someone says, "Well, it's not an issue in pragmatic trials because you're applying the intervention to the whole population. We're not having any eligibility criteria." But I think that clearly that's way far too simplistic and erroneous.

Jonathan Jackson (03:01):

Yes, very much.

Ana Quiñones (03:02):

Yeah. And if I could add to that just for a second, I actually wonder how well we are doing in an efficacy space. So in any design specifically around Alzheimer's disease and related dementia is, I think it might be also an issue of lack of clear methods and understanding of how to do this well and that translating down into the effectiveness world, into the pragmatic world as well. And I think Jonathan made these points really clearly in the Grand Rounds yesterday.

Interviewer (03:36):

Yeah, he certainly. Ana in the Rounds yesterday, I really liked the way you went through each [press E2 00:03:43] domain and tried to highlight aspects of those domains that lend itself to deeper thinking on applying issues related to health equity. You also concluded that just using the press E2 is probably an oversimplification of the issues.

Interviewer (04:00):

That said, there's lots of things to consider in the design of these trials and I'm going to put you on the spot here and ask if you could think of maybe the top three challenges in terms of health equity or maybe even the top three domains or challenges within those domains. If you're an investigator trying to design one of these trials and really deeply consider issues, health of equity, what do you think are the top three challenges?

Ana Quiñones (04:30):

That's a great question. I don't know if I could possibly rank order them in top three in terms of importance without further understanding how these ramifications play out and magnify. I would say that I think the challenges with understanding your recruitment process, your enrollment process, some of the things that we discussed at the Grand Rounds yesterday wherein pragmatic trials, they may be obscured, so we may not really understand the processes that are involved with ... Because of the randomization level being at a healthcare system or in a clinic site within healthcare systems, not really understanding what that process looks like. A little bit of a black box in terms of getting patients into your trials and evaluating patients through those trials.

Ana Quiñones (05:22):

I think that that's really disambiguating that that process and understanding those pieces I think in the pragmatic space or the pragmatic context might be the most important thing to think about or one of the most important things to think about and really work through the exercise of carefully considering health equity.

Ana Quiñones (05:42):

And as Jonathan made this point at Grand Rounds yesterday, thinking about this not just in terms of health disparity populations, but really thinking about this in terms of doing really good science and thinking about the threats to validity and the threats to the study design that may be specific to health equity populations or health equity considerations, but really what's involved here is doing really great science.

Ana Quiñones (06:06):

So the enrollment concerns, having some due diligence there and understanding who your population is, where it comes from, how it enters into your study, how you're analyzing that, thinking about how

patients are ultimately being offered these interventions, and then carrying it all the way down the line and thinking about the analysis that we're doing, the primary outcomes that we're identifying. All of these have important health equity considerations and all of these have implications for how we ultimately determine what's effective and what isn't.

Interviewer (06:40):

Yeah, those are great points. You know, sometimes I get the feeling people almost throw their hands up here and think, "There's so much stuff I've got to consider in designing my trial that you can't possibly think of everything. But what you're really saying or describing is quite a paradigm shift, I think, and an important one and trying to really just embed this in good science.

Interviewer (07:06):

Jonathan, you described a really interesting method yesterday for ... And you had a name for it that I can't quite remember, but that allowed a investigator to get a better handle on the demographics, socioeconomic and ethnic profiles of a certain catchment area for a region they may study or consider studying. Can you tell us a little bit more about that and if somebody wanted to access this tool or use it, how they might do so?

Jonathan Jackson (07:37):

Yeah, so I believe you're referring to the floating catchment area family of metrics. So there's a lot of different flavors of FCA or floating catchment area and then there's multiple corrections and I guess families of analyses for it. But in brief, what a floating catchment area allows you to do is to really precisely define the individuals who are using any kind of service. So this is a tool that is primarily used in healthcare settings to look at actual utilization rates rather than theoretical utilization rates. And usually those utilization rates are pinned to a specific zip code or a specific County. So you can look at who has been using a service.

Jonathan Jackson (08:29):

In the United States, the way that floating catchment areas are often used are to really differentiate two kinds of health systems that may exist in America. So one is a health system where most of the people who utilize a service are within a small geographical region. And then another kind tends to serve more suburban or rural populations where the utilization is much more diffused over a large geographic area.

Jonathan Jackson (09:02):

So you can add a lot of bells and whistles, different kind of distance decay functions, different sorts of corrections and methods. But it's a really great way of understanding who's actually able to use a particular healthcare system. So if you have a wide swath of individuals within a geographical region and then one dark spot where maybe no one is able to use, or no one is going to, a particular healthcare system, then that's a bit of a red flag. You can also stratify floating catchment metrics for demographics.

Jonathan Jackson (09:36):

So in one classic example, [Bisnett 00:09:40] and colleagues looked at languages spoken in the suburb of Canada, in a suburb of Toronto in Canada and found that the floating catchment metrics were different depending on what language physicians spoke. So that was a really great way of illustrating how even

thinking about theoretical distribution of who's able to access a particular healthcare system can be stratified by race, by language spoken, by any of these aspects of health equity that we often consider.

Jonathan Jackson (10:13):

So usually there's a really great, robust literature on how to implement a floating catchment area. The formulas are actually not so complicated. Maybe if there are show notes associated with this podcast I'll put in one of my favorite papers, Delamater et al 2019, which gives you the formulas right in the paper. And then in terms of receiving the data, usually most departments of health at the state level will have information on utilization rates and those can be obtained either for a small cost or sometimes for free depending on the state.

Interviewer (10:49):

That's great. Thank you. Thank you very much. So as you know, one of the main activities of the IMPACT Collaboratory over the next five years is going to be funding small pilot studies to prepare for a full scale EPCT. We're still trying to work out within ourselves what an ideal pilot study is, but already we're running into a lot of what people perceive as competing important aspects. It could be stakeholder engagement, it could be collecting it outcome pragmatically. There's probably a dozen things.

Interviewer (11:31):

Ana, I wonder if you could maybe give some tips on how someone who, an applicant who may be thinking of putting in a pilot study, how they begin to integrate this into their small pilot and then what the health equity team can offer in terms of helping applicants design their study and also their study.

Ana Quiñones (11:55):

Yeah, that's a great question. So the health equity teams, again as we discussed yesterday at the Grand Rounds, I think a lot of the novel and the forward thinking ways in which we're approaching this work is how to improve the science really and how to try to make this as inclusive, as generalizable, as applicable as possible to all Americans with dementia, not just a select few that that happen to be studied more often or happen to be pinged more often.

Ana Quiñones (12:27):

One of the strengths that we have as a team and one of the things that we think about often is our charge and our responsibility, and our interest in really integrating very closely and very tightly with all of the other working groups and the other team in the Collaboratory. So in a lot of ways I don't really think about this in terms of competing priorities, but how can we best align and how can we best coordinate?

Ana Quiñones (12:51):

I think a lot of the working groups on the other team have very valid points about what's important and what needs to be considered, but ultimately we're all interested in improving the nation's portfolio of forward-thinking science and of important science with regard to this important disease. We do have some great expertise in the Collaboratory and in specifically in the health equity team to help the pilot applicants and the pilot grantees in thinking through their projects.

Ana Quiñones (13:23):

So some of the things that we have been talking about and that we provide consultancy services for applicants and for the pilot awardees is around some of the themes that we talked about yesterday at the Grand Rounds. So doing a lot of that upfront work that may be gets subsumed, or gets buried, or doesn't get prioritized as much as it should. Thinking about how to engage with particular populations that often get dis-included or disenfranchised in the research process, how to best do that. How to best garner trust and cooperation, how to best work with and get that stakeholder engagement so we can be better informed about outcomes that are important to a variety of patient population groups.

Ana Quiñones (14:05):

How to think about some of the issues that Jonathan raised and that Jonathan and I raised at the Grand Rounds in thinking about these multiple levels that are occurring as well. It's not just about the patients, it's not just about the healthcare systems or the clinic sites, but also thinking about potentially the clinics that are delivering those interventions and how these interrelated levels influence and effect across multiple domains of putting up and setting up a study from beginning to end.

Ana Quiñones (14:31):

So we can offer some consultancy services around specific things such as cultural competency, maybe training and resources and providing guidance to make sure that pilots are aware, first of all, of that upfront work that needs to happen. And second of all informing them and going through and putting together these larger demonstration projects, all of the work and all of the resources that are really involved in conducting and doing good science.

Interviewer (14:58):

Oh, that's fantastic. Thank you.

Interviewer (15:00):

Well, we all are certainly looking forward to the work that we'll be emanating from the health equity team to move this field forward in a much needed way and for your expertise in helping our pilot applicants and career development awardees make their science more rigorous by intertwining health equity from every stage of the scientific process.

Interviewer (15:28):

So I want to thank you both very much. Stay well and look forward to more.

Jonathan Jackson (15:35):

Thanks so much.

Ana Quiñones (15:36):

Thanks for having us.

Jonathan Jackson (15:38):

Okay, have a great day. Bye-bye.

Jill Harrison (15:40):

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.