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 at impactcollaboratory.org. Thanks for joining.

Susan Mitchell: 00:31 Welcome everyone. This is Susan Mitchell. I'm one of the PIs on the NIA IMPACT Collaboratory. And today we're having a follow-up podcast to our Grand Rounds yesterday. And we have with us today, two members of our technical and data Corps, David Dore, who's a Professor and Vice Chair of Medical Informatics Clinical Epidemiology at the Oregon Health and Science University School of Medicine. And we also have Vinod Vydiswaran, System Professor of Learning Health Sciences, University of Michigan. We had a terrific Grand Rounds yesterday entitled, using and leveraging electronic health care systems, administrative databases for identifying and studying outcomes of pragmatic trials in people living with dementia. So welcome David and Vinod. Thanks for being here.

David Dore: 01:28 Hello.

Vinod Vydiswara...: 01:28 It's a pleasure. Thanks.

Susan Mitchell: 01:29 Great. So that was a really terrific Grand Rounds. As I said, at the end of the Grand Rounds, this feels like a field very much in a rapid motion with a lot of evolving and improving methodology. David, I'm going to start with you. One of the slides you had yesterday had a picture of sources to go to for various standardized algorithms for people setting out to do these types of studies. And you encourage people clearly to try to not make this up, to use one of these standardized algorithms or approaches that were published and validated. There still seems to be a fair bit of choice though, within what's published and what standardized out there. And so my question as I saw that slide was well, how do you choose among what's out there for one's particular trial? Because there's fair bit published in this area. Not all the same I might add.

David Dore: 02:25 Yes, not all data are the same and not all, what we call concept sets to define a phenotype or, a phenotype is as a physical manifestation of a disease for informaticians like Vinod and myself there. How you define a condition like dementia for

people living with dementia, or how you identify caregivers using coded logic or using advanced algorithms that might even search through data. So we encourage a standardized approach and really for most people, it's actually a goal of the technical data corp to get better and better answers to this and keep them updated. As we go along with the collaboratory right now, there are a couple of simple recommendations I have for people. And that's that one thing that people can do right now easily, that's probably part of their preparation is actually looking at the literature.

And when they're looking at the literature for what's been done before and where people have done similar things, they might look in their trial design for identification steps from those other studies that are quite similar to their own. And then look to the degree in a different way than they might normally to say, what is the degree that this group validated their approach for identification? How well did they identify people using these algorithms? And did they publish the codes, the concept sets, as we say that they're using to identify this? If they did, or they referenced a standard tourist, then that might be a good indication that that's the first step for them to go. The places where you can go look besides the literature, if there's not much out there, or you're not really finding one that standard, there's a couple of different places.

One is identification of dementia is done in lots of different ways. And there are standard ways that people are already doing this outside of trials. So a classic case is, electronic clinical quality measures, or different concepts that go into assessments. And you can look at what we call the value set authority center, which is at the NLM. It's easy to search on and they have these standard sets available, where you could just go to a site and search on dementia and see where that's been used before. There are similar ones for long-term care definitions, ones that for groups that are pretty savvy, we often recommend they go to phenotype knowledge bases. And there's actually one called PheKB, P-H-EKB, that has standard sets and tell you how well they work. And there's one called PhenX, which is P -H-E-N-X.

The difference between those is PheKB is all EHR based, and PhenX is really focused on research study use of these concepts. So I'd really encourage people to look in the literature, as they're finding what they need, try and link that source down, even ask the authors. Otherwise, we have these sources that people can go to to see a good match. And one thing about this

is none of them are perfect. So don't let perfect be the enemy of good, try to find something that's been used before. And that will really help a lot in terms of moving you forward in your identification using standardized approaches.

Susan Mitchell: 06:26 Awesome. Thank you. Very helpful. One thing that really distinguishes pragmatic trials and any trials, frankly, in dementia, is that often we're dealing with dyads. So not just the patient, but patient giver dyads, we talked a lot yesterday about identifying patients with dementia, what pearls or anything, or is there anything out there, any standardized approaches to identifying their caregivers, either using claims or EHR data so that these dyads can be studied pragmatically?

David Dore: 07:04 Yeah. This is a very interesting area and Vinod may have some comments as well. Most of my research has been done in primary care, looking at issues related to complex conditions and situations. And so one of the things that we did in our work was identify caregivers because so many of the groups that we were working with had caregivers. And one way that people do this now is to record a little more regularly in the EHR, some kind of key contact and give that a little bit of a role. So there's information, it's in the demographics section of the EHR, but structured information. And many health systems now, do have a place where you store information about if there's a primary caregiver. It's not used reliably and it's not coded in a way that we could use the same approach everywhere, but it is possible to do that.

Similarly, people are now recording surrogate decision-makers as part of some different legislation that was passed, especially for post hospitalization, where you're trying to identify caregivers that way. And so that can be used as a proxy, but a lot of times, to be honest, this is in the narrative note and it's just not recorded. I should mention that Jennifer Wolf out of Johns Hopkins and I, she's the PI, have been looking at proxy access. So someone else having access to your electronic health records often through the personal health record, the patient portal as a good proxy for this. And so to encourage that, to get all caregivers with that access, and then it's very easy to find who the caregiver is because you actually have their information as part of that proxy access.

Susan Mitchell: 09:18 Great. Vinod, do you have anything to add?

Vinod Vydiswara...: 09:23 Yes. So thanks, Dave. I think he correctly identified these two places where information about caregivers would be available.

One in the form fields that kind of asked specifically who would be your surrogate and the other clinical notes. There are some recent K proposals that have tried to identify caregivers in a systematic way from clinical notes. So this area is getting actively researched on right now. One bit I would want to add is how our pilot applicants looked at this problem. So one of the things that was interesting when I looked at them was just asking them about the people they care for and then looking for mentions of dementia or mild cognitive impairment in how they described the people that they're caring for. And so it was using almost like a proxy, a self disclosed proxy, so to say, of identifying caregivers for people living with dementia.

Susan Mitchell: 10:37 That's really interesting. Thank you. Yeah. One of the supplements we're doing in impact collaboratories, trying to improve advanced care planning and assisted living. And this particular healthcare system has a patient portal. And for patients with dementia, it's largely the caregivers or the proxies that are accessing it. So that's clearly in this electronic health record. So that's the way we're doing it. Great. David yesterday, I was particularly taken with your description of what you were calling almost a rapid validation of approaches to identify people living with dementia in your particular healthcare system, before embarking on a large pragmatic trial. In other words, to make sure whatever standardized, hopefully methodology you've chosen actually works well in your particular system. Yesterday, I remarked that, that sounds like a pretty tall order if you're just trying to layer that onto already probably a complicated project and you described, I'll call it a mini validation process. And I thought this would be something that would be really good actually to the field if you could describe this for a broader audience and people could use it. So can you tell us just a little bit about your approach?

David Dore: 12:08 Yeah. So in general, the way we approach validation, especially from standardized approaches. So we're just implementing it locally, but somebody else has developed it and it is a quick and dirty. It is a mini validation and it is agile. And we use that in a very specific way in software development and it's really important here. And I described basically relative amount of error in validation checking. So what we'll do is we'll get the algorithm, we'll work with whoever's implementing and it's usually somebody with closer access to the data, but we'll say in an agile process, you are talking, you're communicating frequently. And so what we'll say is implement the first set, just send us five patients back or a small number. And then we'll validate the first five. And if there's any errors in the first five,

we know there's probably a greater than 20% error rate right now. And that's too high, right? One out of five would be greater than 20%. So they need to fix that.

We'll do five again after their second round, and basically we'll try and get that expected error rate down to whatever level it needs to be. For a lot of these, if we're just going to be validating them further, 5% error is totally great. It's fine, positive, predictive value. So the number that come back that are a hundred percent accurate is often low, right? So the percent of those coming back that will be eligible is often low in many of these algorithms. And so we don't need a really great example. We just need it to work the way we expect it to. And so I often end at 20, if I get 19 out of 20 are accurate enough, then I know I have about a 5% error rate. The difference is we report that, we record that process and then we report how often we think it's an error in part just to plan our recruitment and our approach, but also I think to further validation overall.

And I think that's a perfectly good way to do it for the validation without burdening. And it takes a very short time, but it does require frequent communication with the people implementing it and making sure they know you want them to not try to make it perfect first, but to try and implement what's there and get you a response quickly.

Susan Mitchell: 14:50 Yeah, that's great. I would, again, encourage a one or two pager, even that we could post on our website of like a how to, so that as the pilots come along, we don't have to re-explain and re-explain, but it's a general approach certainly. It's so much objective, but I think that it would be really helpful for the applicants and for the field to jot that down in some way, for reference. Question for Vinod, you have a conference coming up, it's a workshop, we're calling it future priorities for identifying people living with dementia, from digital health care data for embedded pragmatic clinical trials. Could you tell us a little bit about this conference and what is vote and what you're hoping to accomplish?

Vinod Vydiswara...: 15:38 Yeah, absolutely. So we, we planned this as an in-person workshop, a hands-on workshop, but because of COVID pandemic restrictions, we are going to move it online, but still would want to keep that closed group understanding. I should not say close group, a small group, understanding of how different groups around the country are looking at this problem and in different settings, right? In nursing home settings, in academic medical center settings, and so on. And interestingly

highlighting within the sessions that we have designed how people went from, how their thought process evolved, or the process of going from let's say, structured data to a more approaches that use electronic health records in addition to just the structured information. So that was one example.

Another one is to have a panel discussion that brings in those who work in nursing home facilities and other advanced care organizations, along with those who work in hospitals and ED with ED patients. To try to conduct, see how they are trying to identify the same group of patients, but have access to different data elements. And how can we come to some sort of a consensus about how these approaches differ and how they could be utilized across settings.

Susan Mitchell: 17:22 Well, that's great. I've been advocating for this kind of a workshop for a few years now, so I'm very excited about it, and I think it'll be a great contribution to the field for the products emanating from this workshop. I want to thank you both. I look forward to much more coming out of the technical and data corp. You've already been so helpful with all our pilots and with real practical help that I know will advance this field. So thank you both and have a good afternoon.

Vinod Vydiswara...: 18:00 Thank you very much.

David Dore: 18:01 Take care, thank you.

Jill Harrison: 18:05 Thank you for listening to today's IMPACT Collaboratory Grand Rounds Podcast. Please be on the lookout for our next Grand Rounds and podcasts next month.