Jill Harrison, PhD:

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.

Hello, everyone. I'm Jill Harrison, one of the executive directors at the NIA IMPACT Collaboratory. Welcome to today's podcast. I'm joined today by Dr. Julie Bynum from the University of Michigan. Julie, thanks so much for being here.

Julie Bynum, MD, MPH:

Thank you for having me.

Jill Harrison, PhD:

Of course. This is the companion podcast that accompanies a presentation you made earlier in the week at our monthly grand rounds on the topic of "Diagnosed Dementia in Medicare: Benchmarking for Study Planning and Equity." Can you please give folks tuning in today a high-level summary of why benchmarking is important for study planning and equity?

Julie Bynum, MD, MPH:

Yeah, I'd be happy to. So, many times when we set out to recruit people for our studies, we can't really know the underlying population from what we're selecting. And so when we get a group of people, we don't know whether the set of people who have been willing to join our study actually reflect the community and population that we want them to reflect. It can be really difficult to know what ways our recruitment has been biased. So using external data sources about our target populations through other sources so we can understand, well, what is the real age of the population of people with diagnosis of dementia, for example. So you can know whether the people who are actually enrolling in our studies reflect that. That's the big idea. It's not very complex.

And I think what the presentation really highlighted is that there's ways in which there's nuance and understanding even the population data and in particular how place matters. We often look for balance on say, age and sex and race, but we don't necessarily think about place, where people are recruited from and how that might influence some important differences across the populations in our studies.

Jill Harrison, PhD:

Thank you. After your talk, it really stuck with me just how impactful this data is not only for investigators, as you're pointing out, conducting clinical trials that target people living with dementia, but also for healthcare systems. And specifically, I was thinking how the regional and setting-based prevalence data that you described in your talk could be used to inform enterprise-wide operations, understanding patient needs, volumes as they vary by region and setting and so on. What utility do you see for healthcare systems using this data, and are they?

Julie Bynum, MD, MPH:

Yeah, that's a great observation and in fact, all of my research has been observational research, which uses the data in precisely the ways you're talking about. And yes, I think organizations try to use data this way. In fact, I've been giving other grand rounds talks recently based on data related to this to help people understand if, say, they wanted to do the new dementia care program that CMS is conducting, like how might they assess their own health system to know where to locate it? Where are these populations across the various hospitals and clinics and emergency rooms if you had to decide where to put your and recruit for your dementia care program?

So yes, absolutely. These data can be used to inform operational issues. They can be used to inform decisions about participating in payment plans. The trick though is they're actually not that easy to get. It's costly if you're going to purchase these kinds of data from investigators, and usually health systems have their own data, so they have the data in their electronic health system, which is good. It's good for everybody who receives care, but what they can't see is the other people who are in their service area who's not receiving care from them. And that can lead to some important gaps and omissions in their strategy as they think about how to implement their healthcare operations.

Jill Harrison, PhD:

One thing we talk about quite a bit in the IMPACT Collaboratory in terms of pragmatic trials that are embedded within healthcare systems is this need for investigators to create a compelling value proposition to use when they're approaching healthcare systems about participating in a trial. And we've developed some resources for this, but I wonder what your thoughts are on integrating these data into that value proposition or that elevator speech, so to speak, in terms of helping the healthcare system understand why a particular trial or intervention is important, and even sharing that data with site champions or interventionists who are delivering the intervention. How do you think this could be used in that value proposition?

Julie Bynum, MD, MPH:

Well, I think sometimes we only think about... of course, we think about the data from our own perspective. And I will say if you're trying to make a value proposition and you're using national averages of numbers, that's not going to be really compelling to a particular healthcare provider because all healthcare is local in their local community, their local environment, and as I pointed out, I think one of the major points I tried to make is that in any given place that national average may be way off what a certain community is really trying to address or is in their community need. So from an investigator's point of view, we can't use the shorthand. That's the first three sentences of every article about dementia, right? Oh, the population's increasing.

We have to actually cater it and tailor it to our group that we're working with, with our partner to localize it to their own environment and their own needs. Whether it's this kind of data or others, I think it really shows a much stronger understanding of your stakeholder group or your partner group, your healthcare organization. If you can put yourself looking at the world from their point of view rather than just trying to use generic numbers that you've pulled from some national report to motivate what's going on. I mean, we say this all the time, right? You have to understand the other group's needs, but that also goes for the population they're serving too. You need to understand the population they serve.

Jill Harrison, PhD:

One aspect of your talk that generated many questions is how investigators can utilize the query resource that's available through IMPACT about the number of beneficiaries diagnosed with dementia in the United States. Can you talk about that website and the process?

Julie Bynum, MD, MPH:

There is literally a website with an entry for typing in your question or your query that will then go to a human being who assesses whether that's something that can be answered with the data and try to connect you with either that data source or a person who can help answer it. It really is about specific questions around interventions is the way this is designed. I'm sure there's lots of, lots of people who would like these data sets for their observational research, but this is not set up for that purpose. It's sort of more catered to the scope of what IMPACT Collaboratory is all about.

And part of that is this data has a lot of fine-grained detailed information by race, ethnicity, and age, and that leads to a lot of important issues of data suppression that makes it so we can't just sort of post it online and it would actually be kind of hard for people to understand if we did that, we think. So the mechanism is to go to that website and you can actually enter your question or concern about your study, and they will actually hook you up with either an answer that can be sent to you, email, or talking to someone who can reference the data and help you out.

Jill Harrison, PhD:

Fantastic. Well, for folks that are listening, they can navigate to that website through impactcollaboratory.org, and I have no doubt you will see more traffic in those requests after amplifying the message to the large number of attendees at grand rounds. There was tremendous interest in accessing this resource.

Julie Bynum, MD, MPH:

I think today one of the things we have to be concerned about is it's actually getting more expensive and harder to get access to population data through Medicare for many complex reasons, and the sources for it are sort of fewer than there used to be. So figuring out ways to help people understand the population they serve and get that data is certainly something that is not directly related to conducting a clinical trial. But those underlying benchmarking data, finding sources for them are important for all of us who are doing studies and trying to make sure we're aligning with the population needs and maintaining high levels of health equity in our studies.

Jill Harrison, PhD:

Has there been an activity to look back to see how representative have trials been now that we have this data available to us?

Julie Bynum, MD, MPH:

Most of the data I showed today is brand new, so to say that it's been available as a little bit, it's not really been out. So no, I don't think... certainly our group hasn't done that. I mean, certainly there's lots of published studies about how poor age representation is in many, many studies of diseases that affect older adults. There's been a lot of studies around those issues, but I don't know of any that sort of uses this kind of data to go line by line of how representative these groups are because, of course, clinical trials, not necessarily pragmatic ones, but randomized trials that recruit one by one, they have all sorts of exclusion criteria too. So it's really hard to translate these population data directly to the representation of the study. But for pragmatic trial where you're doing much broader recruitment with a goal to get the true population, I think these data could be much more helpful.

Jill Harrison, PhD:

Fantastic. So I have five questions that came in from our audience members and we just ran out of time during grand rounds to get to them. So I'd like to ask them now, and many of them are specific to the data. So the first one is, are types of dementia differentiated in the data or are all types of dementia lumped together and being referred to as Alzheimer's disease?

Julie Bynum, MD, MPH:

So we refer to everything as Alzheimer's and related dementias. We don't refer... I mean in shorthand when I'm speaking, I might say Alzheimer's disease, but there are specific ICD-9 and ICD-10 codes in this case for each diagnosis. But this algorithm puts them all together. I personally don't believe that there is enough validity in claims data to be confident that codes that say somebody has frontal temporal versus Lewy body disease are actually good enough within their accuracy to be used in that way. So I don't recommend people use it that way. This algorithm identifies people living with dementia, dementia of any cause.

Jill Harrison, PhD:

And a related question, can you comment about how the algorithm has been validated?

Julie Bynum, MD, MPH:

So that was a whole topic of a whole nother grand rounds, and I did go over it briefly in this one, but we created and validated against the Health and Retirement Study, which has objective measures of cognitive health, and then we did a secondary validation against a gold standard, the RUSH Alzheimer's disease cohorts, where they actually have in-person evaluations adjudicated by neuropsychologists and neurologists. So it's actually been dually validated, and I would point anybody to the papers that we published, but also to that other grand rounds if they want all those details.

Jill Harrison, PhD:

During the grand rounds, you had presented some setting-specific data. A question came in from one of the audience members that said, "Have adult family homes, which are increasingly common in our community, are those captured when you look at nursing home data?"

Julie Bynum, MD, MPH:

No. So these data are the national data sets that are used for payment. So for the nursing home, it is certified skilled nursing facilities that are paid for by Medicaid or Medicare. It does not capture other kinds of settings. Similarly, the hospitals are all these Medicare or Medicaid certified, so there would be any VA hospitals, for example, in that data set. Certainly there's lots of other settings where people with dementia get care, adult daycare, assisted living, all sorts of places like that that Medicare doesn't pay for, so they don't appear in these data.

Jill Harrison, PhD:

Two final questions from our listeners. You had mentioned that the VRDC should aid in real-time identification of potential study subjects using claims. Is this going to be true for non-fee-for-service MA beneficiaries, and how real-time, meaning within a month or six months or a year of a dementia diagnosis, would we be able to identify potential participants?

Julie Bynum, MD, MPH:

I don't know the answer about the Medicare Advantage question. I just don't know. And for observational research, so the kinds of work I do, we can start seeing data with a three to six-month lag, but for studies that are actually collecting data directly, they get them with a much shorter time window. Like outcomes for a clinical trial, meaning if you have a cohort of people and you're following them for hospitalizations, I believe they come in a much shorter timeframe. So it's actually getting better. I'm not going to say it's easy to necessarily get these relationships up and running and use the data that way, but it is the intention if you're partnering with certain organizations to try to be able to use these data, which are now much more rapidly available.

Jill Harrison, PhD:

Well, the final question is related to the Medicare Advantage beneficiaries. So as more and more people enroll in Medicare Advantage plans, how much do we know about them? Are there racial differences among those who enroll in MA plans versus fee-for-service?

Julie Bynum, MD, MPH:

Right, so I showed that data during the talk, and in fact, there are differences. Certainly a lot of the enrollment data we've known for a long time, and there's work by a number of people who have put this in the published literature. In the slides that I showed, and it depends on whether you're talking about the Alzheimer's disease-related dementia group or the entire group. If you look at all Medicare over 65, there are more people who are non-white in Medicare Advantage. On the dementia side, that's also true, but we also see more people who are dually eligible for Medicaid on the fee-for-service side and an older group in the fee-for-service side. So there are differences. Partly has to do with who disenrolls, which David Meyers has some papers about, clearly who enrolls. And generally what that boils down to is we see somewhat more severe dementia cases in the fee-for-service side, although I can't point to data that actually validates the severity of their disease. Just based on age is the main issue there.

Jill Harrison, PhD:

For junior investigators and trainees that are interested in learning more about how to use this data to optimize their trial designs, where should they start? What other resources should they focus on?

Julie Bynum, MD, MPH:

Well, I think using a centralized resource like the IMPACT Collaboratory is really the way to go. I mean, I don't think a junior investigator would primarily do these data themselves to sort of sort out the optimization. And I will say that you can use accessing something like I just said, the IMPACT Collaboratory, but there are other groups that report public data. The Brown Group has all the long-term care data online. The Dartmouth Atlas has information about populations by different geographies and their racial distribution and things. You can find chart books from the Medicare Current Beneficiary Survey or some of the other regional data sources.

So there's lots of different sources out there and you really need to know to look for them. I think the main message here is we don't necessarily think about going out and finding those benchmarks for what we should be targeting or what we expect to have in our studies. And this isn't the only source. There are many others to be going out there and trying to sort out. Even the county health rankings may be another great example of something you could use to try to get a grip of what the population looks like in any given area.

Jill Harrison, PhD:

Fantastic. Well, Dr. Julie Bynum, thank you so much for sharing your work with us and all you do to improve the lives of people living with dementia. Thank you so much for your time today.

Julie Bynum, MD, MPH:

Thank you.

Jill Harrison, PhD:

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.