



**Katie Caviness-Crolley** 0:03

Welcome to Medicine Made General, where real doctors break down real health issues. Whether it's a simple question or a complex concern, we're here to help you take charge of your health with confidence.

I'm Katie Caviness-Crolley, GIM's Communications Specialist. I'm joined by my co-host, Dr. Bimal Ashar, Interim Director of GIM.

This episode is part two of a special two-part series featuring Dr. Claire Snyder. In this episode, we focus on the power of the patient voice in cancer care and how Claire is helping ensure survivor perspectives are incorporated into every step of the care process.

If you missed part one, be sure to check it out — we talked about how cancer specialists and primary care providers work together to take care of cancer survivors.

We pick up the conversation where Claire shares the importance of cancer survivor quality of life.



**Bimal Ashar** 24:43

You've done some work in in quality of life in cancer survivors. I wonder whether you could talk about that a little bit.



**Claire Snyder** 20:42

Yeah. So one of the parts of my work that I'm most passionate about is making sure that the patient's perspective is central to their care and asking patients about how they're doing.

Is what we refer to as patient reported outcomes or pros. And so going back to definitions, pros are patients own reports of how they feel, function and live their lives. So they include outcomes like symptoms, functioning, well-being and health-related quality of life. And they're collected using standardized, validated questionnaires so that we can get results that are more structured and better able to inform care than just asking the question, you know, how are you today?



**Katie Caviness-Crolley** 21:36

So patient reported outcomes, I think that maybe is a phrase that some of our listeners might not be the most familiar with. So let's go into that a little bit more. Patient reported outcomes or you called it PROS for short. Can we talk more about how PROS help improve care for people living with? Cancer or after they've had cancer.



**Claire Snyder** 21:59

Yeah. So pros have been involved in cancer and actually just health care in general for for decades and the traditional use has been in clinical trials. So when you think about comparing treatment A and treatment B and you might have.



**Claire Snyder** 22:19

Outcomes such as like survival and cancer, or if you're talking about diabetes, it might be, you know, hemoglobin A1C or whatever. But what the patient reported outcomes do is they tell us about.

How these treatments are impacting patients lives. So in cancer, are they not just living longer, but how do they feel? How much of their usual activities are they able to do? I think, you know, cancer in many ways was a huge impetus.

To the quality of life and patient reported outcome field because we could see, you know, the old treatments were incredibly toxic and you know, it raised the question, you know, is the cure worse than the disease?



**Claire Snyder** 23:13

Unfortunately, cancer treatment has come a long way, but it's still important to think about, you know, the quality of life that patients are experiencing, not just the quantity.

More recently, what we've seen is in addition to comparing, you know, treatment A and treatment B on patient quality of life in clinical trials is incorporating the patient's own voice in a structured way as part of their routine care. So that's.

Me filling out a questionnaire and my doctor and me looking at my results together and seeing, hey, I'm really fatigued and that affects my ability to do my routine activities. You know, is there anything that we can do about this?

And that way we're not just looking at whether my lab values are going in a good or

bad direction. And we're not just looking at an imaging study about whether something is bigger or smaller than it used to be, because whether something is bigger or smaller on an X-ray or some kind of scan.

Doesn't necessarily affect like your ability to. It doesn't necessarily affect how you feel or your ability to do your day-to-day activities. And so I think it's just critically important that the patient voice is part.

**CS** **Claire Snyder** 24:40

Of informing their care.

**BA** **Bimal Ashar** 24:43

You know that's it's a fascinating thing and and you know it's basically a tool it sounds like and but I wonder you know one of the one of the difficulties in medicine is is getting those tools incorporated into care and I'm wondering.

What has what has really helped advance the use of these patient reported outcomes or pros in routine care?

**CS** **Claire Snyder** 25:08

So I think there have been several developments in the field in recent years. I mean, first is just the recognition and emphasis on patient-centered care. Um And I think clinicians have always been interested in patient-centered care, but just to lift up that. Concept and make it a focus of care delivery has been critical. The second factor is advances in technology that have enabled us to seamlessly collect these patient reported outcome questionnaires.


And integrate them in the electronic health records so that when my provider is looking at the screen and seeing, OK, this is what your lab values are doing, this is what your imaging studies are showing, but this is what you are telling me about how you're doing and the clinician.


Can then bring all of those pieces together and use that to inform their care. Now, just like anything else in medicine, pro scores like saying that my physical function is a 60 is not something that is immediately interpretable by clinicians.


Like BMO. So what we need to do is make sure that we make that number 60 meaningful to them and that the way we share the information and the electronic health record doesn't just tell him a number, but tells him the implications.


And so a lot of my research has focused on how best do we communicate that


information to providers and to survivors so that it is well, well suited to inform the patient's care.


 **Katie Caviness-Crolley** 27:01  
You know.


 **Bimal Ashar** 27:01  
Yeah, you got, you gotta make it as simple as possible for for people like me. That's that's that's my take away from this.


 **Katie Caviness-Crolley** 27:06  
Yeah.

 **Claire Snyder** 27:10  
Well, what we've said, you know, when we've talked to people is they say, OK, well, this is what we've put together to help explain it to patients. You know, what do providers need? And we say they need the same thing, like patients and providers need to get the same information both so that they're on the same page.

 **Bimal Ashar** 27:23  
Yes.

 **Claire Snyder** 27:30  
And also so they have a joint understanding of what the meaning is.

 **Katie Caviness-Crolley** 27:35  
Yeah. Well, and honestly, Claire, as I listen to you speak, I just, I would love to touch more on like, do you have any examples either from like an individual person or across the health system? Can you share, you know, an example of how listening to these patients in this way has changed their care?

 **Claire Snyder** 27:55  
Yeah, so you know, just from a high level, one of my favorite quotes comes from a mother of a child with cancer. And what she said is when the doctor asks how are

you? And you say fine, the doctor thinks he has collected clinical facts.  
Well, you think you have been polite.

 **Katie Caviness-Crolley** 28:15

Oh yeah.

 **Claire Snyder** 28:16

And like, I genuinely believe that the doctor wanted to know how the patient was doing, but sometimes informal communication is insufficient for collecting that kind of information.

 **Claire Snyder** 28:33

And some topics are just hard to bring up. So, you know, it's going to be hard for a patient to answer the question, how are you and say, well, you know, due to some of the side effects from my treatment.

You know, my sexual function has really been hurt and it's affecting my relationship with my husband. Or like another example is we've asked, we ask patients about questions about body image, if it's relevant.

 **Claire Snyder** 29:08

And you know, seeing the question on the questionnaire was.

Oh.

Made this patient suddenly realize, hey, this is something that my provider cares about. I never would have thought to bring up like my body image issues, but I I did and you know he was able to address them and I feel much better and I will also say that that.

That patient's provider also told us, hey, I was able to help that patient and I feel really good about that. So you have kind of these conspiracy of silence topics where clinicians won't bring it up if the patient doesn't raise it and patients won't raise it if the clinician.

Doesn't bring it up. Then there are other topics that it's just harder to diagnose in a brief visit, things like depression and anxiety. But if you have these structured questionnaires and you can see how scores are trending overtime or even you know.

 **Claire Snyder** 30:17

If their absolute scores are bad, it can help identify issues that might have otherwise gone unnoticed. So what we see with PROSE is a cascade of benefits. It facilitates patient clinician communication that leads to informing.

How patients are monitored and managed, and then that can lead to improvements in symptoms, function and quality of life. So it's rewarding to see the benefits at every step of the process.

30:50

Yeah.

BA

**Bimal Ashar** 30:52

You know, I want to switch gears a little bit, Clara, and and you know, something that I just learned about is this. You lead this Proteus consortium, which brings together patients, clinicians, researchers from around the world. I wonder whether you could tell me about your work with Proteus and.

What? What you're really proud of with this consortium?

CS

**Claire Snyder** 31:15

Well, I do appreciate your asking about Proteus, because Proteus is one of the things I'm most excited about in my current work. And what is unique about Proteus is that it's not about doing the research, it's about making sure the research that we have is translated.

Into practice. So we have all this information from our decades of work on the best ways to use pros in clinical trials and the best ways to use pros in clinical practice. But so often research results fit on virtual shelves and.

Virtual journals and what Proteus does is translate that knowledge into resources that are user friendly and enable clinical trialists and health systems to incorporate the findings. And we do this by partnering with.

As you said, the key sectors involved and that includes patients and clinicians and researchers and regulators and industry sponsors and policy makers and payers and the electronic health record vendors and health systems and so bringing all of these groups together.

And discussing how we can help navigate the use of patient reported outcomes both in clinical trials and clinical practice has probably been the most impactful and important work that I've done.



**Katie Caviness-Crolley** 32:49

Hmm.

Well, Claire, I cannot thank you enough for talking with us. This has been fascinating and exciting. If I may, you know, just one more question while we have you. I would love to know more about, you know, what motivates you? What? What keeps you motivated to do this work?



**Claire Snyder** 33:09

Well, I think that my enthusiasm for doing this kind of research is obvious, but you know, it is incredibly rewarding to do research that focuses on what matters most to patients.

And the opportunity to do research that I care deeply about and the opportunity to improve the lives of millions of patients is just incredibly gratifying. And I feel so lucky to be able to do this research and to be able to do this research with my.



**Katie Caviness-Crolley** 33:35

Sure.



**Claire Snyder** 33:44

Fantastic colleagues at Johns Hopkins, both in the Cancer Center and in general internal medicine. And I really appreciate the opportunity to share some Nuggets of knowledge with your audience. So I appreciate the opportunity to join you today.



**Bimal Ashar** 34:04

So this was great. I mean, this is awesome. Thank you, Claire. I mean, for the important work that you're doing and you know, for the future, you know, we know cancer's going nowhere, right? I mean, there are cancers here. So this is great and I think patients benefit immensely from what you've been doing.



**Katie Caviness-Crolley** 41:09

Thank you for tuning in to Medicine Made General. In this episode, Dr. Claire Snyder shared how she's working to ensure that the patient voice plays a central role in cancer care.

If you haven't yet listened to part one of our conversation, check it out to hear Claire discuss how cancer specialists and primary care providers collaborate to provide comprehensive care for cancer survivors.

Until next time—stay informed, stay healthy.