Adrian Hernandez: Hey, this is Adrian Hernandez and welcome to the NIH Collaboratory Grand Rounds Podcast. We're here to give you some extra time with our speaker and ask them the tough and interesting questions 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 our Grand Rounds content can be found at rethinkingclinicaltrials.org. Thanks for joining.

Hi, this is Adrian Hernandez, and today we're with Megan Ranney, who will be reflecting on a recent Collaboratory Grand Rounds presentation entitled Online Recruitment in the Era of COVID-19: Pitfalls and Progress. Megan, thanks for doing that Grand Rounds and thanks for joining us on this podcast.

Megan Ranney: It's my pleasure to be here Adrian.

Adrian Hernandez: Well, Megan, you've had a lot of attention towards trying to make things simple for a recruitment of studies in COVID-19. And I wonder if you could just share your local experience and how you all have approached it?

Megan Ranney: Absolutely. So we had, like most of us, a number of ongoing studies when COVID-19 hit. We also had a bunch of studies in planning when everything shut down and we used slightly different strategies for those different studies. For the in person clinical recruitment studies, we honestly stopped recruiting for a bit and then switched to a hybrid model where we did the minimum necessary in person and did the rest of recruitment online. There was one study, which we had already planned to do purely online recruitment that started just prior to COVID hitting, and that one went absolutely swimmingly. And then we had other studies that were still in the planning stages that we were able to switch to being purely online recruitment. Interestingly, we found slightly different success rates from all three. I think probably just because when you design a study from the get go to do remote recruitment and retention, it tends to be a little more effective than when you try to retrofit after the fact.

Adrian Hernandez: Very true. What type of studies were these? Can you describe a little bit about the so called phenotype of these studies?

Megan Ranney: Absolutely. So one, the one that was totally in person prior to the pandemic was a large factorial, randomized controlled trial, where we were recruiting adolescents in the emergency department and then randomizing them to a couple of different interventions and following them for about nine months afterwards.

The one that was purely online was a simple RCT of an app for cyber victimization. We had previously recruited in person and wanted to try out online recruitment because we felt like kids who were spending more time online were also more likely to be cyber victimized. So it was a good place to recruit regardless.

And then the third study, the third type of study, we actually have a bunch of them that we're now doing mostly online. One was something that we planned during COVID, a survey, mixed methods survey plus qualitative study of youth during COVID-19, looking at their kind of resilience and social media use. Another one that will be starting soon, hopefully, is looking at an app to provide peer support to folks in recovery from opioid use disorder. So it's really a wide variety of different types of trials ranging from classic RCT through cohort or mixed methods.

Adrian Hernandez: Wow, so those are not necessarily easy settings or easy topics. So setting in the ER, adolescents, difficult issues or topics to test different interventions or strategies. So did you find that online recruitment was always easy, always hard or in between, or depends?

Megan Ranney: So I would say that it depends, and we definitely did some playing around with the types of advertisements that we used, the places where we advertised and the strategies for targeting advertisements to the right community. I think that an important part of both online recruitment and retention is being intentional just as we would be about training of research assistants in the clinical setting, being really intentional about the way that we advertise our studies.

In the online RCT of adolescents who were cyber victims, we actually went through a number of different iterations of advertisement design pictures, language placement, to figure out what was most effective, which was fun in and of itself. It was like a trial within a trial. I think we keep improving though every population and we're doing a pilot for another project, I'm doing with a colleague at University of Colorado, where we're recruiting caregivers of older adults with cognitive decline. And the trial and error process for the advertisements there is very different. What we're learning that we need for those caregivers of older adults is very different from what attracts adolescents. So I think my biggest takeaway is just to listen to the population that you're trying to recruit.

Adrian Hernandez: That makes a lot of sense. So you talk about advertising or engagement of potential participants, what's your approach or methods to make sure that people understand that here's an exciting opportunity to contribute to the larger good without going over the line of coercion?

Megan Ranney: That's a great question. So there's the question of coercion, but there's also the concern about privacy. There's this concept of ambient privacy in digital interventions, which I first started learning about and thinking about when I was doing work with a colleague of mine around HIV and substance use. If you're developing an app for a potentially sensitive topic, your patient or your participant might be looking at the app when they're riding on the bus, or sitting at their parent's house, or next to their kids or their grandkids. And so you have to be careful about what someone who is looking over their shoulder might see. That's the concept of ambient privacy. The same thing applies when you're

doing social media advertisements to participate in a study, you have to be thoughtful about the pictures and the wordings, that it doesn't give away or stigmatize or label someone just because the ad shows up on their feed. And then you also have to be clear that this is research and who's sponsoring it.

All of our ads of course get approved by our IRB. And then once they click through making sure that they understand that they are participating in research, and I, and many others across the country right now are doing some interesting work looking at how that online consent process works. REDCap obviously has created some nice modules for allowing remote signature, but we found for instance, that we feel more comfortable if we ask our participant's questions, to make sure that they understand the key parts of the study before letting them ascent or consent. And so we've built that into the process once people click through the ad to make sure that the folks that are enrolling actually comprehend what they're agreeing to.

The last part is that when you're advertising on social media, there's a risk of bots, particularly if you offer an incentive for enrollment. And so we've put some pretty strict precautions in place to try to avoid those, not just like the reCAPTCHA, which we're all used to, clicking the box to say, I'm not a robot. But some more complex things to like asking folks to do calculations, asking confirmatory questions about things that they will have read to make sure that it's actually a real person who's doing the study.

Adrian Hernandez: Well, that's very interesting. And I think it's really important to think about the environment, that digital methods allow people to go. And so it's not just in the privacy of your home or the privacy of a waiting room or an exam room. Last question. So there's so much interests or hype around digital methods for research. In the coming years, do you think it will be the cure all, or where do you see its role?

Megan Ranney: I see digital clinical trials or just digital clinical studies in general as falling in the same category as digital health, which I spend a lot of time working on, but which I see as an adjunct. It's another tool in our toolbox. It can extend our ability to recruit diverse populations, folks that may not come to tertiary care clinics because of geography or cost, folks that may live with stigma around their condition, folks that may face other structural barriers to recruitment and retention in trials. So I think there's a great potential for digital recruitment and retention, expanding who we can engage and keep in research, and who we can provide the benefits of research to. But I don't see it as a wholesale substitute just as I don't see digital health in general, as being a wholesale substitute for us as physicians or nurses or social workers. It's an adjunct, it's an add on, it makes our work easier and better, and it makes our patients lives more importantly, easier and better. But there are times where that in person touch is needed, whether it's in the research space or in the clinical space.

I do hope that we're going to have better online recruitment and retention and trial methods going forwards. I think it's going to be really interesting over the next year or two to watch us all define what best practices are for different types of populations. I could imagine for instance, that online recruitment really becomes the norm for some rare diseases where the process of in person recruitment is just so time-consuming and expensive and difficult. And by engaging with rare disease forums, you can get a cross section of patients who might be more interested in participating in research. There may be other conditions where online recruitment gives you a bias sample that's not like what you would get in real life. And for those will still rely on in person recruitment. There may be other studies still where we're going to do a hybrid.

I'm doing one project where we recruit kids in the emergency department and enroll them in a cohort study where we look at social media use, self-reported mood and experiences violence. We get audio recordings, little snippets of their day, and also get some ecological momentary assessments. And that's a great example of a hybrid study where that first touch is going to be mostly in person. But the rest of the study is going to happen through a mix of in person and even more so online, in ways that we wouldn't have necessarily thought about doing pre COVID.

Adrian Hernandez: Well, Megan, those are excellent points. And thanks for having this conversation with us on this podcast.

Megan Ranney: It's my pleasure. Thanks for having me on and thanks for hosting these Collaboratory Grand Rounds. It's a great service to all of us.

Adrian Hernandez: Great. And we look forward to the continued work that you and your group are leading, trying to make sure that we really understand both the pitfalls and progress and how to fill in the gaps with online recruitment and other digital methods, taking the lessons learned from COVID-19 and going beyond. And thanks everyone for joining us for this podcast. Please join us for our next podcast as we continue to highlight interesting areas that are changing the research world.

Thanks for joining today's NIH Collaboratory Grand Rounds Podcast. Let us know what you think by rating this interview on our website. And we hope to see you again on our next Grand Rounds, Fridays at 1:00 PM Eastern time.