CCHP
Digital Health in Homes and Communities: Emerging Opportunities for Patient Engagement
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>> ARIA JAVIDAN: Hello, my name is Aria Javidan, and I'm the Program Coordinator for the National Consortium for of Telehealth Resource Center. Today's presentation is Digital Health in Homes and Communities: Emerging Opportunities for Patient Engagement. These webinars are provided to have timely demonstrations and support the implementation of your telehealth programs.

And they are presented on the third Thursday of each month. Just to provide some background on the consortium, located throughout the country there are 12 regional telehealth resource centers and two national telehealth resource centers. Each serve as focal points for advancing the effective use of telehealth and supporting access to telehealth services in rural and underserved communities. A few tips before we get started. Your audio has been muted. Please use the Q&A function of the Zoom platform to ask any questions. Questions will be answered at the end of the presentation. Please note that closed captioning is available for today's webinar and is located at the bottom of your screen. Today's webinar is being recorded and you will be able to access today's and past webinars on the NTRC YouTube channel.

And with that will I pass it over to Jonathan Neufeld.

>> JONATHAN NEUFELD: Great. Thank you, Aria. If you can stop sharing, then I can share. All right. Just a few too many clicks here. So, I just wanted to welcome you all, as well, and I'll be introducing George in just a minute. I will highlight the fact that we're the Great Plains Telehealth Resource and Assistance Center. We're in that north part of the country. We provide technical assistance and training for organizations of all kinds trying to sustain and build telehealth programs. We would love to hear from you, as well as any of us in the consortium would love to hear from you to help out with your telehealth efforts. I just also want to highlight something for you. We the Great Plains Resource And assistance Center will be hosting our annual conference. First time in three years. We are eager to be back. Fingers crossed that we can do this safely. We are going to be implementing a lot of safety protocols to make sure this is a safe conference. But you can get some information about this. It's going to be at the Radisson Blu in Minneapolis on May 23rd-25th. The main conference is the 24th and 25th. You can find out more on the website. Now, I want to introduce Dr. Demiris.

Dr. George Demiris is a professor at the University of Pennsylvania. Joint faculty appointments in the department of nursing, biobehavioral health sciences, epidemiology and informatics at the school of medicine. He directs the Penn Artificial Intelligence and Collaboratory for Healthing Aging and co-creation. Dr. George Demiris explores ways to use technology to support older adults in home and hospice care, and also focuses on designing and evaluating personal health systems that create patient-generated data,

including smart home solutions for aging. I'll just also point out that Dr. Demiris is going to be our keynote speaker at the GP Track Conference. We hope you'll listen to him today and benefit and also come back around and join us in Minneapolis for his keynote address there, where we hope that he will expand on some of the ideas that he is going to provide us today. With that, I will welcome you, Dr. Demiris, and turn it over to you. >> GEORGE DEMIRIS: Thank you so much. Thank you for the invitation to be with you today and for the great introduction. Let me share my screen. So, again, thank you. It's great to be with you. I'm going to talk today about Digital Health in Homes and Communities and highlight some of the opportunities as well as potentially challenges that arise when we think about new ways to facilitate patient engagement. So, all this work fits within this framework of precision medicine or precision health that we often talk about because it calls for collecting and analyzing large data that take into consideration the unique individual patient's behavior, lifestyle, genetics, and environmental context. It calls for assessment that goes beyond just the episodic clinical assessment we see during a clinical encounter, and calls for new tools and techniques to better understand what is going on with people's lives and behaviors in the homes and communities where they find themselves. And in that concept, we often talk also about opportunities for digital phenotyping, mainly the moment-by-moment quantification of the individual-level human phenotype in situ using data from personal digital devices. We're looking at using tools to understand how people's behaviors and their physiological or other variables may change at any point in time outside the clinical observation space. So, we have many opportunities with digital health to facilitate behavioral sensing. And usually that is based on passive monitoring and wearable technologies. The goal with all of these tools would be to objectively, remotely, and continuously monitoring patient behavior, physiology, and symptoms. The advantage here is we can understand what is going on with an individual in their own home and community and capture behavior of daily living without needing human observers or having to rely on self-report. As we know already from the literature self-report has a lot of limitations because of recall bias, the tendency to under or overreport, and the cost that comes with trying to validate and use observers for validating those records. It can allow us to shift from episodic to continuous monitoring and assess people in the real world where they find themselves and not in a laboratory environment. The goal is not to be someone at the other end to watch the data points come in in realtime, but rather to develop significant algorithms so we can identify patterns of the data that show perhaps more attention is needed or a certain trajectory is leading to undesirable implications and could be addressed earlier. So, actively promoting a more proactive rather than a reactive model to the observations that are made through passive sensing. And speaking of sensors in the home, there's a lot of discussion around smart homes. And that is one great example of passive sensing that could give us insights into people's daily living. A smart home is broadly defined as a residence with embedded technology that facilitates passive monitoring of the residence to enhance their safety, independence, and well-being. And this was a term that originally in the '80s was used mostly for energy-efficient buildings, but in the '90s it became clear that a lot of these could be used for other purposes. A lot of internet of things devices are available for

entertain., security, and can also serve health-related purposes. We've done a lot of research here at the University of Pennsylvania looking at smart homes. And we've tried to look at even commercially available sensors to see how they could specifically support older adults as they wish to age in place, namely stay at the residence of their choice for as long as possible rather than changing settings of residents every time people's healthcare needs change. So, we've been specifically looking at community dwelling older adults, 65 years or older, who live independently in their own home and retirement community, or even in an assistive living facility. And we've been doing some research to understand what types of sensors people would be willing to have installed in their homes and also how they would share data that are resulting from these sensors with trusted others. In our studies, we give people options between door and window sensors that basically capture door and window activity tracking and can give you an idea of how much time people are spending inside the home versus outside the home. How much they're moving in the home using things like motion sensors to track overall mobility and potential sedentary behavior, but also sensors that capture temperature, humidity, luminosity, and motion. It can give you information about activities of daily living, how much time they're spending in bed, how much they're engaging in meal preparation or hygiene or being sedentary or more active inside and outside the home. And even inferences about overall potential social isolation and loneliness. So, the advantage with a lot of the smart home solutions is that you don't have to do an extensive retrofitting of the home. You can easily install these sensors in the existing infrastructure. And the passive sensing solution has the advantage that it works passively, which means you don't have to train users in operating new hardware or software, which can be a benefit especially when you have people who may be dealing with multiple chronic conditions or may be experiencing cognitive limitations who may not be willing or ready to operate any new hardware or software. And once you have the infrastructure in place, you can easily replace individual sensors when more advanced technologies become available. And in our studies we do give people the choice as to what types of technologies they want to have installed. And oftentimes people who are with us for a year or two might change their mind and say I really want the motion sensor after all and we can add the sensor later on. We are trying to avoid cameras or face-recognition technologies to choose sensors that would have more privacy-preserving technology. Stored in a server deidentified from the individual. But obviously privacy can be an important consideration as we think about these types of tools, and I'll talk about that later, as well.

So, in my presentation, in the title, I talk about patient engagement. And this can be a challenge when we think about passive monitoring. How do we find ways to engage users so that they can actually make sense of their data and find purpose and utility in these types of smarter data. In our work, we're trying to develop different types of dashboards for residents and their family members and trusted others to be able to review the data that's collected from the smart homes. But the challenge here is to create actionable information, not just descriptive data about how much time they spent inside the home versus outside the home. But rather, what does this mean for overall

social engagement and those trajectory over time? How much am I moving and I'm on my feet every day? And whether this is increasing or declining over time? They might become more restless at night? How much time am I spending preparing meals and in the kitchen and so forth. So, in addition to look acting the trajectories and saying oh, it looks like I'm becoming less active, it's also important to know if the sensors indicate that it looks like I have fallen and I'm not moving, or I left my apartment and left the door open and didn't return. There are specific alerts we can define so we have trusted others who will be notified when such an alert occurs. As we think about visualizing smart home data to facilitate patient engagement, we have to recognize that we're dealing with various stakeholders. We're having older adults with different information needs and preference, different levels of experience with computer technology, family members and clinicians, and even administrators in retirement communities. And they all have different information needs and purposes of use. A lot of our older adults participants want to use these dashboards to actually annotate daily events and provide a lot of information with granularity that may be of less interest to a clinician who is more interested in longitudinal interventions. Many times family members are more interested in certain details than say an administrator of a retirement community who is more interested in aggregate information. It's important to support goals pertaining to events, trends, and pat nerns the data. We use a lot of density maps for the sensor activity. And here are some examples of those types of sensor maps. If you look at the lower part of the slide, you can see two different density maps of the same resident, one year apart. The density map basically shows on the X axis the hours of the day, and the Y axis the days of the month. And what you see is the amount of motion inside the home based on the motion sensor firings per hour. You have the whole spectrum. Black meaning time outside the home. Y meaning the person is inside the home, but then there's no movement. And then ranging from gray all the way to dark blue is the level of moment. Dark blue means there's a lot of motion happening during that hour segment. So, on the left side, you can see this density map. A resident who tends to show very little motion activity in the early hours. So, that's because they're in bed. So, usually they sleep from about 9 p.m. to usually 6 a.m. They're pretty standard or consistent in terms of waking up around 6 a.m. and there's some motion in the apartment until about 8 a.m. where most days they leave the amount for about an hour to have breakfast. They come back, there's a little bit of motion, they leave the apartment again around noon, usually for lunch. They come back, and then they leave around 6 p.m. consistently for dinner and come back. Now, this is the same resident a year later on the right. Here you can see their density map being completely unpredictable and definitely less consistent. You have a lot of motion even at night. Even in one instance you have at midnight the resident leaving their apartment for one hour. You see that they're skipping most lunch and breakfast. Their sleep quality has definitely changed from a year before. But they're somewhat consistent in that they spent time between 6-7 again in the community having dinner in the dining area. These are the real data from a resident whose actual vital signs like their blood pressure and glucose levels didn't change from one year to the next. So, the community nurse didn't indicate any alarming trends. But the same resident if you look at their density map,

clearly something else may be going on, even though the community members didn't recognize them being absent. That was a person who was experiencing some early stages of cognitive decline and that manifested itself earlier in the density map in this type of visualization, information we can extract in daily living, and perhaps give us insight before a catastrophic event occurs. Another typical example of the value of smart homes that has been demonstrated in literature has to do with urinary tract infections. And you could see the difference early on so that you could interfere before a hospitalization becomes necessary. I wanted to also briefly talk about another initiative we have at the University of Pennsylvania looking at smart home technologies. But here we're looking specifically at fall prevention. We started an initiative we call sense 4 safety, which is a technology enhanced fall risk prevention and nursing intervention for socially vulnerable older adults with mild cognitive impairment. And here we're trying to look specifically not just at fall detection, but actually fall prevention. We're focusing on falls because it's such an important and critical issue for older adults. And mild cognitive impairment and housing conditions are each independent risk factors for multiple falls. As a matter of fact, cognitive impairment is the leading risk factor for falls in older adults, and over 60% of older adults with mild cognitive impairment will fall 2-3 times the rate of those without cognitive impairment. Socially vulnerable older adults are at greater risk. Twice the risk of falling. We were thinking about creating a solution that uses digital tools like smart home features that could actually keep people safe before the fall occurs if at all possible and specifically targeting older adults with mild cognitive impairment who live in low-resource neighborhoods. So, with Sense4Safety, we're looking at technology again and we're using depth sensors, and I'll talk about them in a minute. But we link the older adult with a nurse telecoach who guides them in implementing evidence-based individual plans to reduce fall risk. The idea is we are able to identify escalating risks for falls realtime through this monitoring, and we can employ machine learning to inform individualized plans to reduce fall risk. The depth sensor is basically using silhouette extractions. So, you don't actually see a video of the individual, but rather their silhouette extraction. That video itself does not get permanently stored. Instead, the depth sensor allows us to extract information about gait such as stride speed, but they're important for calculating fall risks. All we ultimately end up saving, if you will, or storing, is fall risk scores for these individuals based on their gait characteristics, not the actual silhouette extraction videos. The silhouette extraction videos can be used for a fall alert if the nurse or the trusted other wants to confirm it's not a false positive so they can see the last 10 seconds up to what was classified as a fall event. So, our nurse coach can access this dashboard and look at the information that is generated by the depth sensors, the stride length, average speed, stride time. All are used to calculate the certain fall risk score. And we're working with engineers at the University of Missouri who have been working with depth sensors for a while now to use their formulas for fall risk calculation and fall risk prediction. Our nurse coach can then annotate this dashboard by entering additional information that has to do with medication information or hospitalization information that's important in order to have a more complete picture as to what's going on with that person in their lives. And then the coaching sessions can use the information about fall

risk changes to inform educational or exercise intervention. And people can then have more tailored behavioral or educational or other interventions based on their own ever-evolving fall risk profile. When we think about smart home technologies and in general digital tools in the home, one of the challenges becomes how obtrusive these technologies may be. And that's not only about privacy, although privacy is definitely an important aspect and consideration in that. So, we use the term "obtrusiveness" that we define as a summary evaluation by the user based on characteristics or effects associated with technology that are perceived as undesirable and physically or psychologically prominent. In other words, it's basically the subjective assessment by the individual as to whether they are willing to tolerate, appreciate, or reject certain features of the smart home. And that's especially important when we think about technologies that we introduce in one of the most sacred spaces: Ones own private residence. So, we developed an obtrusiveness framework to better understand what could be all the different dimensions that ultimately affect one's subjective assessment of the technology. Those have to do with the physical dimension of the technology. How does the technology get installed? Does it cause obstruction or impediment in the space? Or maybes a thetically it's not aligned with the phone to have cables hanging from the ceiling. Do you have big boxes that you have to install in your living room? And for those that have to operate any part of this technology, whether it's software or a software solution or perhaps deal with the hardware sensors, what are the usability dimensions?

Are those systems easy and accessible? Easy to use and user friendly? And do they place additional demands on time and effort. Privacy is one of the core dimensions. Here we need to think not only about the technical specifications, have we encrypted the data, is the server password protected, which are very important considerations, but we also have to understand what are the needs and preferences of the individual residents. And do they really fully understand what they're signing up for? Even if the technology is not perhaps violating somebody's privacy, if people feel they are living in an environment that might be intruding into their own privacy sphere, that is a problem whether technically it's addressed or not. Another dimension has to do with the function of these tools. Are they reliable or perhaps inaccurate or restricting in how they operate? Or perceived as not really accurate or useful? Some systems work better when people are home bound and may not work as well when people are moving around the community. So, we have to think about the function aspect of the technology. A key element in a lot of these digital tools is how they may interfere with the existing relationships and ultimately the human interaction dimension. Do these digital tools introduce a threat to replace in-person visits? Could there be a lack of human response in emergencies, and what effect would the technologies have on relationships? One of the concerns that several of our participants in smart home status have raised has to do with in my loved one or family member can log in remotely and see that I'm doing okay, does this mean that they're going to come less often? Or come and visit me less often? Does it mean the community nurse is not going to come as often as she used to because she can check on me remotely and what does this mean

for these relationships that are either ongoing or new relationships in a retirement community, for example. Another has to do with self-concept. Having all that technology installed in your home and whether it losses a lack of independence or a cause of embarrassment or stigma. This is something that has been found over and over again with literature with some of the older fall-detection wearable bracelets where people were refusing to wear them because they thought they could be stigmatizing. If I'm the only one in the community wearing a fall alert, does this mean I'm the most frail and in need of assistance. And similarly with smart homes, when we first started conducting smart home status, long before it became more accessible through internet providers and safety and entertainment packages, originally the idea of having sensors in the home was concerning to some participants and we would have participants saying I will sign up for this only if I'm not the only one in the building who does or only if my other neighbors also signed up for this. What does having these digital tools in the home mean in terms of the daily routines and how the technology may or may not interfere with daily activities, and whether it requires that users acquire new regions. And then ultimately concerns about the sustainability of the technology. Am I learning to depend on a technology that I might not be able to afford in the future? Or that I might not be able to operate in the future? And how will my future needs change? And will I still be able to accommodate the use of the technology in the near future? All of those are diverse sets of considerations that deal with a lot of different aspects, but they all feed in that framework of obtrusiveness and highlight that when we think about smart homes and passive monitoring tools, it's not just about the amount of training that those tools may require, but there's a lot of other underlying factors that should be assessed. So, rather than saying a smart home solution is in the background and doesn't really interfere with anything, we have to think about what the specific implications are for the person living in that home as well as their own set of connections, their personal and social network. When we think about these digital tools, there are research policy implications but also clinical and practical consumer considerations and I want to briefly touch on all of those categories.

When we think about research, a lot of the smart home research right now is focusing mostly on feasibility work. Can we really install the technology? Will this be acceptable and accessible to older adults and their families? But we definitely need more evidence, even though the status may be difficult to carry out in terms of the long-term impact of a smart home solution on health outcomes cost and efficiency.

Can we use this to reduce hospitalizations or keep people safer with high quality of life in their own home? Sometimes the design that is required can be difficult because of the time and the resources necessary. For example, it's really hard to do a clinical trial where people are randomized to smart homes or non-smart homes. But we do need more evidence and more longitudinal data to have a better understanding of the impact of those types of platforms on patient outcomes. But also on things like patient engagement and shared decision making. We know that people want to access their data. And our participants become more engaged and aware of their own daily living

once they get to access these dashboards. But what does this really mean in terms of the quality of care that we're seeing? A lot of times we hypothesized that smart home research would lead to new models of patient-care delivery because people can be more actively informed in their own care, but we still need more research as to what that really means in terms of patient behaviors and also diagnostic and treatment-related decisions. How does the smart home solution affect healthcare utilization? Is it that people are people kept safe at home and therefore they are utilizing healthcare services less? Or is it that because the system monitors those trajectories and alerts at an earlier point when something is wrong, it actually leads to an increased utilization. What's the accuracy and reliability of data in various settings? How can data be standardized? And ultimately, how do we visualize and communicate that data? I already showed you some of our dashboards, as well as our density maps, but there's a lot of other complex questions around visualizing data in a way that's meaningful and actionable. The smart home data should not be only available to researchers and clinicians, but they need to be not only available, but accessible, and actionable for the general users to actually make use of them. And that, I think, still becomes a great challenge when we deal with a broad range of users, when it comes to their computer experience, cognitive and functional abilities.

As we think about introducing new digital tools in the homes and the communities, there is clearly concerns around interoperability and whether these systems will talk to each other. And I know that speaking to a group that's quite familiar with telehealth, you know that interoperability is not a new concept when it comes to thinking of new digital tools and some of the same challenges apply to smart homes, too. How can we think about interoperability, but also standards around tracking modalities and issues around who is to be reliable and accountable for all the data that are collected outside of the clinical setting. And if information were to be extracted from smart home data, but was not acted upon, who would be in charge of that. What are the privacy policies for those different sensor solutions, and ultimately as we've seen more evidence, if we do get to see more evidence of a lot of these systems, what would be the reimbursement strategies? And what could be the potential models for those digital tools to be easily integrated into existing models of care or to potentially introduce new models of care. There are implications for the clinical workforce. How do we integrate these types of tools into the digital or into the clinical workflow? And how do we create systems that help with interpreting data without burdening clinicians? Who would be shifting through those large quantities of data? And what is the burden and fatigue that may be introduced through realtime alert systems? How can we refine our algorithms so that we don't actually need people to be shifting through the data, but rather responding only to pieces of information that have been extracted from this large body of data.

And what are the responsibility to review the data and how can those be delegated? And then also clinicians need guidance as to how to identify which tools to recommend to their patients for those patients who want to become more actively involved. We now see where patients may be asking not only what type of wearable should I get in terms

of the fitness tracker, but are there available solutions for sleep monitoring that I could use. Are those accessible and clinically meaningful? What about solutions for activity tracking? Sleep quality? Energy expenditure? Things that perhaps people were not necessarily familiar with before or we didn't have that many commercially available options, but how do you navigate that complex landscape, and as a clinician, how could you help your patients identify the right tools if they wanted to use these tools.

That also brings us to consumer education because there are specific implications for any of us as a patient and/or health consumer. How can we select accurate and reliable tools? There are already many commercially available smart home solutions and sensor systems. There's obviously a lot of wearables, too. How would we know which of those to choose from and would be the most appropriate for whatever it is we're trying to monitor? And how we can interpret data. We need to discuss expectations and what the role of these digital tools would be in terms of health monitoring. And another big concern is that we're trying to create this new innovative system to increase access, but it might be at the same time as an unintended consequence a way to exacerbate existing disparities. For example, when we think about smart home solutions, a lot of those require broadband internet availability. So, people who may already have access to resources may just be enjoying additional tools. But people who are already perhaps left out of specific spaces would then be further excluded with systems that exacerbate those disparities. So, how can we think about inclusive design for telehealth and inclusive design for smart home systems, or in general, inclusive design for digital health tools? When we show participants what sensors we collect and we describe the sensors, it becomes very clear that people have different levels of experience with previous technologies, and some participants can make a lot of sense of our graphs and data and others cannot. We have to think about health literacy and data literacy. Data literacy has to do with users understanding the use of their data, what gets stored, and who has access. And these are complex factors to address. It's not only how can people make sense of their data and what is their ability to process graphs or other information. And also understand aspects of data access. For those of us who do research in this space, sometimes we develop consent forms where we have to think about how to use layland language to explain complex terms like the cloud and how data are transmitted and so forth. And we put in a lot of effort to try to make this material accessible. And we use the teach-back method where we tell our participants what it is they're signing up for and then we're asking them to reiterate what their understanding is of what they're signing up for. So, these take a long time and we've developed educational products to achieve our goals for consenting and to make sure that participants understand what they're signing up. And in spite of all these efforts, we often do get people who a few weeks later will look at their dashboard and it will indicate that they had let's say a week where they didn't spend much time outside the home, and they'll say how did you get that information? How do you know that I didn't have an active week? Even though they had signed up for the smart home sensor study and we went through this elaborate consenting process. So, it's obviously something that becomes very clear and is said over and over again that consent is not an event, it's not

a one-time thing. Living with these tools may alter someone's perception and preferences. The same goes for the regular use of consumer products. We don't often pay much attention to terms of agreements for a lot of the hardware and software that we sign up for. And oftentimes we don't know what we're signing up for or how we can get out of things that we've signed up for. But as we think about these digital health tools, it's an imperative that we create systems that allow a user to access their information, to have informed decisions about what they want to share, and to recognize that those preferences may change over time and may change a lot or they may not change over time. But we need to have that flexibility embedded in the systems so that users have both control of what it is that they're collecting as well as receiving feedback as to what is going on with their data and who has access it to. This complicates matters further when we think about solutions that are designed for people with cognitive impairment. We have quite a few products in the literature you can see globally that look at smart homes for people with dementia. So, in these cases, when we think about data access, the consenting process, privacy policies, it's usually not the patients themselves, but the family members or people with power of attorney function who make the decisions on behalf of the patients. And here it is a complex ethical dilemma how do you honor the participants' wishes and preferences while at the same time wanting to have information that could potentially keep them safe at home or what the specific risk is. So, the fact that we are looking at systems that are very data intensive allows us to get more and more information about the daily living of an individual, but at the same time, it opens up even more data collection streams that may or may not have been acceptable or desirable by the participant. So, when we think about dementia care, smart homes are emerging as desirable tools, but I think we need to continue that discussion around the ethical implications to ensure that we've heard all the stakeholders' perspectives and come up with an ethical framework that honors the individual's privacy and autonomy to the extent that it does not compromise their safety and well-being. That is in general, I think, something that becomes important with a lot of these digital tools. And that is that we need to put in the clinical, the ethical, and the legal considerations ahead of this deployment. A lot of times technology advances at such a fast rate that we try to catch up and have these considerations after the systems are already out there. But now that we see how they become more and more part of our daily living, we have the opportunity to actually think about the right framework to integrate systems that are safe and at the same time are addressing issues of safety, security, obtrusiveness, and users' autonomy, and honor their values and preferences. So, with that, I would like to thank you for your attention. I would be happy to answer any questions now in our Q&A session. And here is my email if you have any follow-up questions after this talk. Again, thank you for your attention.

>> JONATHAN NEUFELD: Thank you, George. That was fantastic. As we've opened it up now, and Aria, perhaps you could join us. Let's take a look at the Q&A and see. It looks like we don't have anything in the Q&A right now. If anyone has questions, you can put something in there and we will see that. I have one, George, that perhaps you can get started with. One of the things that University of Minnesota is working on is translational studies. So, I wonder if you could address that sort of gap a bit. Gap is

probably not the right word, but that transition from looking at what is possible technologically to implementing what is practical and feasible and doable in the healthcare space because it seems like just amazing things are going on, and in doing the kinds of interventions that you've talked about, but remarkably, it's remarkably slow to be picked up. Maybe it isn't. Maybe I'm just not aware. But it's challenging to get it picked up and widely used because of a number of the limitations that you talk about. But I'm just wondering if you could say a little more about that transitional space or translational space and what's needed there and what are the key factors driving that translation?

>> GEORGE DEMIRIS: Yeah, I think that's a great question and I'll answer it with a little bit of a bias because I have a researcher's perspective and we often worry about the work we're doing in an academic setting and how that will translate into the real world. I think part of the challenge has to also do with the way we conduct our research studies and the funding we receive that is sometimes siloed. And we don't yet, although we're getting better at that, have those translation considerations early on in the conceptualizing of the study. So, oftentimes we'll have a great idea about a new system and we'll focus on does it even work. So, let's do a feasibility study. Okay, now we did a pilot study with 5-10 people, and they seem to really enjoy this digital tool. We found some more information about how to improve it and refine it. Now, let's do a study with 20 people. And in this study we found great, people might like it. And now let's see if we can get funding for more, which is great and a traditional way of conducting the studies. The problem with that is at some point you stop and maybe funding was no longer available or you can get mixed findings. The translation considerations should be taking place much earlier than when you deploy this in a large number of homes and I think should become part of the early design specifications. The reason why we think participatory design is important and is becoming more and more accepted as a way to design digital tools is not only because you empower people to sit at the table and give you their perspective, but ultimately if you want to know if a digital tool is going to ultimately become used and part of people's lives, you have to have the patients and the clinicians at the table when you design that system to identify, you know, what the problems or the challenges may be.

And also have policymakers and administrators at the table because we can come up with great systems, but it turns out there's never going to be any type of reimbursement. So, those considerations need to happen early and there is a little bit of a somewhat conflicting viewpoint of oh, first we need to do this as a siloed feasibility study, and then we move on. And there's a certain life cycle that isn't really aligned with the real-world needs. I think more and more we see translation becoming a consideration that is addressed earlier on. We have, I think, seen some improvement in terms of also interdisciplinary work so we don't have people in the technology space creating solutions and then hoping to find a problem for the solution and then somebody trying to adopt that software or hardware. And now we see more synergy. But I think there's definitely a lot of room for improvement. Another thing that I think will help with translation has to do with more pragmatic trials. So, a lot of times we design these research studies where you deploy a digital tool in an ideal, controlled circumstances.

And it takes so long to do the study and get the funding and get the data, and by the time you have your findings the technology has already been outdated. There's been now new and better and smaller and faster processors. And so that also is not perhaps how we want to be examining the use of digital tools. We want to test them in real-world conditions, but also recognize we need to have some flexibility as to how the systems would also evolve. In an ideal research study, the unit of the observation stays the same. You can't tweak it or change it.

But in the real world, things do change and evolve much faster. Even with wearables, some colleagues started their wearable study. By the time they were ready to start collecting data, there was a new Apple Watch that was kind of taking care of all the things that they were hoping to measure. So, it is something where I think we need to be more pragmatic in the design of our studies and like I said going back to your question, thinking about implementation not as an, or translation, not as an after-thought, but actually at the very beginning of conceptualizing the whole product, system, and the study.

>> JONATHAN NEUFELD: And with that last little comment you point to the fact that I think we're all aware or growing increasingly aware that a lot of this translational work is front and center for technology development companies or organizations that are traditionally intensely involved in technology and they're seeing the healthcare space as a new potential space for technology development and just sort of bypassing the existing healthcare system, the existing research systems. Saying we're just going to go straight to the consumer with it. And we've got our own scientists and our own engineers. We'll just figure out a way that it works as a consumer product rather as a system to be deployed in a health system somewhere. And I think that that's a dynamic that the healthcare system possibly hasn't had to address quite so much in the past. There's a question that just went into the chat and I'm going to go ahead and read it to you, George. I was curious about reimbursement. Have the tools only been implemented by research? Or scaled and used as part of a healthcare intervention? I'll let you respond and I have some things to say about that, as well. But go ahead, George.

>> GEORGE DEMIRIS: Yeah, so some of the, especially when talking about smart home tools specifically, they have been used and tested as part of intervention. So, in addition to the smart home types of sensors I showed you, there's commercially available solutions where you can buy a set of sensors and it works and it's a subscription model. And they have been tested in long-term care facilities or independent retirement communities. So, there are systems that have been deployed similar to what you were saying directly from the vendor in partnership with the clinical side, not necessarily a product of research. Just the vendor, the hardware vendor worked with a network of retirement communities, for example, and they've deployed their sensor solutions. Yes, a lot of these tools are implemented and have been scaled. I think one of the challenges sometimes with this model is that it's easier to show some benefits or outcomes with one's own research. But then how is it to generalize to other settings. You know, there's sometimes gaps during the translation of the evidence. But there's definitely a lot of those digital tools that are not only commercially available, but

have been tested outside of academic research in partnership with clinical sites. And there are even smart home solutions, we have several on the east coast, where you can have as a family member of a loved one who lives alone can subscribe directly. It's direct to consumer. You don't even need to be a member of a retirement community or part of a health-related organization. You as a consumer can directly subscribe to the vendor and purchase the monitoring solution, the software, the hardware, and the monthly fee. They're definitely available and have been tested. What would be ideal is a combination of doing that and having a solid evidence base based on research, that way we could have both the real-world implications, as well as the solid evidence as to what works and what doesn't work. And I feel that we're not there yet, especially with some of the tools I talked about today.

>> JONATHAN NEUFELD: Yeah. I agree. And I would say, too, that where I've come across it in its most advanced form is either as you say a subscription direct to consumer model. I understand that there are a number of retirement community type settings that have deployed it on a larger scale and they use it sort of as a value-add. You're moving here and we will keep track and intervene. And in fact, as you probably know, there are retirement communities that include your Medicare Advantage plan as well as your rent. There's a whole package. They're motivated there. They have a financial motivation and there's value that they're creating with the tools. What I wonder, and I'm hoping to see more of, is as we do more chronic disease management in the traditional healthcare setting that a bridge will start to open up there to producing value using these sort of tools. I mean in the home health setting, you have kind of the person's value in that they want to stay healthier, or the family value if they want to stay healthier. But reducing healthcare costs is also a potential value. And so there are drivers there. But we're not quite linked up to them yet. In fact, you have to pay your own way to reduce your medical costs. And it would be great to see payers and health systems have a way to say if you've got a smart home or if you've got this technology available if you can register it, kind of like we did with gym memberships, back in the wellness plan, we'll reduce your premium or we'll subsidize that because we recognize that that's going to reduce your overall costs.

>> GEORGE DEMIRIS: Absolutely. I want to add to that that there is now more consumer awareness. We hear a lot from administrators who say it is family members who say I want my loved one to come to your facility, but what types of technologies do you have to keep them safe? There's an increased awareness from the public that there are those digital tools. Whether they work or not, it's something that family members value as an extra service that the facility has to offer.

>> JONATHAN NEUFELD: Right, right. This is really fantastic George. I want to thank you once again for agreeing to come and share your knowledge, wealth of knowledge with us. And look forward to hearing from you again at our conference May 24 and 25 in Minneapolis. That is bound to be a stimulating conversation, as well. And with that, I guess we will turn it back to you, Aria, to close us out.

>> ARIA JAVIDAN: Thank you, Jonathan. Just a reminder that our next webinar will be held on Thursday, April 21st, focused on innovation and integration of telehealth into population health, and hosted by the Northeast Telehealth Resource Center. And lastly,

we do ask that you take a few short minutes to complete the survey that will pop up at the conclusion of this webinar. Your feedback is very valuable to us. Thank you again to Dr. Demiris for his presentation today and to the Great Plains Telehealth Resource and Assistance Center for hosting today's webinar. Have a great day, everyone.