ROUGH EDITED COPY

WESTERN VIRGINIA UNIVERSITY - CENTER FOR EXCELLENCE IN DISABILITIES

CED GRAND GROUNDS
SEPTEMBER 10, 2018
2:00 P.M. ET

CART CAPTIONING PROVIDED BY:
HOME TEAM CAPTIONS
WWW.CAPTIONFAMILY.COM
800-335-0911
INFO@ACSCAPTIONS.COM

(Writer standing by.)

>> SPEAKER: Hello, everyone. We're a little early. We're just going to wait on a few people to join us and we'll get started. Stacey, can you hear me? Stacey, I can't hear you. Let's see. Are you there?

>> SPEAKER: Can you hear me now?

>> SPEAKER: I can hear you. Hello.

>> SPEAKER: Hi.

>> SPEAKER: Hi. I just realized one thing that I forgot to ask you was whether you wanted to proceed, um, to steal the screen and share your slides directly, or if you wanted me to forward for you. What's your preference?

>> SPEAKER: Um, whatever is easiest for you.

>> SPEAKER: Oh, either one.

>> SPEAKER: If you have them up there now and

you don't mind, that's perfectly fine.

>> SPEAKER: Okay. Feel free to say next, when you're ready for me to move it, okay?

>> SPEAKER: Okay.

>> SPEAKER: So, it is a little after 2:00. So, I appreciate everyone joining us for, um, CED Grand Rounds for September. I've had the wonderful opportunity to work with Stacey for, I'm not going to tell you how many years, but, um, seems to go by really quickly.

(Laughing.)

>> SPEAKER: Um, so, Stacey works within our clinical translational science institute, which is physically located on the Morgantown campus, um, but it actually spreads throughout the state, and what she's going to talk with us about today is one example of those ways that it goes throughout the state. Um, Stacey has many hats; community outreach coordinator, and each, just to give you a little bit of a structure, the CTSI is a large infrastructure support system, and, so, there are many cores within it, um, Stacey's really involved in the community engagement and outreach core, but again, multiple hats. So, um, just kind of brief

background, bachelor's degree in biology from Wesleyan, master's degree in public health from WVU, and then she's been with the CTSI since about 2013, and like I said, has done a lot within the CTSI and even outside of that. So, I don't want to take too much time, but, Stacey, I'll turn it over to you to educate us a little bit about the PBRN.

>> SPEAKER: Thank you. Um, I really appreciate the opportunity to speak with you all. Um, this is sort of, like, as Leslie mentioned, just a small piece of the CTSI, but, um, you'll see kind of along the way how you can utilize the services that are offered by the CTSI to carry out our research, and, so, I'll mention those pieces as they come up. Um, but we are the West Virginia practice-based research network, so, um, I'm going to go into a little bit more detail of that, but there's, um, this is sort of the piece of the CTSI that really focuses on clinician-driven research. So, as you can see, we are state-wide, so even though we are located on the WD campus in Morgantown, we really do cover most of the entire state. We have 107 individual clinics that we work

with, and most of them are federally-qualified health centers, and we also engage our academic partners as well. We are starting to pick up a few critical access hospitals, um, that are starting to kind of branch out and work with us, and then some rural health clinics as well. When we started this PBRN, when we started it in 2013, we were the only PBRN in the state, and that is still true. Um, a lot of other PBRNs around the country, if you've looked at any of those, they are primarily in urban settings, so there will be multiple PBRNs listed for a single state. We chose a different route, um, as partnering with the CTSI, that would be a state-wide institution as well, we decided to make our PBRN, um, state-wide as well.

So, PBRN is really just a network of healthcare providers, practices, and academic researchers that are partnering together to improve public communities. There are a couple of ways that we really started to build that foundation, um, and building and maintaining the partnerships that already existed, and we really utilized those as that foundation for what we started and engaged various groups around the state. We rely on that

local expertise in the different communities, um, so we know that as we work with different clinics and sites and communities, that they're all going to come with, um, unique characteristics and challenges, and, so, not one piece is going to fit every one. One of the big pieces that makes us a little bit unique is that we are focusing on translating the research into practice, and what that really means is being able to look at the results and doing something after that, and one of the phrases that I use frequently is leaving a footprint on that clinic from the research that we're doing, something that once that project has finalized and has results to share, what's left behind, what kind of value did the clinic have by participating. Um, and then providing this opportunity just to work together. So, as you can see, there's many sites across the state that would not have normally had the opportunity to work together, now come together on a lot of different project topics and ideas and information-sharing across the state is, um, at an all-time high right now, just getting them together, on the same page.

So, um, over the last year, this is just sort

of a snapshot of what we've done, um, we've picked up 21 new sites, and we don't actively recruit sites, necessarily, we want to make sure that we're reaching out and engaging providers that are, um, ready to take on, maybe, research projects or have some interest, so how we generally recruit is when we have a project that has specific needs or wants to cover a specific geographic region, that's how we target who we're going to recruit. So, adding 21 new additional sites is pretty significant, that was the biggest jump we've had, and mainly, you'll see that that's just because we've picked up a lot of extra projects as well. We had 20 grant submissions over the last year, and 7 were awarded, so you can see there we've got some externally-funded projects and internally-funded projects here at the CTSI, and then we have 12 other projects that are still kind of working in development phase, trying to get organized for submission. Then, um, kind of progress to date, so when we take that snapshot and kind of step back and look a little more broadly, we've had 33 projects over the last 7 years that we've completed. 36 of them are still active right

now, which is pretty common for practice-based research to continue that long, because the busy clinicians that we are working with are seeing patients, so this isn't their full-time job, so a lot of the projects tend to take a little bit longer.

We have 9 projects that are awaiting funding currently, and 7 that, um, are in development, that have a submission date ready to go that we're just waiting on that date. Um, 39 projects have come to us since the beginning, that we're really just, um, we call them kind of services, which means that we started to work on a project that, you know, a lot of the clinicians that we work with don't have a lot of experience in research, so sometimes, it just gets put on hold and we leave that there for a little while. Maybe, that project was either submitted and didn't get funded, and now we're trying to figure out what the next step is, or maybe it's just an idea that didn't get a lot of support from the other sites, maybe it's more of a specific problem, but we're just trying to figure out, you know, we don't want to completely toss out the idea, but we're waiting to see where the best

fit is going to be, so we kind of keep those in a little bucket, and then you can see our little chart continues to have grown over the last few years with the number of projects that we've taken on. So, this is the staff that we have for our co-directors. They're both community clinicians, and they took over the leadership in 2017. Prior to that, we had some academic, um, leaders, and it was decided among the group that we really wanted to reach out and have the community at the leadership level.

Jennifer Boyd is a, um, physician's assistant at New River Health Association, and Bill Lewis is a provider at Harpers Ferry Family Medicine, and both of them have come with unique strengths and skill sets. It's really taken off with their leadership, and, so, we're very pleased that they're, um, willing to be at our leadership level. So, one of the things that we really started to work on early on was that networking opportunity among the different members of our network. So, we have instilled an annual retreat that we hold, and this actually is how the network really got started. We brought everyone to the table early on

to talk about how we wanted the network setup and what were our goals moving forward, and, so, this yearly event has morphed into really talking about how we are utilizing those goals, and if they need changed or updated for the coming year and setting priorities. Initially, it was whatever project came in our door, we wanted to do it, because we wanted that experience. Now, we really have to be careful that we're not taking on more than we can handle, so we have to prioritize some of those areas. We talked, my favorite one is sharing recent successes. Um, we've been able to start a poster presentation and be able to share some of the information that we've learned, which, early on, we didn't have a lot to share yet.

So, every year, the poster presentation gets larger and larger, and this coming year, we are probably going to need a separate room for it, it's getting so large, so that's, obviously, the highlight of my part of the retreat, is being able to see, um, people share their information with other sites and other members, being able to talk about their projects with the larger group, and really sharing the network success in that. And

then we also, just on a networking opportunity level, we have the retreat open to other community partners as well. So, if there's a particular topic, we'll bring in other folks to be able to share and learn about the PBRN as well, so it's really a unique opportunity to work in areas and with different folks that you may not normally interact with. So, as I mentioned, we were talking about priority areas, and during the retreat, we always revisit this to really talk about what is going wrong right now in primary care in West Virginia and how are we responding to it. So, um, on the left-hand side, you'll see that there's three different sort of buckets that are color-coded there, and what often comes to the top is substance use, but many different levels of substance use; chronic disease prevention, whether that's the primary care side or the patient's lifestyle changes, and then social determinants of health and how all of those pieces can relate to the different disease focuses that the primary care providers have.

So, on the right-hand side is just a couple projects in each category and how we've really

tried to seek out projects that fit into those pockets. They're not exclusive. If there's other projects we want to entertain, we absolutely do, but this just shows that as the primary care and membership come together to really talk about what the snapshot looks like for West Virginia primary care, that we're able to respond to them and say that we've got, hopefully, some projects that are going to benefit their clinics, because they've identified these areas. So, that's just sort of our check and balance to make sure that we're still following in the right priority areas. So, this is sort of a unique piece to our PBRN as well. One of the things that we wanted to track early on was that footprint, and nobody really had looked at that before to really say what kind of impact does this have on primary care, and anytime there's research projects being done, the metrics that most people look at are the funding that it received, was there additional funding later on, what project did it lead to, um, publications, was there a publication that came out of it or a presentation that came out of it, and all of those are really valuable and really great things to track. A lot

of times, it doesn't involve a lot of the primary care side, um, they may have a provider that wants to participate in, um, publication development, but there's a large majority of that staff that touched that project in some way, yet their work is not being captured.

So, one of the things that we started to, you know, practice changes or policy changes that happen as a result of research results being transferred over to the clinical sites, how they utilize them. Um, so, up to now, we've had 60 practice changes among 49 of our states, so what that really means is that they've looked at results that came out of a practice or a research project and said I like the results that came out of this, I think that's going to help our clinic, so let's make a change and somehow incorporate that in. You'll see some examples here in just a few moments of how we've been able to do that. A policy change is a little bit harder of a change, so it usually is an institutional change that needs some type of documentation, really show that it's going to be something that a larger group is going to have to be affected by, and there's another good example of

this in a few minutes, but, so, paying payers are a good example of folks that need policy changes before anything would really change in their scope of work. Um, educational institutions would be another one. Um, and then systems changes is more of a community-wide effort, and, so, um, we have two regional health alliances that have really worked to, um, deliver some systems changes, and just basically how different the community works, um, and if that project had any effect on that, that's what they, um, what we're collecting there, so that's one thing that we really to continue track in addition to all of the other research metrics, just to make sure that the clinic is still getting a benefit out of participating with us.

So, in terms of services, we are, um, part of the CTSI, so the, um, CTSI is a service-based organization, um, and, so, we do provide services that don't necessarily, um, have to fall within the PBRN leadership. Um, so, that's where we really make the connections here with the other cores. So, um, you'll see in a minute that we have a really structured, um, infrastructure that we do, um, while we're working with projects, but in this

particular slide, what I'm trying to show is that there's other times that we interact with clinicians or projects that it may not be from beginning to end, um, and, so, we have support for evidence-informed decision-making, just being able to talk through some of that with the researchers, making those connections to investigators and clinics and communities. Sometimes, they lead to further projects, and sometimes, it's just a good partnership that you can rely on later on. We provide guidance on study design and implementation strategies for communities and clinics. Um, we do have a study design core in the CTSI, and they're really looking at the scientific -- audio breaking up -- we're really looking at feasibility and how this would be, um, you know, really utilized in a clinical setting, is that type of guidance that we provide there. We provide technical assistance in training or in community-engaged research or practice-based research, um, and that looks different depending on the audience, but we really want to train folks to be able to continue these types of strategies moving forward, because they do have really good success and outcomes, and a big

one that we've really focused on over the last year is to disseminate research results for folks.

Um, so, they're, a lot of times, there's publications and presentations that come out of it, which are beautiful to share results, they don't make it to the clinical level, so we've developed different strategies, including social media, newsletters, um, local newspapers, um, we're really trying to engage that local level dissemination and set those plans early on, so we remember to really hit the areas, um, of that particular project, who's being affected by it, we want to make sure that they know, um, about the project and how what that community did really setup for success. For the network as a whole, we have a protocol review process, and, really, what this is for is just to make sure that the projects that we're taking on as an entire network would be beneficial for both the research team and the clinical teams, um, and make sure that that is going to be a balanced partnership moving forward. So, we have a committee that's comprised of providers, clinical administrators, researchers, um, just a variety of people with a lot of different backgrounds to

provide that input into the project, and, um, so, as research projects come up, no matter where they come from, whether it's an academic institution or out in the communities themselves, um, we have sort of a submission, um, process that we use.

The study idea does not necessarily have to be completely formulated in this case though, so we keep the questions very broad, it could just be getting input from the committee, it doesn't mean that the project's ready to take off tomorrow, and anywhere in between there. We do have, offer consultation beforehand, so if, um, the investigator or clinician wants to meet with us, um, as a staff first to talk through some of those project details, we're happy to do that, and then moving on to the next level, which would be the protocol review, um, but our protocol review, once it gets to that point, it really provides some feedback on the relevance to primary care, um, in West Virginia, so, you know, primary care as a whole may have a different opinion than West Virginia, so all of these folks represent the West Virginia primary care. Um, we want to make sure that it's going to be feasible in the primary care

setting or whatever setting it's really looking at, so, you know, that provides a lot of input back, you know, that different clinics work differently, so we have a lot of varying, um, perspectives there that are really helpful to make a project as tight as we can and be able to offer, um, more clinics the opportunity to participate, if the protocol can accommodate more than one design. Um, then the capacity ourselves to take on additional projects. So, um, right now, that's something that we are working on, as we've increased the number of projects that we're currently working on, you know, we need to sort of prioritize that, and, so, the protocol review committee helps with that as well to determine is this something that we are able to take on now, and if so, what kind of resources can we put forward to it.

And then we also want to just gauge that impact on the clinic or patient care to make sure that what we're getting out of the project in terms of the clinical side is also helpful for the folks who are participating. So, a strength that we have, um, in the protocol review is to look at that impact, um, on patient care, and what, how we do

that is, really, um, outside of just a normal, um, kind of incentive process. So, sure, anytime we have clinical support for a project, it's great to include some type of monetary compensation, um, for if there's staff time or resources or clinical space or whatever might be used into the project, but that may not be the only piece that is attractive to the site, so that's the, this is sort of the unique piece that we would spend a lot of time working on, um, and developing with the providers and researchers that are submitting these projects. Sometimes, um, some of that site participation incentive could come in the form of training or increased access to different, um, resources, it could be, um, you know, anything for the site that if they had a practice change would not only just affect the patients that are, were involved in the project themselves, but really impact the entire patient population they serve, and, so, really talking through how large is that impact, and how is that partnership working, um, between the site and the researcher is important. And, so, going back to the dissemination, that's a big factor, so, sometimes, we have to, um, you

know, get to the end and disseminate that information, um, even to find out, you know, what is, where did that impact come from. Well, a lot of times, we'll find new things that we hadn't even thought of initially.

We try to plan ahead the best we can to make sure something is really going to be impactful in the end, but a lot of times, it even goes further than that, so it's really been interesting to circle back and share with other clinics as well, who maybe weren't apart of the study, but can learn from how a particular site handled the study and what they did after, so that really is much larger than, um, just the project itself, when you utilize a network. So, we have a couple of things that we've, um, started to do over the last couple of years. Um, up until that point, we really just focused on projects, and as projects came in, we were looking at all of these components, finding research partners across the clinical population that is part of our membership, and then, also, disseminating the information at the end, and a couple of places had come up where we thought we could utilize that captive audience of clinicians

and, maybe, um, really focus our efforts in a couple of different areas. So, this is a new initiative that we started called the CORE survey, and that stands for the collaborative outreach and research engagement survey, and what this is is an opportunity for several different surveys to be compiled into one and sent out to our membership, so they're kind of taking several different surveys all at once. Um, just to kind of give you some, um, overall kind of time period information, we have the submissions due sometime in the middle of January, and then we review the submissions, and I'll talk about that here in a minute, but the survey is actually put together and released to our membership sometime at the end of March.

We usually try to coincide that with our annual retreat, so we can promote it there, and then give some extra time at the end to close the survey sometime in May. We use a REDCap survey platform, that's something that's supported here in the CTSI, so we've got a lot of support there through the, um, research design core. The purpose of this, um, was really to, a couple of things. The main goal was to limit the number of surveys

that our network takes in a year. There was several that, in the first couple of years, just wanted to get general information from our network, we put information into a survey, and we were sending out surveys several times a year, and every time we sent a survey out, the participation dwindled lower and lower. This was one way that we thought, if we did sort of a guaranteed survey once a year and really kind of packaged it, that that would help the clinicians not to feel so overwhelmed with the amount of surveys coming through. The other thing is that this really offered a good opportunity to pull up some preliminary data for either upcoming proposal submissions or presentations or even a publication has come out of this, and, so, it really kind of gives some information that, otherwise, would not be readily available with our membership. Oftentimes, it's kind of geared toward how they practice on some things that they would like to see happen at their clinic, some perspectives on some, you know, clinical practices and how they can improve or things that they need, and, so, it's more than just pulling information out of their

electronic health record, and, so, it's really valuable to put together.

So, what we do is we send out information for, um, submissions to take place, where it's a little, kind of a small background into the project, sort of that relevance piece and why the information that the investigator's looking at is important to them, what they plan to do with it, and then we ask them to draft about ten questions that would go along with that proposal. Um, the first year, as you can see there in that little graph, we got six submissions, and this year, we increased it to eight, and from those six and the eight respectively, um, we chose three, so the max amount of survey questions that go out every year is generally about 30. We kind of gave ourselves a little bit of wiggle room there, but we try to keep it around 30, so it's a quick survey, but provides information to, um, about three different projects all at once, so it's been a huge time-saver and really kind of a unique process, and through that, we've been able to, um, provide that preliminary data that's gone into two grant submissions so far. We have one that just pulled together some

information that she's writing into a publication, and, so, these are all things that were kind of a by-product of what we were thinking of, but turned out to be even more beneficial to the network than we anticipated. Another initiative that we started just this year is called Design Studio, and what we were really trying to capture here was finding a way that providers could talk together in a group learning setting and be able to talk with our research design core at the CTSI and just talk through ideas.

A lot of times, there's investigators that are either here on the WVU campus or some of the other academic institutions that will, maybe, setup meetings or just in passing speak with some of the research design folks and just bounce ideas off of them and be able to talk through that. Our clinical folks didn't have that opportunity, and instead of setting up a bunch of different calls and meetings and tele-conferences, we decided to lump it kind of all together, so they were learning as a group. Um, we know that primary care is valuable, um, to research, and they're great partners on a lot of our projects, but we wanted to

see if there were clinics that really wanted to initiate their own research and carry out, um, some unique perspectives in rural settings that maybe aren't being captured in some of the academic settings yet, or even if they don't want to initiate them on their own, but be able to formulate ideas that we can then take and partner with somebody during a similar type of research, and, so, what we've, um, created is this opportunity, um, for clinicians to call in or video conference in, so they can see each other, and talk through some of that, um, general kind of idea-sharing and generating. They get clinical feedback from their peers, but then also design expertise from the design core, um, and it's really basic information. A lot of times, the clinicians will say I don't remember a lot of the research that I learned in school, and, so, this is just sort of a refresher, so for the design, um, research design experts, it's very basic one-on-one stuff, but it's really valuable to our providers.

So, we have kind of a similar format, where we ask for folks to submit ideas, and they do not have to be at all formulated. We actually don't want

them to be. We want to get an idea of what types of questions are they hoping to get out of it, to make sure that the call is being responsive to their questions, um, and it gives our design core folks, um, a chance to kind of read through and get some ideas that they can jot down prior to the call. Um, so, as we're, we have the call, you know, we do provide, um, that general feedback back to that clinician, but then I also make written notes that I can share with them as well. A lot of times, during that discussion, it's hard for them to take their, the right notes, so we have folks here that do that as well and then follow-up with the clinician afterward, and a lot of times, we're following up with them with the study design teams, or sometimes, it's just following up and making sure that, um, they get all their questions answered, and then we can help them move forward. So, to date, we've had 31 community clinicians that have attended the Design Studio, 31 unique clinicians. Several of the clinicians have participated multiple times, and we've only had four sessions. We tried to make this a quarterly thing to start out with, to see how, um, folks were

going to be interested and how many folks were going to be interested to present, and so far, we usually do about one project, um, a session. We have tried to do two, but it did get a little bit pushed for time, so we're trying to do, take one at a time.

Um, so, our first project that was presented really was an idea that came out of one of our partner's clinics regarding back pay and maybe some unique strategies that she thought helped, but as she talked to some of her peers, a lot of the other folks were not thinking about utilizing new strategies. So, we really talked through how she could come up with a way to find out what other providers are doing and how to collaborate on future research projects, um, and, so, she was one that actually submitted to the CORE survey and was accepted. This is a clinician that, up until this point, had, really, no, um, interest or experience in research and was able to pull together a really great set of questions based on the feedback she got from design studio. Um, another project submitted a grant application, and we're awaiting to hear that result, and then a third project is

really, um, already collecting data, we wanted to make sure that it was collecting the right preliminary data for what she was hoping to get to in the end, so that was a really unique conversation as well, but as you can see, we're really trying to just help the clinicians and go to them for the types of services that they're wanting to achieve in their clinical practice. This is one of the ways that we've been able to do it over the last year, which is very cool. Um, so, I have a couple of project examples here, it kind of hits on some of the things that we've talked about.

So, this project, I don't know if anyone has heard of it, this is probably one of our most long-standing projects, for sure, um, the IRIS diabetic retinopathy project was really something that was initiated by one of our clinical partners early on. They determined that the need for diabetic retinopathy care and screening in their clinics was, um, very high, and they had no specialty in the area that they lived in. So, one of the things that we were able to do was pull together, um, a new strategy that was feasible in the primary care setting, but was able to detect

and screen for diabetic retinopathy. So, diabetic retinopathy is often one of the silent blinders, so a lot of times, the disease is manifesting without a lot of symptoms. So, it's really important to get screened once a patient is diagnosed with diabetes, but if you're not having symptoms, it's hard, especially if you're going to have to travel to a specialty that's not nearby, so this is one of the ways that we've been able to respond to that need and find a way that primary care can change what they're doing to reach those patients that fall into that category.

So, we collected data out of this project, and now, um, we still have many of these cameras that are out in the communities, even though, um, the project itself has ended, which is really great, um, but when we went to really look at the data, we found that almost 17 percent of patients who had not received an eye exam, and probably wouldn't have in the near future, needed immediate treatment,so we were able to refer those folks to treatment, which we also know is a limitation, if there's no specialty care for screening, then there's probably not specialty care for treatment.

It was a little bit easier to get folks to go, travel a little bit further out than just to find out whether they were, um, affected by it at all. We also got some local folks, um, in these different communities to find better ways to refer patients, to kind of take out that barrier as well, so the whole process just moves a little bit easier, for the patients and the clinics. So, we were able to improve the quality measures of the sites, which was important for their reimbursement, um, we created a sustainability plan, so these are still being utilized, and then we also, this is the project that went to the four policy changes, so we submitted this, um, data to policymakers in West Virginia and nationally, to say these types of new technologies need to be covered in primary care, because we're missing patients who are going to have extreme, um, difficulty with their vision or even lead to blindness, if they're not screened in an appropriate timeframe, and, so, the policy, um, changes occurred because of this project. It was just really a highlight of this project, for sure.

Another project that we've worked on was a chronic pain study called CAIPEC, and, really, the

purpose of this project was to improve the chronic pain management by using a toolkit and a clinical application that was provided to the clinics with training. So, what we found is that we had five practice changes that came out of that, because the toolkit allowed clinics to try things and get to work with the study team, and through whatever, um, in the toolkit they wanted to use, um, they were able to choose their own strategies. So, among the three clinical sites that participated, they all did it differently, which was great. It was all customized to their site, and with that, we saw an increase in controlled medication agreements and an increase in, um, the use of the different medications and just improvements in pain level, and that was at the patient level. So, the clinics themselves got the benefit there, because they were able to change their clinical practice that is still utilizing these strategies today, um, but then the patients also were satisfied with the difference, which was another bonus for us.

This last project, um, has really developed over time and been extremely successful for us. It's, um, looking at suicide screening, and when

this investigator first came to us, um, the goal was to increase suicide screening rates in West Virginia, but we identified early on that in order to really address the screening rates, we needed to find out what the challenges and barriers were, so this investigator did 15 provider one-on-one interviews, to really talk through what their current practices are around suicide screening, how comfortable they were, what their satisfaction levels were with the different techniques that they're using, sort of what they would like to see happen, and from that phase, that first phase, we were able to, um, put that into a grant application and was awarded to pilot the new screening tool that she developed, and, so, we started with two PBRN sites, one in Charleston and one in Huntington, and that project was very successful and ultimately went through, um, the entire practice that it worked with and developed those practice changes among their clinics, and, so, the next step, which is going to be starting soon, is to expand that screening tool to more sites than the PBRN, and, so, um, the two sites that were in the pilot are really advocates for this next phase,

because they've been able to show the success that they've had, um, and, so, this project, to me, always just stands out, because it really started, um, very small, just an idea that one of our investigators had, and really has progressed to something that a lot of the sites are participating in, something they can all talk about when we get together, and it's something that, I think, really started to provide more information to the sites on and prioritize a little bit higher than, maybe, they originally had it prioritized.

So, um, this is definitely one of our success stories too that I like to mention, how it went through all the phases, but that's just a couple of projects that, um, sort of had different pieces that I wanted to highlight, but, um, we have many others that fall into many different topic areas. We know that obesity and diabetes are very high in our state, and, so, a lot of projects, even if it's not directly impactful to those, um, somehow utilize that information as well. Of course, the substance abuse disorders that, um, are occurring high in our state have also gained a lot of traction in our network. They often feel very

overwhelmed with some of the resulting, um, diagnoses that come off of that, hepatitis C being one of them. They're just being inundated, and, so, we were able to respond to that as well and try to get them some support for their hepatitis C patients, and now, unfortunately, some HIV patients. So, it's a way that if they need help, they can reach out to us, and we can respond, um, the best way we can and connect them to the right resources. So, um, that's a PBRN. That's basically all I have, but I can answer any questions.

>> SPEAKER: All right, can you hear me?

>> SPEAKER: Yes.

>> SPEAKER: Okay. Thank you very much. I'm going to un-mute everyone, and we also have the chat function, in case you feel more comfortable listing your question in the chat, and if you want to go back on mute, feel free to do that, I just want to make sure that I'm not limiting people from asking Stacey some questions. Before I ask any questions, anyone have any particular things they want to ask? Well, Stacey, I'll go ahead and start then. I think the, um, couple things, just to give

you a little bit of background, um, and as you were talking about, thank you so much for going through all the things that the PBRN has been doing over the years, um, I had two questions for you. One is what percentage of the projects that the PBRN has taken on, whether it's, you know, kind of stuck in that whatever status that you mentioned at the beginning, um, that would focus on individuals with disabilities, either explicitly or implicitly? And is there an opportunity there?

>> SPEAKER: Hmm. Um, percentage, I would say, um, I'm, like, scanning the list in my head right now, because I was looking at it this morning, I would say at least, um, a third of our projects.

>> SPEAKER: That's wonderful.

>> SPEAKER: Yeah, and the reason I say that, our project list, it may not be quite as obvious just looking at it, but knowing sort of the insides of it, you know, I think a lot of folks fall into multiple categories, and, so, having that sort of comorbid, um, disease list kind of puts them into a lot of buckets, and, so, what we try to do is when we're helping a patient, um, either in one of these

projects or on a clinical level, is really get them the entire, um, anything that they need, any resource, and, so, one of the things that we've been able to utilize in some of these projects is to provide additional support to the site to have, there's sort of a different name for all of them, but for someone in-house to really do the social determinant side of, um, addressing the patient's needs. Some people call them, like, a social worker, but it's a little bit different than that even, um, but it's, whatever title they give them, it's, really, the purpose is to take that patient at the center and be able to offer any type of support, and that, even just being part of a project, even if it's something as specific as substance use disorder, it doesn't stop there, and, so, we're able to connect folks for other, um, needs as well. That's why I say that I think, you know, that might even be sort of an underestimate, but I believe a lot of them probably do touch folks with disabilities, and as far as opportunities, absolutely.

One of the things that we do, just because there's so many projects going on and all the

different stages, it's sort of hard to keep track at times, we do have a quarterly newsletter that goes out to really try to keep everyone informed of things that are coming up or things that are finishing. We have some of that information on our website as well, um, though that's a little bit harder to get, you know, updated quite as readily as our newsletter, so anyone that's interested in that, I'm happy to put you on our newsletter list, just to keep up-to-date on what projects are going on, but specific things that would be helpful for the PBRN to be apart of, we're happy to meet and talk about that as well. So, opportunities are always available.

>> SPEAKER: That's fantastic. I mean, we have the information dissemination, direct services, trainings, um, and research, so I think all of those overlap with your, with the CTSI and perhaps the PBRN submission, so that's helpful to know, for sure. Um, also part of our background is, in general, we've had a lot of the service programming, right? Direct services out there, so we're similar to your primary care providers. There's a, I think I'm speaking for most people, we

have traumatic brain injury, we have specialized family care with placements in home providers, institutions, we have lifespan focus, so some pediatric and some up to geriatric, so, but it's been direct services, so, um, we are moving, in the past few years, we've been trying to add more program evaluation and more research, and we would be growing with your PBRN, um, knowing that there's that R in PBRN, um, to explore pieces of our projects that would be research-based, but I think would be valuable, in not only the services provided, but with the focus areas. I think it would be great.

>> SPEAKER: Sure.

>> SPEAKER: So, that's helpful. Malina, I see you're on here, I'm going to put you on the spot, in terms of information dissemination, um, Stacey, I'm not sure how much, I know you guys put out a lot of materials in terms of accessibility, if that's a criteria, I know Malina and Courtney keep us really, um, mindful of accessible, um, web and others, but I didn't know if that's an area of opportunity as well. They might be on mute. Um, and not just, um, I'll speak more, not just, um,

Braille and things of that sort, but screen-readers, stuff like that, I mean, Stacey, when I was just in pediatrics, I honestly, and I hate to say this, but I did not think about those items, so a lot of the programming materials that we put out really weren't accessible to all, so maybe that, as we start to collaborate, that'll be a piece too.

>> SPEAKER: Oh, absolutely. Yeah, and that's one of the things that, um, kind of on a more broad scale with primary care providers is it is easy to not think about it, so when we reach out to our, um, protocol review people, they're really great at identifying things that, you know, as they're thinking about their patients, they'll pop in their heads to say, oh, this would not work, because we need A, B, and C, and, so, you know, we can definitely support, um, the idea of connecting with those providers to talk through that, so if it's a project that might need that primary care perspective, I think that would be a great sort of goal for us to work together, but then on the flip-side, you know, we provide help to projects that maybe you all are working with as well, and,

so, one of the things that, you know, we're able to do is really find different partners across the state, um, that are a little bit different than sort of the normal kind of community groups. We work with them as well, but the providers are kind of the unique sort of niche that, um, they're often just really busy and hard to, um, kind of recruit for different projects or initiatives, even though they know that they're really valuable, but they just can't always, um, be reached, and, so, we've found, um, kind of the best strategies to do that within our network, and, so, um, you know, that's one area that we've just been able to customize, we know sort of where the target areas are for things, um, we know what clinics respond best to certain projects, um, we know that there's some topics, for instance, if we're talking about substance use disorders, um, going to the providers is going to be more successful than their administration, just average, I mean, not for every site, but most generally, the providers are the ones, because they're at the forefront, and they're seeing it day in and day out, the administrators know it's a problem, but they may not have that same

perspective, so that type of insight is something that we can provide to other projects outside of our network, um, and also just the dissemination partner, because I think that's something that really drives our success, but also just the advancement of, um, primary care research is just being able to talk about it, um, and share ideas, share results, share whatever we wanted to share about projects, success stories, or maybe challenges that we ran into, and that's where we've really developed, I think the most, is being able to provide that.

So, we're happy to be a dissemination partner as well, but like I said, we've got all our services, and we can help tie into other, um, CTSI initiatives, and, um, our cores, there's professional development information that we can share, there's, um, study design that I mentioned a good bit, we have some computer technology data analysis pieces, um, and, so, you know, that, sometimes, those are really overwhelming, to kind of come in to explain a project to someone that they're an expert in, so we provide that support also, to help folks get ready for those types of

interactions and making sure that their needs are met from the CTSI standpoint as well. We want to make sure that the communities, the way that we respond to community needs is much different than how we would respond to, um, some of the investigators that are here on campuses, um, and, so, we want to, our goal is just to make sure that everyone gets what they need and, um, being able to drive their own success, so we're happy to help in any way we can.

>> SPEAKER: Fantastic. Any, um, other comments or questions from people, maybe program-specific? And doublecheck, if you're on mute. I see some movement. Okay, um, so, this has been fantastic, Stacey. I really appreciate it. What is the best way, would we be able, you think sending you information about our programs as some of the background and then to start discussions and then bringing in, each program has a program manager and a PI --

>> SPEAKER: Sure.

>> SPEAKER: Does that seem like the reasonable --

>> SPEAKER: Yes, absolutely.

>> SPEAKER: Okay.

>> SPEAKER: Yeah, I think that would be a great place to start. We also, I didn't mention this earlier, but we have a steering committee for the PBRN also that meets monthly, and, so, if there's an opportunity for some folks to join and kind of describe, um, some of the efforts that you all are working on, we'd be happy to have you on one of those future meetings as well.

>> SPEAKER: That would be great. Yes, thank you, if that's available, that would be wonderful.

>> SPEAKER: Absolutely.

>> SPEAKER: Okay. All right, well, hearing and seeing no other questions or comments, I really appreciate your time, Stacey, and, um, and resources and just willingness to support our efforts, um, and lead us to people with similar interests. Um, so, thank you for your time, and I appreciate everyone else's time. We'll, um, make sure that this is available, you'll be able to follow-up, Stacey, we might have some questions for you afterwards.

>> SPEAKER: Sure.

>> SPEAKER: But this has been great. Thank

you very much.

>> SPEAKER: Thank you. I appreciate the opportunity to talk.

>> SPEAKER: All right. Well, everyone, have a nice afternoon, and, um, we'll see you soon. We'll see you next month.