

Linking Research to Rural Communities with the NIH National Center for Advancing Translational Sciences – 3/31/2020

Kristine Sande:

Good afternoon, everyone. I'm Kristine Sande, and I'm the Program Director of the Rural Health Information Hub. I'd like to welcome you to today's webinar, Linking Research to Rural Communities with the NIH National Center for Advancing Translational Sciences, or NCATS. I'll quickly run through a few housekeeping items before we begin. We do hope to have time for your questions at the end of today's webinar. If you have questions for our presenters, please submit those towards the end of the webinar using the Q & A button that's at the bottom of your screen.

We have provided a PDF copy of the presentation on the RHHub website, and that's accessible through the URL that's on your screen. We've also sent the link via the chat function in Zoom. If you do have any technical issues during the webinar, please visit the Zoom Help Center at support.zoom.us. Now, it is my pleasure to introduce the speakers for today's webinar.

Dr. Kay Miller Temple was board certified in Internal Medicine, Pediatrics, and Hospice and Palliative Care before leaving clinical medicine and getting a Master's Degree in Journalism and Mass Communications. She currently is a content writer for the Rural Health Information Hub, where she uses the perspectives gained from both her 30 years of clinical practice in urban and rural environments, as well as growing up on a family farm in South Dakota.

Next we'll hear from Dr. Michael Kurilla, who is the Director of the Division of Clinical Innovation at NCATS. In this capacity, he oversees the clinical and translational science awards, or CTSA Program, and that supports innovative solutions to advance the efficiency, quality, and impact of translational science with the ultimate goal of getting more treatments to more patients more quickly. Prior to joining NCATS, Kurilla served as the Director of the Office of Biodefense Research Resources and Translational Research within the National Institute of Allergy and Infectious Diseases where he focused on translational efforts toward infectious disease product development, including vaccines, therapeutics, and diagnostics with emphasis on biodefense and emerging infectious disease threats. Prior to joining NIAID in 2003, Kurilla was an Associate Director for Infectious Diseases at Wyeth. He also worked in antimicrobials at DuPont and on clinical microbiology and molecular pathology at the University of Virginia Health Sciences Center. Kurilla received his M.D. and his Ph.D. in microbiology and immunology from Duke University. He was a postdoctoral research fellow at Harvard Medical School and completed a residency in pathology at Brigham and Women's Hospital. He received a B.S. in chemistry from the California Institute of Technology.

And finally, we'll hear from Dr. Laura P. James, M.D. She has been the Director of the University of Arkansas for Medical Sciences Translational Research Institute since 2014 and is the UAMS Associate Vice Chancellor for Clinical and Translational Research. She is a member of the Clinical and Translational Science Awards Programs Steering Committee. James has a 25-year history of translational research in clinical pharmacology and toxicology at UAMS and Arkansas Children's Hospital. As a clinician, scientist, and founder of the startup company Acetaminophen Toxicity Diagnostics LLC, she is leading development of a rapid diagnostic test for Acetaminophen liver injury. In 2014, she was named Inaugural Fellow of the Arkansas Research Alliance. With that, I will turn it over to Dr. Kay Miller Temple to start us off.

Kay Miller Temple:

Good afternoon. My name is Dr. Kay Miller Temple, and I'm on the content writing team at Rural Health Information Hub. The nation's federal health agencies have a charge of ameliorating health disparities, so after learning that the National Center for Advancing Translational Sciences

at the National Institutes of Health was interested in increasing collaboration with rural health stakeholders, last October in our Rural Health Information Hub online magazine, The Rural Monitor, we published a two segment story featuring the agency and their work. So today we'd like to talk more about what they do and allow our audience to think about partnership activities.

Octobers in depth story introduced our readers to NCATS as the center is known, and the story described what translational science is and does. Here is the agency's strategic plan and its goal, color coated in regards to alliance with its science, partnerships, workforce, and stewardship.

While doing the background research for the story, I found a free online course about translational science posted by one of the universities associated with NCATS. The professor started the course with this statement. "Notice NCATS has a verb in its name. Advancing, that's what we do. We advance science from one stage to another."

To explain these stages of science, also referred to as the spectrum, here are the descriptions and definitions which I've paraphrased based on the website information. You'll note preclinical research and clinical research, clinical implementation, and public health integration. A strategic step when I write any Rural Monitor story involves my own research looking for academic studies on the topic, so this step usually starts of course with NIH's National Library of Medicine's, PubMed. For this story, I used a simple PubMed research search using the words "rural" and "translational science," and sifting through those search results, I found a significant number of articles, a few of which are shown here. Notice the yellow highlighted paper. It's actually a recent report on rural concussions, also known as mild traumatic brain injury. I've interviewed the lead researcher on that paper, and we are hoping to publish that story next week.

In a few moments, you're going to hear from Dr. Kurilla, head of the NCATS Division of Clinical Science. I had the privilege of interviewing him for the October story. And during the interview, he explained his division's translational science work using four words. Turning science into health.

Another way to look at the overall work of NCATS is by looking at their summary infographic logo, and the logo further highlights the NCATS mission, a mission centered in the three Ds. Develop science, demonstrate science, disseminate science. You'll note the logos central icon. It's really important for researchers, clinicians, lay audience all alike to recognize that turning science into health will always include patient involvement.

NCATS also has a grant making charge. Their grant program is called Clinical Translational Science Awards, or CTSAs. Many of their grantees have a strategic focus in translating science into health for rural Americans. These grantee award programs are referred to as C TSA hubs, and the hub awardees are usually academic medical centers and other organizations with activities that center in the three Ds. Just as no two rural regions are alike, no two C TSA hubs are alike. You'll note that the grantees are charged with five goals. Listed second is engaging patients and communities at every phase of the translational process. That's one spot where rural health stakeholders can join in. As I mentioned, the grantees differ from one another in their research focus, however they all use community engagement programs. Again, here's an area were rural stakeholders and patients may be able to participate.

If you've read or decide to read the October Rural Monitor story, you'll notice that the language varied a bit from the usual language of our stories that are focused on public health and health services research. Why the language difference? Because clinical research varies from the work done by public health and health services research. It might be helpful to use these two logos

side by side as a comparison of the two activities. On the right, you'll see a logo that demonstrates Public Health Corps activities, and the left reflects the NCATS activities. Though there are differences, you will see similarities. For example, NCATS does intersect with public health activities. We've talked about the CTSA hub engagement programs, and they're similar to the public health activities that mobilize community partnerships. Though differences exist and the language varies, the end game is the same, to improve world health disparities.

As rural health care stakeholders consider future partnership opportunities with these clinical researchers, the funding structures of these opportunities are also likely to look different from those our audience is familiar with. But again, language and funding differences aside, the work of translational sciences again has the same goal as the work of public health and health services research, to improve world health disparities. We can't say that often enough.

Wrapping up my segment, I wanted to share this photo of where I live in South Dakota. This is about a mile and a half south of our homestead looking west. I took this photo a couple years ago in June. Some of you are thinking, "Yeah, that looks rural." But for me, that photo is not rural. That photo is home. It's home to me, to my family, to our friends and our neighbors, and all of us are involved with and have issues that our health disparities are looking to you all for answers. So as I hand off to Dr. Kurilla and Dr. James to further review their work and review what potential partnerships might look like, I want to thank them and everyone listening today, every rural stakeholder in the audience for looking at this as a further opportunity to decrease rural health disparities. Dr. Kurilla?

Michael Kurilla:

Thank you, Kay. All right, so yes, thank you. As Kay pointed out, NCATS is within the National Institutes of Health. There are 27 institutes and centers that comprise NIH. While the bulk of those institutes and centers are categorical in nature, focused on very specific segments of health overall, people will be familiar with the National Cancer Institute, obviously focused on cancer. Right now a lot of attention is being focused on NIAID, the National Institute of Allergy and Infectious Diseases because of the current COVID-19 outbreak. NCATS is a little different. We are disease agnostic, although I like to emphasize to people that that does not mean we are disease atheistic. But we are not targeting or focused on any specific disease, rather what we're trying to do is to focus on the methods and technologies that will enhance the development, testing, and implementation of diagnostics and therapeutics across a wide range of human diseases and conditions, including those that are clearly emerging that we don't even have a good scientific handle on at this point. There we go.

So my division within NCATS specifically is charged with overseeing the clinical and translational science award or CTSA program. This is the primary extramural funding, so all of my funds go out across the country to support the CTSA program to academic institutions that are distributed all across the entire United States. There we go.

Currently I should mention we have 60 different hubs. The one issue I think that's important to emphasize however, is that obviously most major academic medical centers are located typically in urban high density population centers for historical reasons. As a result, reaching out to rural is something that they have to actively pursue and work at. All of them have a community engagement core, which is focused on really trying to bring in as diverse populations as possible in order to really provide, to give us an overall sense of the health space and to make sure that what we do in one particular area is applicable to a wide array. These are just some examples of difference CTSAAs. The Indiana program, which really covers the entire state, has the Community Health Coalition Development Program that is their method of outreach. Dr. James will speak a little bit more about Arkansas, but they offer a community scientist academy, which is a very productive way of engaging with the community in order to identify and foster collaborations with specific patient populations.

The University of Washington is in a unique situation. They have what they call the WWAMI Network. So in addition to Washington, Alaska, Idaho, Wyoming, and Montana are four states that are associated with Washington for historical reasons because none of those states have their own medical school. So they began an arrangement in order to provide for medical education and training through the University of Washington. The Institute of Translational Health Sciences, which is their CTSA, has actually capitalized on this and has established a very large practice base for search network as well as a network of community hospitals spread throughout the region, where it's really a grassroots effort from the bottom up to identify issues and concerns that those community practitioners are really interested in addressing. That includes a variety of small urban but mainly rural healthcare settings.

Then finally, the University of New Mexico, which actually when I visited them, they explained to me that there is a division beyond even rural that they refer to in their state as frontier because of a couple of unique conditions such as limited cell phone coverage and limited paved roads that they have to try to address. They are in fact utilizing a lot of technology through Project ECHO to really enhance the training and educational opportunities for healthcare providers working in a wide variety of settings and primarily in low population density and rural settings where they just don't have access to the specialty community.

There's a couple of special focuses in terms of rural health. So the Appalachian Translational Research Network is one of about nine different institutions that are focused on issues of particular relevance and concern for Appalachia. Five of those nine institutions are in fact CTSA's, and they do quite a bit in order to coordinate projects that are applicable and directly involve the entire Appalachian Region. Then again through the University of New Mexico, their Rural Health Research Support Network includes several other CTSA's, University of Kansas, University of Arkansas, as you can see University of Kentucky, University of North Carolina, and University of Utah. Again, focused on really trying to identify specific issues and concerns and research opportunities involving rural communities and rural health issues and as well as trying to address disparities.

Finally, on the right hand side, this is a very interesting collaborative effort. We have a grant mechanism for allowing different hubs to come together to work on a joint project. This is run, the lead is out of Oregon, but it is a peer based retention of people who use drugs in rural research. It's a specific project to try to identify different ways to conduct research in rural communities specifically to address drug use and drug overdose issues. So let me move on.

Now one area I think which is of particular interest for us and a lot of activity is going on in this area is informatics. We have a whole program referred to as Clinical Data to Health, CD2H, that is really trying to accelerate the innovation in clinical care through the utilization of more digital formats. If you look on the left hand side, the current discrete clinical data that historically clinicians have been used to working with. We're moving into an era on the right hand side of really emerging high throughput data where the amount is just exceeding what people can either hold in their heads or that can write down on paper. Trying to be able to integrate all of this is a major effort. I think this offers us some really unique opportunities from a technological standpoint to really innovate how we not only do healthcare, but how we deliver healthcare and the manner in which we can in fact deliver healthcare.

Again, moving out just beyond the healthcare provider, these are just some examples of what we're seeing, a wealth of information and unique applications. In the center is a sort of schematic of how wearable devices can be integrated to provide data back to the individual user, but also to their healthcare provider. The left hand side is a very interesting project from a group at the CTSA at Emory. It sounds a little bordering on science fiction, but this is an app that can actually determine your hemoglobin level simply by taking a photograph using your cell

phone of your fingernails. The idea is this is literally putting a clinical laboratory in the palm of your hands, and that the potential for patient self-monitoring for different types of therapy is really exploding. We see a lot of applications, again, for the more remote types of healthcare delivery, this offers the opportunity for more self-monitoring but as well as being able to alert clinicians without having to directly have access to the patient.

So on the right hand side, from the University of Rochester is an app that has been developed specifically for self-monitoring Parkinson's Disease. This is just an area that is exploding, and we expect to see more and more of these types of applications for all different sorts of diseases going forward. The focus on rural health has been something that there's always been a focus within the CTSA program. Individual hubs have always had a tremendous interest in this, but this sort of was raised to a national level when our federal budget for 2019 specifically called out for NCATS to put more focus on addressing rural health disparities. So we have a mechanism that we refer to as an unmeeting, which sounds a little corny but is a design of a meeting format where all of the boring talks are taken out and all of the very interesting collaborative interactions between people are really accelerated, highlighted, and encouraged as much as possible.

We had this in Gainesville, Florida, just about a year ago, and this was a overall tremendous success by the response of people who came in. One of the things that is really valuable about these types of meetings is it brings together a lot of disparate groups with a lot of different areas of expertise and specialty and interest. I think the real take home lesson for me was the recognition of which lead to our having an engagement with the US Department of Agriculture through their extension service. Many of our hubs were very actively engaged with their extension services, already doing a lot of projects, but there was an equal if not more number of hubs that were completely unaware of this capability and opportunity that they had. So this led to a lot of engagement and opportunities that people had not realized were actually available to them.

At the NIH level, there is now a special interest group within NIH focused on rural health. It was surprisingly highly encouraged and interested by a lot of different groups, and so last fall we had our Inaugural NIH Rural Health Seminar. There were three ICs, of which NCATS was one of them sponsoring, but there were additional 10 ICs that were involved in this. Five NIH Institute directors and two deputy directors actually participated for the whole day. It was very well received. It really highlighted a lot of unique aspects and really targeted the focus in terms of unique aspects that really need to be addressed for rural health.

Finally, training and educational opportunities are a very important component of our program. We're doing our best to try to support a diverse workforce as much as possible. That diversity extends beyond just the traditional types of racial and ethnic minorities, although we highly encourage that, but we're looking for a diversity including rural versus urban type diversity as well. This is just one example of that at the University of Alabama Birmingham that is, their hub is partnered with the Department of Community and Rural Medicine and the Institute for Rural Health Research at the University of Alabama. Dr. Mercedes Morales-Aleman is focused on looking at multi-level factors that underlie the health disparities in adolescent Latinas in the United States throughout the south using a community based participatory research. So I think I'll stop there. We have a website. On our website, we have a specific page devoted to rural health where people can find more details and information about some of the things I've talked about here as well as other activities that are going on. We hope to keep populating this rather pastoral scene with more and more activities. So I'll stop there and turn it over to Dr. James.

Laura James:

So thank you, Mike. I appreciate the opportunity to share the stage with these two individuals today and wanted to specifically talk about some projects that we are developing and in the

middle of at the University of Arkansas for Medical Sciences, which is in Little Rock, Arkansas. All right, so as this slide shows, Arkansas is a state that really has a very large population that is considered rural. Up to 42% of the citizens of Arkansas live in rural areas compared to 15% of the US population. As the audience likely knows, folks living in these rural areas have unique characteristics. They have higher rates of certain diseases such as hypertension and obesity, higher rates of unhealthy living such as smoking, reduced rates of physical activity. We find that Arkansans have a difficulty at obtaining access to primary care in addition to specialty care, health care.

Our citizens are more likely to be insured. They are likely to have high rates of poverty, to have greater distrust of physicians, and to have greater rates of motor vehicle accidents as well as opioid and other drug related issues.

So as we learn about reframing our CTSA for the most recent round of renewal, we decided that we really wanted to address some of these health challenges. Our mission was established, and that is simply that we wanted to develop knowledge and new approaches that will really measurably address these complex health challenges of both rural and underrepresented populations. Some of our strengths that we are leveraging to help us excel and addressing this mission is that we have a long standing history of strengths from our College of Public Health and community engagement. We have national expertise under the leadership of Dr. Geoffrey Curran who is an expert in implementation science. Then we have a number of faculty across many departments who have a lot of expertise in working with special populations, both pediatricians, folks in the College of Public Health, as well as expertise in our Northwestern Arkansas Regional Campus in working with the Marshallese population.

We also have a lot of strengths in biomedical informatics as well as a strong supported Department of Statistics. Because we are small, I think we in particular have some very strong across college and across institution interactions and collaborations that have allowed us to move forward with our challenges.

So we are a state of three million. The University of Arkansas for Medical Sciences, or UAMS, is located in Little Rock, which is right in the center of the state map. Our CTSA has two collaborating institutions who we consider to be our partners in addressing these challenges, Arkansas Children's Hospital, or ACH, and then the Veteran's Hospital in Central Arkansas are all within either contiguous locations or about a mile or two apart from the UAMS campus. Then this slide also shows that we have a number of clinical and educational outreach centers throughout the state as well as regional campuses. The most established is the regional campus in northwest Arkansas, which is about a two-hour drive from Little Rock. So as we look at how we can impact rural populations, we are very much relying on established clinical and educational infrastructure that is already in the state and is linked to either UAMS or our participating partner service.

One of our goals is to take what we have developed or what we consider to be our strengths and or CTSA tools that we have adopted or developed and use those to strengthen our partners and to strengthen other NIH programs within our state. As I mentioned earlier, we have a lot of strengths in informatics. We have converted our electronic health record into a resource for research which we call ARCDR. We are currently working with a children's hospital to help them do the same, and we're in the middle of something called I2B2 implementation, which is really a software program that will allow the pediatricians at Children's Hospital to better leverage their electronic health record for research. We're partnering with them to get that done.

Then the final bullet refers to really taking an NCATS innovation, which is the smart IRB model. This is best thought of as a single IRB model where participating sites seem to be a delegated

individual IRB. The advantage is that we are able to get through the regulatory processes to human subjects research much more rapidly. Rather than doing this as a sequential approval, we're able to seed multiple sites to a single IRB. So one of the things that we are proud of is that because UAMS had already adopted the smart IRB model, we were able to use that for another funded network that is available to pediatric centers that live in the IDeA states.

So I'll show another example of that in my next slide that's just an example of taking an NCATS innovation and leveraging that out to other NIH funded research networks. As I mentioned earlier, our College of Public Health has a very strong history of community engagement. This program is led by Dr. Kate Stewart, and you can see her staff. The two ladies that have the blue stars by their pictures are individuals that were our former trainees. They were former KL2 scholars, which means that they had two years of dedicated funding to develop their research programs. Both of these individuals now have independently funded research programs that are addressing rural health. They are also continuing to lead our initiatives in community engagement.

As Mike mentioned earlier, all CTSAs have a focus on community engagement. These are some of the examples of programs that we have supported. I want to focus a little bit on our Community Scientist Academy because we think this is innovative, and this has really allowed us to broaden our reach. The idea of the Community Scientist Academy actually came from our member of our Community Advisory Board. The basic concept is that we are training community members through a 12-hour training program the basic essentials of human subjects research and the entire process for clinical research. So by providing them training on research, we are then giving them the opportunity to participate with us in decision making about which sorts of research programs and projects we are going to support. This has been extremely successful, and I think everybody that's been involved with it has really seen the benefit of this.

As we have expanded this program, which we started in 2016, we have launched some Community Scientist Academies that target certain special populations. We now have one that's tailored toward Veterans, and we also have launched a Community Scientist Academy that's targeted toward high school students. When we first started the program in high school students, I thought, "This will never go anywhere," but fortunately I was proved wrong. The photo on the right is an example of high school students that were trained about research, and then they were able to serve on a community review board to advise Jessica Snowden, who is the individual in the red sweater on the slide. They were able to provide advice to Jessica Snowden about recruitment and retention for a clinical study. It just happens that Dr. Snowden is the Co-PI of the Coordinating Center for the IDeA States Pediatric Clinical Trials Network. So I think this is a nice example of showing how a particular innovation supported by NCATS and by the CTSAs is now being leveraged to support other NIH funded programs in our state.

The other thing that we are excited about is that other CTSAs have liked this model. The Ohio State University CTSA is in the process of adopting our Community Scientist Academy model, and we look forward to seeing the results of their effort from that program. Another thing that we are engaged in now is trying to build a greater capacity to do community partnered research. CPEARL is the name of our effort to do that. The foundations listed on these slide are all local foundations or volunteer organizations that are participating in a research training program with us. You can see that some of these are addressing issues that are challenges either in special populations or in individuals living in rural areas. So the goal of this program is that we will be co-training researchers as well as community groups, and that they will learn from each other and develop joint research projects where they will produce preliminary data that will allow them to apply for future research grants. So this is kind of our effort to grow capacity for community partnered research in Arkansas.

Then the last part of my talk I want to focus on work that we're doing with special populations and specifically work that is being led by Dr. Pearl McElfish, who is the Vice Chancellor for our Northwest Arkansas campus for our CTSA. She directs our special populations research.

This slide shows a map of our regional campuses for UAMS, and you can see that we have eight regional campuses scattered throughout Arkansas. We are in the process of leveraging these campuses to better underlie infrastructure that will enable research. The second thing that we are doing is reaching out and beginning to incorporate our digital health resources in our research approaches. The little blue symbols throughout the state show all the spots in Arkansas where you have digital health or telehealth resources available. This has widely been used by the clinical operation to lower adverse health outcomes. There have been programs addressing high risk pregnancy, strokes, as well as trauma. We are beginning to leverage this resource as another platform for conducting research.

The last slide shows what is basically the launch of our Rural Research Network. I'm showing in the four green stars that we have four regional programs that are in the process of being trained to launch our first clinical trial throughout these centers. Our original plan was to start this trial, which is funded by PCORI. Our goal was to start this May 1. This has been admittedly pushed back a bit with the COVID-19 situation, but we are still moving forward with training and implementation of what will be a multi-center trial in Arkansas.

Diabetes is a disease that this is more common in Arkansas, and in fact in the last seven years, we've seen rates of diabetes increase by 24%, going from 11.2 to 13.9% of adults in Arkansas. This study that will be launched in our original programs is going to be comparing diabetes self-management and education program. One intervention will be a family-centered program, and we will compare that to a standard program through a comparative effectiveness trial supported by PCORI. Again, this was all really lead by Dr. McElfish, and she is in the process of implementing this study in four centers. We hired a director for this program in December, and we are, as I mentioned, training these four sites to launch at this study in the near future.

Our goal is that we would continue to leverage our existing political and telehealth platform, to engage special populations in research. Many of these are living in rural areas, and we will also be addressing underrepresented minorities, older adults to children. We hope to continue to build a sustainable infrastructure across the state by leveraging new awards, hopefully at the federal level, to continue to conduct research in the regional program site.

We also have a similar diabetes study that will be launched in two sites in the summer that will focus more on the Marshallese population. Their rate of diabetes is about eight fold that of national rates for diabetes. Again, we hope to continue to build this model in subsequent years to address other disease conditions. I want to close with this picture which shows a picture of Veronica Smith, who is our Director for the Rural Research Network. This is a photo from early March during which she was conducting a Patient Family Advisory Council meeting at the regional program site in Pine Bluff, Arkansas, which is about 45 minutes south of Little Rock. So I think with that, I'm going to end my presentation and pass controls back over for in time for questions.

Kristine Sande:

All right, thank you very much. This is Kristine again, and at this time, we will open the webinar up for question. So you will see the Q & A button that's down at the bottom of your screen. If you click on that, the questions box will pop up, and you can enter your question. If possible, if you can let us know who the question is for, that's helpful. Thank you so much to our presenters for this great content. I know when Kay was working on this story, we were really excited about the amount of work that's already being done with rural communities by the CTSA's, and we certainly know the importance of including rural patients and rural providers in that research. So

just to, a question about if rural stakeholders or organizations that work with rural facilities and rural providers want to engage with the CTSAs, is there a best way to do that?

Laura James: Mike, do you want to?

Michael Kurilla: Yeah, I'm just trying to figure out if I just start talking. I didn't want to... Yeah, so in terms of interacting with the CTSAs, there's a couple of different options here. If he went to the NCATS's website through the CTSA, you can find what local CTSAs and what the closest regional CTSAs are there for you, or else you can contact me or my staff directly. We'd be happy to put you in touch with the relevant points of contact within the CTSAs, recognizing that these are very large institution wide programs. Each academic medical center usually has multiple. It's not atypical to have five to nine partners and collaborators regionally that they engage with. So putting you in touch with the right person may require a little bit of contact tracing on our part, but we'll be happy to sort of broker those arrangements.

Kristine Sande: Great, great. Thank you. A question came in. It says do you see a role in this for rural community colleges?

Michael Kurilla: I think there clearly is a role, and I think it's a matter of bringing that rural community colleges certainly would be able to bring particular types of populations that would be available for the types of addressing questions that are being raised. Those particular populations may not be something that your typical academic medical center necessarily has a direct outreach to or is familiar with. So I think there's always those options are available.

Kristine Sande: Great, thank you. Question for Laura. Are your CSA and CPEARL curriculums available for the public? Is there a cost? How could we implement in our communities?

Laura James: Yes, we do have the curriculum for the CSA available. There is not a cost for that. We have shared that with other CTSAs, but we've not really shared that with the public yet. But we would certainly be willing to do that. You can certainly reach out to me for that information, and I could connect you with Kate Stewart and her team. The CPEARL curriculum is newer for us, and we're still... We've had one launch of that curriculum and may need to fine tune it a bit based on feedback, but that would also be something that we would certainly be willing to share with other groups.

Kristine Sande: Thank you. Another question is what grants can you point us to to do a feasibility study for synchronous livestream delivery of an Alexander technique based course for self-management of PD symptoms for rural populations?

Laura James: Ooh. I don't think I can answer that right now. We could investigate a little bit and try to um . . .

Michael Kurilla: Yeah, I'm assuming PD is Parkinson's Disease, is what the question is referencing. I mean, we could identify particular Parkinson's Disease programs that we have going and maybe put you in touch with relevant subject matter experts who are interested in this field. To be honest, I don't really have off the top of my head. Nothing comes to mind immediately that would address that specifically, but I'm sure we could identify someone who could.

Kristine Sande: Yes, it was in reference to Parkinson's Disease, so. Let's see. Are there plans to convene another rural health unmeeting in the future? This person is specifically interested in learning about connecting with extension services as channels for engaging with rural communities.

Michael Kurilla: So I currently... The short answer is no, although I will say that this last one was very, very well received. I wouldn't be surprised if individuals were not interested in continuing something like

this. That unmeeting was actually... So we put on several unmeetings a year, and we allow for our community to actually propose topics, and the rural health was a topic that rose to the top. It's not something that we at NCATS actually selected. It's a complete community driven effort. So there are obviously, as you might expect, there's a lot of competition for the slots for those meetings, but there was quite a bit of output in terms of engaging with extension services. If people are interested, if they contact me, I can put you in touch with some of our CTSA's that actually have well established and long standing extension programs that they've been interacting with for a very long time. It really was one of these true lessons learned that there was a lot of best practices out there that just the community as a whole is not aware of.

Kristine Sande: Right. So is there a way to define rural populations that NCATS could recommend so that CTSA's can be consistent in describing their populations reach? So what definition should they use I think is the heart of the question.

Michael Kurilla: This is something we looked at very carefully because there are multiple definitions, and I think NIH itself has been a little reluctant or hesitant to actually define to actually settle on one specific because we're only going to get a lot of arguments and rationales and justifications for using any of the others. So I'll leave it to that type of thing. You kind of know it when you see it. It is an issue, but I don't... There's a lot of different reasons, not just medical, economic and other types of things for how these definitions come about. It's just not something that we feel we want to really put a stake in the ground to sort of create our own or rally around a single one.

Kristine Sande: All right. Question for Laura. Do you have experience working with Farm Bureaus and engaging rural populations? Also, any lessons learned in terms of Advisory Board memberships for rural engagement?

Laura James: I personally do not have any experience with Farm Board Bureaus, but I think that was probably discussed at that unmeeting, and we may want to let Mike comment on that. Lessons learned on the Community Advisory Board, Kate Stewart has really been the guru at our place in setting up Community Advisory Boards. We have tried to have representatives broadly from all areas of the state, and I think that has been important. Then we have tried to rotate the location of the meetings. Sometimes they're held in the rural communities themselves. Sometimes they're held in Little Rock, but we try to vary the location so that not a single group of people is always making the effort to travel. We have a quarterly meeting with our CAB. We've done a lot of other things directly with the CAB that I think has really helped to strengthen that relationship.

For example, several years ago we launched a publicly facing research recruitment website and registry, and we had members of our CAB advising us on the look of the website. I think the more that you can do in directly engaging members of the CAB in your efforts, the stronger that partnership will be.

Kristine Sande: Great, thank you. I guess in our current times with the COVID-19 situation, have things had to pivot in terms of activities that the CTSA's are doing, and does that effect their work with rural?

Michael Kurilla: The short answer would be yes. The vast majority of our CTSA principal investigators like Dr. James are senior official within their institutions. You can just imagine the amount of staffing issues and material and just the logistics as well as trying to put in place procedures and protocols for how you're going to deal with patients of all types, and worried about not only standard of care, but contingencies standards of care for when you begin to run out of things, what you do. So there's a lot of just normal operations of the hospital itself that have been impacted by this. A lot of the key personnel on these grants are intimately involved in that.

The other aspect, which sometimes gets lost, is that a lot of research that was ongoing has actually had to be either put on hold or has had to be modified because you just can't. It's not business as usual at these institutions. So there's a lot of effort that's gone into... We have a trial going on, and someone is supposed to come in for some sort of procedure or some sort of assessment, but that's not possible. So what can we do?

Then finally, the CTSAs, because of their generically rather agnostic in terms of what they're focused on, they are brought in on a lot of very rapid institutional activities that people are trying to start of very quickly. So we've heard from quite a few of our CTSAs of wanting to very quickly set up clinical trials. People have I'm sure heard about the whole chloroquine hydroxychloroquine and a number of other things that would be relatively straightforward to do, but getting all of those details in place to actually do that is not trivial. The CTSAs bring to bear all of the subject matter expertise. They can bring together people who know about dealing with the FDA. They can bring together statisticians who understand how to power and how to do the analysis of the study. They can bring together people who write protocols. They can bring together all of the required clinical coordination elements, both facilities and personnel. So there's been a tremendous all hands on deck kind of activities. The CTSAs have been a tremendous component of the institutional surge capacity to be able to respond quite quickly.

Kristine Sande: Thank you. I'm sure that was on a lot of folks' minds. There's a couple of more questions. I just want to check with our speakers to see if they're able to stay on for another few minutes to finish up the questions.

Michael Kurilla: I'm fine for time.

Kristine Sande: Okay. Great. The first question is can one of the speakers comment on how they have used CD2H in a rural setting to address a clinical translational question?

Michael Kurilla: So I think the key element with our CD2H program has been primarily focused on what I would refer to as interoperability. Each hospital has its own electronic medical records and the ability for researchers and investigators across different institutions to share data is not trivial. They focused on how we can do that most efficiently. Where we've seen a lot of digital applications though is in another program that we have referred to as the Recruitment Innovations Center. They have worked with people running trials to very efficiently do two things in particular beyond just a lot of general recruitment and creation of materials to assist in recruitment. A lot of times in general in recruitment, there's the old fashioned way of basically typing up a one pager with the little strips at the bottom of a telephone number that you could pull off, and you hang it up all around the hospital.

That's not the way we do recruitment anymore. To reach out to all the various populations that you want, you have to go where those populations are. So there's a couple of things that has been done that have assisted and made this a lot better. So the development for example of apps that can be put on a health provider's phone that they can download and have on their phone in a rural setting where they're a rural based practice, that they could with a little bit of entry of a few laboratories or history determine very quickly whether or not their patient may actually be eligible for a trial. That just makes it much easier on them. In the old days, there used to be this sort of laminated card that people would draw up that they would have to refer to.

The Recruitment Innovation Center has actually created apps to do this. The other aspect is to create apps as part of the clinical research protocol itself, where data can be, you can actually distribute this app to the patient and they can be recording information. So this allows for much easier remote availability of people who would otherwise have to maybe spend a couple of

hours driving back and forth to go to a medical center to see a healthcare provider to stay in that trial. So these sorts of applications make it more not only easier on the patients, but allow for the investigators to reach out to broader populations. There's also been quite a bit of work experimenting with, and there's evaluations ongoing, about even doing informed consent digitally. So a lot of these types of applications are allowing populations that normally were very difficult to engage in research to make it much easier on both the patient side and on the researcher side.

Kristine Sande:

Great, thank you. The last question for today comes from Mark at the University of Iowa. He says, "Our CTSA team has been working to spread uniform biobanking and clinical data marketing within our rural partners regionally and nationally. Are there rurally focused institutions with whom we can partner, and are there further grant mechanisms to support this type of initiative?"

Michael Kurilla:

So I have to say off the top of my head, I don't know specifically, but what we have created on our click site, which is a sort of general website for coordination among a lot of CTSA's, we have we have something now that we've just stood up. We've just been bringing it online this year, the capability for what we refer to as discussion forums so that individuals around a particular topic of interest, and it could be as broad as rural health or it could be as focused as let's say rural patients with rheumatoid arthritis or something like that, or Parkinson's Disease we discussed earlier.

What we did for, very quickly, was to establish a discussion forum specifically around COVID, and it's there. So if you're at a CTSA, you can certainly access this. The idea was to provide an information sharing as well as people asking for information but also looking for collaborations. So I would advise Mark to go onto the discussion forum and to look and see if someone's already raised this, or if not, to raise that question because it is something that people are scanning on a regular basis to see what's going on throughout the CTSA.

Kristine Sande:

All right, thank you very much. I think that brings us to the close of our webinar. On behalf of the Rural Health Information Hub, I'd like to sincerely thank our speakers for the great information and the insights that you've all shared with us today. I'd also like to thank our participants for joining us. A survey will automatically open at the end of today's webinar, and we encourage you to complete that survey to provide us with your feedback so that we can use that in hosting future webinars. The slides that were used in today's webinar are currently available at www.ruralhealthinfo.org/webinars. In addition, a recording and a transcript of today's webinar will be made available on the RHInfo website and also sent to you by email in the near future so that you can listen again or share the presentation with your colleagues. Thank you so much for joining us, and have a great day.