#### Spring 2024

# The NNE-CTR Quarterly Newsletter





### Contents

Welcome	. 2
A message from our PIs	3
Student award winner Anika Advant	4
Investigator spotlights	7
CEO Core Focus	14





## Welcome to the NNE-CTR's Spring Newsletter

The word "spring" is a synonym for hope everywhere, but in few places more than in northern New England, where a long season of short days too seldom kissed by sun leaves us more appreciative than many for the season's bounty of light, color, and—on the unlikely chance we've missed the change—the returning birds to remind us daily.

In this issue of our newsletter, you'll feel the hope. It's embodied by the team that helped a promising medical student produce an important research project. It's woven into an investigator's project that seeks to give pressed caregivers the gift of more stress-free lives. It's embraced by a researcher who's finding ways to help babies born to mothers using opiates. And it radiates from the work of our Community Engagement and Outreach Core, who are making important inroads to understanding and partnering with local communities across our region.

It's an important reminder that what we all do helps bring hope to the world around us—a world that needs it. Keep up the good work.



## Engaging Northern New England Primary Healthcare Professionals A message from our Pls



Clifford Rosen, MD



Gary Stein, Ph.D.

Responding to the NNE-CTR commitment for supporting engagement of primary care professionals in clinical and translational investigation, we have expanded our partnership with the Northern New England Co-Op Practice and Community Based Research Network.

During the past several years, our NNE-CTR has funded "Co-Op" research initiatives that include HPV vaccination hesitancy and apprehension to COVID inoculation. These are programs that relate directly to northern New England community needs and have had immediate impacts on regional health and healthcare. To support and reinforce sustained capabilities for provider-based research by primary care professionals in Vermont, New Hampshire, and Maine, the NNE-CTR is providing up to \$40,000 annually for support of Pilot Projects by Co-Op investigators. And, our NNE-CTR Cores, particularly the Biostatistics, Epidemiology, and Research Design Core, the Community Engagement and Outreach Core, and the Professional Development Core are providing support to PCBRN investigators in the development, as well as pursuit, of practice-based research initiatives.

Our NNE-CTR very much appreciates the importance of enhancing the capabilities of community healthcare providers to address prevention, early detection, treatment, and survivorship of both acute and chronic disease. We are optimistic that the NNE-CTR investment in practice-based research will make a difference for northern New England healthcare and provide a rewarding research dimension for community-based healthcare providers.

We enthusiastically support the continued development of the NNE-CTR-NNE Co-Op PCBRN partnership.

—Gary & Cliff



#### It Takes a Team

When the award for best student research project was announced at the <u>44<sup>th</sup> meeting of the NNE Co-op PCBRN</u>, the winner was nowhere in sight. That's because, after presenting her findings and chatting with interested attendees, University of Vermont medical student Anika Advant had to drive two and a half hours home to study.



University of Vermont medical student Anika Advant

While conference attendees clearly appreciated her research, they might not have been aware of an irony: after a scholastic career as a cheerleader in high school and college, Anika wasn't present to enjoy the accolades directed her way. However, as a former "flyer," or the person atop the human pyramid of cheerleaders, it's likely Anika would have wanted to credit the team that got her there anyway.

#### A Seed is Planted

The genesis of what might be called Anika's winning season started well before she arrived at UVM's Larner

College of Medicine, when she served as a clinical research coordinator for Memorial Sloan Kettering Cancer Center in New York City. "My main role was mostly data and I worked specifically with a physician who did non-small cell lung cancer," she said. "And then I transitioned into more of a direct role with getting people onto the clinical trials."

Fast forward a year when, after an excruciating time on the wait list, Anika found herself at UVM's Larner College of Medicine. Between their first and second years, medical students can apply for summer fellowships that, depending on the position, allow them to substantially contribute to the design their own projects. Anika hadn't forgotten her experience at Memorial Sloan Kettering.

"It was so easy for people to access MSK (Memorial Sloan Kettering), you know, take the bus, take the subway. ... And I just was thinking, are people in rural Vermont able to access what the UVM Health Network has to offer for clinical trials? And if they are not able to access it, how do we make that better because we know that clinical trials can be very, very successful for people and they're integral in the development of new cancer treatments and cancer therapies."

UVM had always been Anika's first choice, due in part to the school's emphasis on public health, and her decision was confirmed as her interests were about to find a home.

#### **Building the Team**

It's said that, in Vermont, everybody knows everybody, and in many ways the Larner College of Medicine exemplifies this idea. Anika applied for her summer fellowship funding through the <u>University of Vermont Cancer Center</u>, an opportunity she first learned about from Hanna Snyder, Assistant Director for Training and Education at the Center. Director Dr. Randall Holcombe, said, "Critical to our mission is understanding everything we can about the patients we serve, and we were pleased to offer Anika our support."

"When a student wants to work with us, I always think about what their passion is and what they are interested in and how we can connect it to all the needs we have here," said Carney.

The Cancer Center then paired Anika with a mentor, Dr. Jan Carney, Associate Dean for Public Health and Health Policy and Director of UVM's Master of Public Health program. Because all UVM medical students undertake a year-one public health project, Anika and Carney were already peripherally connected. "When a student wants to work with us, I always think about what their passion is and what they are interested in and how we can connect it to all the needs we have here," said Carney. "I love mentoring. I love students. They come in with enthusiasm and energy. They want to make things better and it's our job to teach him how to do that."

As it happened, Carney had been thinking along the same lines as Anika in terms of a summer project. So, Carney enlisted the <u>New England Clinical Translational Research Network</u>, specifically Nancy Kaplan and Dr. Elizabeth Woods, who have extensive experience in research methods and community health, to help Anika design her study. "It was basically a perfect match," said Anika

Anika joined the regular meetings of the NNE-CTR's Community Engagement and Outreach (CEO) Core to learn from Carney, Woods, and Kaplan. Here, Anika's network expanded again. In 2023, the CEO Core, along with the Tracking and Evaluation Core of the NNE-CTR, developed the Partner Tool, a network map of community connections for use by researchers seeking to work with communities. Woods said, "We walked her through the type of people she should be talking to [such as] providers and doctors but also some people within the public health field as well, and stakeholders within different organizations just to get that different point of view."

Anika was interested in learning about both barriers and opportunities to participation in cancer clinical trials in rural Vermont but, as she says, "I didn't really have a lot of experience building a project from the ground up." The first step, said, Kaplan, was to talk about the literature review and study design.

The team agreed on using a semi-structured interview approach, where Woods' experience in survey design proved critical. She helped Anika with challenges such as the wording of her questions, reducing the number of open-ended questions, standardizing scales, and "just making sure questions aren't double barreled so she's only asking one question at a time."

This teamwork approach gave Anika access to professional-level services, said Kaplan. "This exact thing is what we do not only with medical students but our CEO Core clients." According to Woods, the result for Anika is that "even beyond the topic and the information that she learned from this project, she learned how to do research so if later in her career she has another question, [she'll] have a better starting point to move forward."

#### The Fruits of Their Labor

"I think part of the reason why I also was interested in doing this research is that there really wasn't that much information about this specific topic as it relates to Vermont," said Anika. "They've done a few studies in West Virginia. They've done a comparison about urban versus rural participants in clinical trials. But I didn't find anything that was specific to Vermont." She continued, "We need basic information about what people know, what people don't know, who's involved in clinical trials, what are things that we potentially can target. We need a starting point, and we need baseline data for what's going on in our state."

Anika spent about eight weeks interviewing people from across the community spectrum and interpreting her data. Her research indicates two main barriers to broader participation in cancer clinical trials: distance and awareness.

"Honestly, the bottom line is we have a lot of work to do in terms of access," she said. "People in Vermont might know about a clinical trial, but they don't know how many times you have to come in to get your labs drawn. And for them, it might be easier to just remain on standard of care than it would be to travel, you know, three times a month, two hours to Burlington. That takes up time. That takes up money. A lot of people don't know that there are ride shares that [they] could potentially use. A lot of people don't know that you can get a hotel room paid for if you're getting cancer treatment."

"Honestly, the bottom line is we have a lot of work to do in terms of access."

Just one benefit of this blending of student interest and professional skill sets is that the resulting product can have real-world effects. According to Holcombe, "Anika's project is an excellent example of research that is critical to our mission of providing the best clinical care to our catchment area."

And indeed, the next stop for Anika's poster is Washington, D.C., for the National IDeA Symposium of Biomedical Research Excellence in mid-June.

#### **A Career Takes Shape**

With her first taste of research during her undergraduate years, Anika thought her career would go in a different direction. "I did an internship after my freshman year of college. It was lab research, and so it was working with cell cultures. And I did that for eight weeks and I was like, I can't do it. I am a people person and I love talking to people. And then I had a friend who worked at Memorial Sloan Kettering, and she introduced me to what she does with clinical research and clinical trials. And so, I realized, OK, I can be a physician and also do clinical research."

Carney, who has now mentored generations of medical students, said, "It's exciting when you have a physician who's interested in research, particularly public health research. You think about the curiosity, you think about lifelong learning and your career over a longer period of time. Depending on what you choose in your practice environment, if you're curious about something [as a physician], you can be part of the practice-based research network like we have at the (Dartmouth) Co-op. If you're in an academic center, you can get involved in clinical research in your institution, so I think it's wonderful."

Once upon a time, in front of cheering crowds, Anika would routinely find herself at a perilously high place atop a human pyramid. "Yeah, there were injuries, and I've had concussions a few times from being dropped. You have to be pretty fearless to flip in the air. But that never really stopped me. I think I've always just been trusting of the people around me."

Apparently, what's good advice in athletics is good advice in research, too.



### Investigator Spotlights

Editor's Note: The NNE-CTR's <u>Pilot Projects Program</u> is for *you*, whether you're a researcher, physician, or community group. The program's goal is to inspire and grow great ideas. In this issue, we're pleased to feature the work of Dr. Kahsi Pederson of MaineHealth and Dr. James Stafford of the University of Vermont.

## **Unwinding Anxiety**

Kahsi Pedersen and Team Study the Effects of a Mindfulness App on Caregivers of Autistic Children



Kahsi Pedersen, Ph.D., of MaineHealth is a behavioral scientist who co-directs the MaineHealth Institute for Research Clinical and Translational Research Course. Her pilot project involves studying the effects of a mindfulness app on parents and caregivers of autistic children. Important to understanding Kahsi's research is a definition of dyadic research, and so here it is, courtesy of Columbia University's Mailman School of Public Health: "Dyads are a type of social network in which there are two individuals that are linked. The analysis of dyadic data has its origins in psychology in the

study of couples and romantic relationships, but its methodology has recently emerged in the field of epidemiology." This interview has been edited for length and clarity.

**Matt:** My theory is that most everything we do as a vocation is tied into a seed in us that goes back many years. So, when you think about when you were a kid or maybe as late as your teens and what that person was thinking and doing, how does that connect with this pilot project?

**Kahsi:** Great question. I've always been interested, and especially in college or graduate school, in how people communicate with each other. And perhaps growing up in a divorce, with blended families, I was always just observing. Just really being fascinated by family systems and how people fit and where they fit and the roles that different family members take on, especially through transitions.

So, when you say something, what does it do to me? How does it make me feel? How does it influence my actions, my outcomes?

**Matt:** How does your interest in dyadic analysis link with your interest in autism regarding family stress and communication?

**Kahsi:** I work with parents of children with autism and my goal is to help intervene at the level of their mental health, with the hopes that it will help improve their own romantic relationship, the

quality of their family relationships, and ultimately the outcomes of their child with autism.

**Matt:** Your NNE-CTR pilot project is about testing the effects of a mindfulness app on parents and caregivers of autistic children. Could you explain more?

**Kahsi:** I settled on the app because I'm trying to reach out to rural populations and that seems to be the most meaningful approach to do that and also because of one of my mentors. His name is Judson Brewer, and he is a neuroscientist and psychiatrist out of Brown University.

"My goal is to help intervene at the level of their mental health, with the hopes that it will help improve their own romantic relationship, the quality of their family relationships, and ultimately the outcomes of their child with autism."

And so, I researched [Judson's] app. It's called <u>Unwinding Anxiety</u>. That's the intervention that we're using for this study, and I really enjoy the approach that he takes for teaching people about learning about their own anxiety, identifying what their own anxiety is like. What's their trigger? What's their behavior? What's their reward? What is this habit loop that they have? And then figuring out how they can learn from and lean into their own anxiety rather than running away from it

The app seemed like the perfect medium to be able to really access the rural population in Maine and to give them a sense of agency that they're able to have some sense of control and power over their outcomes.

**Matt**: What do we know about how apps work versus in-person or group mindfulness sessions?

**Kahsi**: There is growing evidence that [mindfulness apps] show efficacy because there's no travel time and there are less restrictions to receiving different types of treatment. It opens up the opportunities for so many more things.

**Matt**: So, it's almost like the app was sitting there all along saying, "Hey, discover me!"

**Kahsi:** I was thinking to myself, well, the answer is right in front of my face. We're not requiring people to do anything crazy; it's just, breathe. And when you identify a feeling, it's known to reduce your stress and anxiety in the moment by 40 or 50% just by naming the feeling you're having.

**Matt**: To a degree, stress, of course, can be a result of being too busy, and I'm imagining the caregivers and parents of autistic children are already very busy people.

**Kahsi:** The app's meditations are each about 10 minutes long. We are gearing up for our enrollment this month, so I can't speak to what anybody has already said to me about that. But the data manager on my team is a woman with autism who has a partner with autism and a child with autism and who I have been engaging [with] at every phase of the conceptualization of the study, the planning of the study, measuring the study. In conversations with her and with others in the field, she's like, "Wow, this is so great. Ten minutes a day I get to myself. I have permission to take this break and say that I'm doing this for me and I'm doing this for my child and I'm doing this for

my partner, and I don't have to drive to an appointment. And so you're really given this gift of time during the day to benefit you and your family with minimal effort.

**Matt:** I know you're proud of your team. Let's talk about them for a minute.

**Kahsi**: Ellyn Touchette is our data manager and co-investigator. She has been conceptualizing the study, working with me, and providing invaluable insight in every stage of the work.

Ellie Walker is our research assistant, and she was my intern last summer. I selected her through the summer internship program at the Research Institute and her organizational skills and her kindness and her attention to detail and her ability to really embrace this work have been such a gift. And then everyone in navigation has been great. Melissa Graham as an IRB navigator has been invaluable.

**Matt:** How has the NNE-CTR been for you during your pilot project?

**Kahsi:** Oh, invaluable. I mean the support from all of the core leaders, the support from the PI, Cliff Rosen and Tom Gridley; they're approachable, they believe in this work, they want to do anything to help you get this done.

This is my first big grant, and it feels like such a beautiful way to work my way through the grant world now just by working with these people. So extreme gratitude for extreme support. It takes an enormous village.

**Matt:** What do you think works well about the pilot project process?

**Kahsi:** There is genuine investment and desire to nurture strong science. It's [wonderful] to be supported by a well-structured, well-oiled machine. They want people to succeed because they want people to have a meaningful impact on lives through science. If you want to launch your research career and have a very supportive community to help you do that, [the NNE-CTR] is definitely the mechanism for you to start with.

**Matt:** What would be the best outcome of your pilot project? What does somebody's life look like when they're able to get these new skills?

**Kahsi:** Peaceful. [It's] giving people the opportunity to learn more about themselves and to improve the quality of their lives daily. Jon Kabat-Zinn the father of mindfulness [says] "Wherever you go there you are" so why not go there and be happier?



### Investigator Spotlights

## "Altering the Trajectory of Someone's Life"

A Bold Goal Inspires a Pilot Project Regarding Expectant Mothers and Opioid Use



Dr. James Stafford didn't care for science in high school. To understand how the UVM Larner College of Medicine Department of Neurological Sciences researcher got from there to being the recipient of an NNE-CTR pilot project grant to study the effect of prenatal opioids on the epigenome and behavior of the exposed child, it helps to ask a simple question: How can a person, "alter the trajectory of someone's life in a positive way?" This interview has been edited for length and clarity.

**Matt:** At the NNE-CTR, our goal is to improve rural health and in order to do that, we have to understand the communities we serve. You have some direct experience in this area.

**James:** I was born and raised here in Vermont. I grew up largely in Franklin County on a dairy farm. I was very lucky to come back here.

**Matt**: What was that boy on a dairy farm thinking about regarding what he wanted to do with his life?

James: I think when we're young in particular, we want to save the world. But how do we do it in ways that are also interesting and that satisfy a certain part of ourselves? At the core of my main interest was actually asking questions about ways to alter the trajectory of someone's life in a positive way. And I realized that science is a good way to do that. I [had] thought about being a clinical psychologist and then in college I thought maybe I wanted to be a medical doctor because I got more and more interested in the science. And then I realized that maybe being patient-facing wasn't the right fit for me and there was actually a way to do exactly the things I wanted to, which was following the science and following those things I was deeply curious about in a way that would impact other people's lives.

Matt: Give me an example.

**James:** Fast forward to my post-doctoral fellowship. One of the most meaningful experiences I ever had was being involved in research where we are taking pediatric brain tumors--going directly to a neurosurgeon, grabbing these tumors, taking them back to the lab and studying them for a month or two. Sometimes that meant testing drugs that were in the pipeline for clinical trials. And some of the preclinical work that we were doing actually helped give folks confidence to launch some clinical trials and move that forward. And now it has become part of a care package for a large number of patients. And so those were anchoring portions of my research training where there was a really clear link from bedside back to bench and then back to bedside again.

**Matt:** Your pilot project uses mice to investigate the biological and behavioral effects that opioid use has on developing fetuses, and you link those to issues that result later in life. Can you explain further?

James: We know that opiates have the potential to harm the mother and developing fetus in both the short— and long-term. And so, we asked, is there something we can do, and can we create an animal model that helps us decide whether or not there's something we can do to intervene early on in that person's life or somehow reverse the things that have been done and maybe get that person back on a pathway towards health? [And here] I want to take the time to give a shout-out to Nellie Stidham. This project was part of her master's thesis in our lab. She was keen to bridge the gap between addiction in our local communities and impactful research we can do in the lab.

**Matt:** What does this look like when you're working with mice?

**James:** Oftentimes, when people model prenatal opiate use, they're injecting the animal with the drug involuntarily over a period of time. That lets you control the dose really well, but the animal is not overtly seeking the drug themselves. And we know that this activates different circuitry in the brain. It also causes different stress impacts, too, with getting handled every day. So, we wanted to create an animal model where that animal can choose to take the drug.

Matt: What have you learned so far?

"There aren't a lot of people who have actually shown, in an animal model, that we can improve outcomes using some of these medication-assisted therapies."

**James:** We found some new things in there, but we were also able to repeat some of the other studies. We found that there are deficits in development that happened in animals who have been pre-exposed to oxycodone so they don't hit some of the same milestones that they should neuro-developmentally. What we also saw is that they actually accelerate their weight gain, which is different [because] what you might predict is that if you're exposed to oxycodone early on, maybe you're just going to be less healthy, maybe you're going to be a little bit smaller. We also found that animals that are pre-exposed to oxycodone are more likely to go on to consume large amounts of alcohol.

**Matt:** You also have some exciting findings about treatment.

**James:** The cool thing was that for some of those phenotypes, buprenorphine treatment--even though we're starting at about halfway through gestation--actually ameliorated some of them. There aren't a lot of people who have actually shown, in an animal model, that we can improve outcomes using some of these medication-assisted therapies.

**Matt:** NNE-CTR pilot projects provide seed money, with the idea that proof-of-concept work can be used to attract bigger grants. Where do you plan to go from here?

**James:** One of the other things we're really interested in is not just pharmacological, a biochemistry you can target, but I think the best intervention is a natural one. There are a bunch of future studies that we're trying to get funded to ask some of those interesting questions now that we've built that model.

**Matt:** What do you have in mind?

**James:** A therapeutic window is a sensitive period in development [where] we can intervene and pair a drug that's actually going to impact neurochemistry in the brain with a behavioral intervention that maybe will help cement-in lasting behavior change. Leslie Young and Michelle Shepard and others here at UVM have been pioneering evidence-based practice for the Eat, Sleep, Console tool that trains and educates families on care for their children who may have been exposed to opiates during gestation.

I think the mouse model that we've developed allows us to test the idea that behavioral interventions like this may open a therapeutic window. For example, we can put animals that are high-nurturing with pups that were exposed to opiates during gestation and ask questions like, what if we pair this with some other pharmacological intervention? Will it actually help cement in those really good nurturing type effects over the long-term?

**Matt:** In the Stafford Lab, mentoring is clearly a priority for you.

**James:** Being a Ph.D. mentor, I don't do a lot of teaching in big classes or other things, but what I get to do is tailor what I'm doing to the individual students and have those personal interactions where I'm helping them along their career and that's really important to me. The thing that I've come to appreciate is that it's a very small number of Ph.D. students that actually want to go into becoming a research professor, [but] a Ph.D. is really teaching people about a way to think scientifically, and that opens every door for you.

There are so many other career paths, ranging from being a patent agent to being a medical science liaison to being an entrepreneur, to starting your own winery, right? I know microbiologists that have gone on to do that. And my goal is to help students find that right pathway for them. I think you go into a faculty position thinking, "I'm really interested in science, I want to help solve these problems." And then you realize, well, maybe it's actually the people that are the most important thing, right?

**Matt:** I'd like to close by asking you to put your work into the context of the NNE-CTR's target area, specifically rural northern New England.

**James:** I'd like people to know that we're doing work here that has the potential to impact their lives. Outside of here, I usually either have a chainsaw in my hand or I'm wearing flannel or whatever else a real Vermonter does and so people may not know what my day job is. But when we talk, people are sometimes like, "Oh yeah I have a family member that was affected, or their child was exposed to opiates, or we fostered a child like this."

And I think it's actually really meaningful to just talk to people about what you're doing so they know you care and you're doing work that's applicable, and maybe they can even get some little nuggets of information that help inform their own lives or maybe make them feel better about it. We really want to know what it is that affects their lives right now, and how can we take that back into the lab and study it and figure out if we can help improve it.





## Core Focus: The Community Outreach and Engagement Core

Welcome to the second of our Core Focus features, where we explain what the NNE-CTR's cores are all about and how they help our members do groundbreaking research that helps the people of our region. In the Winter 2024 issue, we profiled the <u>Professional Development Core</u>. In this issue, we talk with members of the Community Engagement and Outreach (CEO) Core.

## Listening is Learning

The NNE-CTR's Community Engagement and Outreach Core is tasked with three main objectives. While three seems a modest number, the goals contain an ambitious agenda for better public health.

The first objective is to support research to address health disparities and inequities as defined by national <u>Healthy People 2030</u> goals.

This involves addressing such issues as diet and food insecurity, alcohol and drug use and overdoses, mental health, and more—issues that often have a disproportionate impact on rural populations. This focus is related to the fact that a mere 10% of our health is determined by our genes.



Jan Carney, MD

When I think about health equity, I think about that everyone should have a fair and just opportunity for health and we're a long way from that."

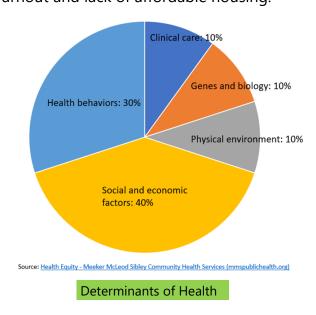
—Dr. Jan Carney

The remaining 90% is influenced by the quality of our clinical care (10%), physical environment (10%), health behaviors (30%) and social and economic factors (40%). In other words, factors that can be addressed to improve the health of the region the NNE-CTR serves. To do that, it's critical to include local voices to understand what each community needs.

Emma DayBranch, MPH, is a Community Engagement Research Navigator at MaineHealth. "Through our state-wide shared community health needs assessment process and regional work with local partners, we know the top community health concerns include social drivers of health, substance use disorder, access to care, and mental health support, especially among young people," she said.

Dr. Elizabeth Woods, a Community Engagement Research Navigator at the University of Vermont, agreed with DayBranch and added, "From our Community Engagement Councils, we have heard

that their main concerns are social isolation and issues around the healthcare workforce such as burnout and lack of affordable housing."



Central to the NNE-CTR's mission is linking community feedback to the research world to address health issues in northern New England. Admittedly, it's a significant challenge. CEO core lead Dr. Jan Carney of the University of Vermont says, "When I think about health equity, I think about that everyone should have a fair and just opportunity for health and we're a long way from that."

#### **Partnerships and Problem-Solving**

Because every person's health is a complex mix of factors, maximizing every individual's potential for optimal health means involving a range of partners. Therefore, a second aim of the CEO core is to link key members of the healthcare chain, including academic centers, rural care

practices, Federally Qualified Health Centers, and community organizations to increase the number of community-engaged research projects and ensure the success of existing ones. The CEO core does this by working with community-based organizations, helping researchers identify funding sources and facilitating communication between investigators and communities.

Dr. Kathleen Fairfield of MaineHealth is the CEO core's co-lead. She said that, traditionally, researchers have "rarely included patient voices, so I think we've come so far in that regard, and I

think for research, one of the reasons why community-based organizations are a great place to start is that they can really amplify patient voices and they understand our language and we understand their language."

Carrie Sullivan, MPH, is a Community Engagement Research Navigator at MaineHealth. She said, "It's been really interesting to be in this bridging role and experiencing on a day-to-day basis how researchers think and how academic institutions think versus how people on the front lines who are trying to solve the problem think, and [then] finding a space to try to find connections between those two worlds."



Emma DayBranch, MPH



Kathleen Fairfield, MD

Whether it's developing programs, creating relationships with potential research participants, or nurturing vital partnerships, the community is front and center in the CEO's efforts. Dr. Elizabeth Woods is a Community Engagement Research Navigator for the CEO core at the University of Vermont. She said it's vital to "give voice and agency to those who normally aren't engaged in the research process."

Woods reflected on her Ph.D. dissertation work, calling the project top-down.

"We did the research and at the end of it I was like, 'Why didn't we just ask the people who are going to be impacted by this?' There's a very simple way to make this better. It's to ask people, right?"

As well as performing a matchmaker function between researchers and communities, the CEO core

also serves as a compass for the rest of the NNE-CTR. DayBranch explains, "You can have all the expertise but if it's pointed in the wrong direction, you're not actually getting at these big core issues. The whole goal of the NNE-CTR grant is to address health disparities and to improve health in our northern New England states, so to me the work of our core is critical in helping with the alignment of the energy of the rest of the CTR."



Elizabeth Woods, Ph.D.

There's one more issue that's critical to improving community health, says DayBranch: buy-in. Research ideas lose value without study participants and community support. "If the question is developed in more of an academic space, [community input] is so valuable because there's nothing like lived experience expertise. It is critical to involve these perspectives in shaping work, because as we know, so many research projects are developed and then no one wants to engage with them because they haven't really thought well about the end user."

#### **Communicating with the Community**

The final major aim of the CEO core is to better understand local health challenges as defined by the community and to encourage community members and health care teams to participate in research. Communities, Fairfield said, "have so many health problems to work on. It's amazing when you can support the methods that might answer the questions. Or the community can help us reach the patients or the community providers that can help answer the questions."

DayBranch agreed, saying, "This is why we do it, because there's just these innumerable challenges to the translation of research. It's taking it out of this ivory tower academic space and really making it practical and translatable. [To that end] there's been greater attention to bringing patient voices to the table through, say, patient and community advisory boards and improved community health needs assessment processes, which have been really great."



Carrie Sullivan, MPH

DayBranch offered an example of how this works. "There's a methodology that we have used a few times called Boot Camp Translation. It came from the High Plains Research Network in Colorado. It's a methodology that is about translating research into tangible action and using community expertise and knowledge to do that. We completed one on adverse childhood experiences up here in Western Maine and it was a neat project because the community identified the topic.

"They pulled together 15 folks from across the community with various backgrounds like school-teachers, business owners, et cetera. And then they together learned about what the issue was and then co-created a message campaign and action campaign based on their knowledge of their community. And now we're doing another one up in Franklin on lung cancer stigma and messaging around getting screened for lung cancer. So really, really cool."

#### Pointing the Way to a Smarter, Healthier Future

Closing the gap between communities and research is a long process that requires empathy, listening skills, and patience in equal measure. In the words of Basu and Dutta (2008), "situating a health communication model within a participatory community-based framework empowers members of the community to articulate their needs, map resources available, mobilize them in the production of positive health outcomes, and engage in health sustenance behaviors."

In other words, listening is learning. And learning is the key to lasting, meaningful change.



## A Heads-Up: We Want to Know What You Think

We want your input! The NNE-CTR Tracking and Evaluation Core will be conducting a survey of NNE-CTR registrants about their experience with their organization's research environment and the characteristics of its registrants. Responses will help evaluate the initiative and assess the diversity of the Network. Please keep an eye out: All NNE-CTR registrants will be sent an email in the near future to participate in this brief voluntary survey.

## What Are You Up to These Days?

We'd love to highlight and share your work. Do you have a story to share or work you would like us to write about? An idea that our members should know about? Let's put it in our newsletter. Email <a href="mailto:matthew.j.duqan@med.uvm.edu">matthew.j.duqan@med.uvm.edu</a>

