

# The NNE-CTR Quarterly Newsletter

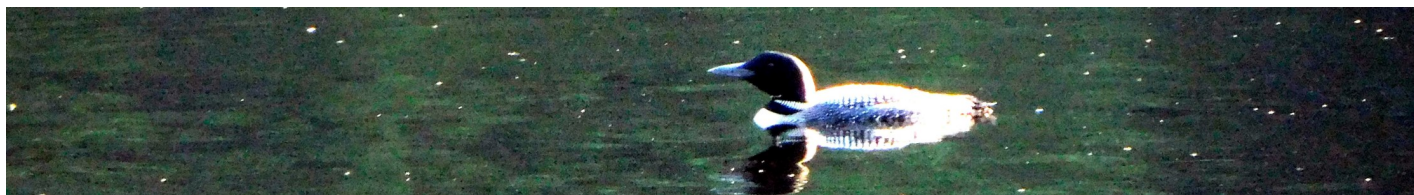
Summer 2024



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# Welcome to the NNE-CTR's Summer Newsletter



In a child's mind, a cat can go to the moon and drink tea with a unicorn. In the sciences, many exigencies prompt us to gain deep knowledge about particular areas, but guidelines can become guardrails can become channels. It can be hard to constantly challenge one's mind to think outside the box—especially when we work so hard to build the box in the first place.

In a March 2023 [paper](#) in *Nature*, social scientist James Evans of the University of Chicago and data scientist Feng Shi of the data company TigerGraph argue that many of the most impactful discoveries come from scientists working *outside* their disciplines. In their words, "The successful scientific mind must simultaneously know enough within a scientific or technological context to be surprised at anomalies, but enough outside that context to imagine why they should not be surprising." On the flip side, when scientists work exclusively within their disciplines, an echo chamber effect takes over, minimizing the possibility of breakthroughs.

At the NNE-CTR, we wrestle with public health issues, which are by definition transdisciplinary and challenge our creativity. In the natural sciences, if you drop a watermelon, 10 out of 10 times, it will fall to the earth and smash open. In the social sciences, nine out of 10 times it'll fall to the floor and the tenth time, it'll float away.

Public health reminds us constantly that it's a world of connections: Environmental health is public health. The built environment is mental health. Social connection is physical health. And on and on. Here, we're invited to be a little more like curious children whose brains are open to any idea.

A central goal of the NNE-CTR is to foster innovation. That's why we encourage collaboration in every pilot project we sponsor. So, community group can pair with a biomedical researcher who reaches out to a social scientist who brings a data expert into the fold. And, say Shi and Evans, no one on the team should feel shy about bringing concepts to the table from far flung fields.

This is the way to see connections where others haven't thought to look.

In this issue, you'll read about a pair of pilot projects where investigators are using creative methods to understand how to improve public health. You'll learn how a exciting new database under development to give researchers access to a new world of possibilities. You'll learn about how our Tracking and Evaluation Core works to quantify far-flung approaches and tell the world how the work we nurture is helping make things better. And you'll find out how we might be able to help you with your new idea as well.

Shi and Evans argue that the current model of intradisciplinary thinking leads to learning more about less. It's a fitting, timely, and welcomed challenge to us at the NNE-CTR to use curiosity and connection to learn more about more.

# Our NNE-CTR Commitment to Clinical Trial Equity

A message from our PIs



Clifford Rosen, MD



Gary Stein, Ph.D.

Consistent with our NNE-CTR commitment to clinical and translational investigation that is responsive to northern New England health and healthcare challenges, we are pursuing two NIH initiatives that integrate clinical research and clinical trials into rural primary care settings.

Building on our NNE-CTR partnership with the Northern New England CO-OP Practice and Community Based Research Network—and leveraging the NNE-CTR’s community engagement, professional development, experimental design, and tracking/evaluation expertise—we are positioned to develop an NIH Common Fund-sponsored program that incorporates research into primary care settings with emphasis on rurality and disparities encountered with rural northern New England Health and healthcare.

The strategy is to expand engagement of primary care practices and healthcare providers throughout rural northern New England in clinical studies that currently are predominantly limited to urban academic medical centers. To enhance NNE-CTR capabilities for engaging primary care practices that are academically affiliated, community-based and federally qualified health centers in clinical investigation, we are partnered with six clinical translational research programs to utilize our clinical trials management systems for clinical trial operations and maximizing applications of the data secured.

We are confident that these NIH investments in CTR programs will decisively accelerate our capacity for understanding linkages of regulatory mechanisms with environmental and social determinants of health that will provide evidence-driven healthcare that is responsive to community and patient-centered requirements.

Looking ahead, our NNE-CTR is positioned to facilitate translating scientific discoveries into effective healthcare by participating in the evolving NIH “Communities Advancing Research Equity (CARE) for Health” program. The potential for expanding access to rapidly developing opportunities for prevention, early detection, treatment, and survivorship of chronic and acute disease will be unprecedented, enormous, and will reinforce our responsibility for support to rural northern New England health equity.

—Gary and Cliff



# Pilot Projects Program

## Have a Great Idea? Turn it into a Pilot Project!

Letters of interest due 8/1, Information Session 7/12

Our mission is to improve health in our region. If you have an idea—or even the seed of one—talk to us. The NNE-CTR funds projects for the initiation of preclinical, clinical, or translational research. We will help you every step of the way, including the application process, study design, collaborators, and IRB approval. Advance your career with research and professional development support through the NNE-CTR's Pilot Projects Program.

- *Pilot Project Awards provide one year of seed funding.*
- *All PIs on the application must be registered with the NNE-CTR. (Need to become a member? Learn more about membership and sign up [here](#))*
- *The NNE-CTR Pilot Projects Program supports a wide variety of projects, from bench science to social science to assessment of clinical outcomes. .*
- *Collaboration is key: Broad collaborations, particularly across our three-state area, are helpful in your pilot project application. This includes co-PIs, mentors, specialists, community groups and non-profits. It's never too early to start collaborating, and we're happy to help you build your team. Consult with the NNE-CTR Pilot Program co-leads Rob Koza (MaineHealth) and Janet Stein (University of Vermont) for guidance.*
- Yes, you do have time to submit your letter of intent! Click [here](#) for particulars. Also, on Friday, July 12<sup>th</sup>, from 12-1pm, our Pilot Project Program Co-Leads are hosting an information session on the general application process, with a focus on Letters of Intent. Paste this [zoom link](#) into your calendar, and come prepared with your questions. Here are some of the projects we've sponsored in the past:
  - Neonatal care in rural settings
  - Breast cancer research
  - Leukemia research
  - Improving outcomes for victims of cardiac arrest
  - Access to clean syringes
  - Pregnancy and opioid use
  - Immunotherapy and heart health
  - Needs of babies of opioid-using mothers
  - Multiple myeloma research
  - Stroke care in rural settings
  - Pain treatment
  - Non-toxic cancer treatment
  - Pain management for opioid users
  - Wood stoves and indoor air quality
  - Mindfulness training and autism caregivers
  - Reducing falls among the elderly
  - Climate-related health consequences
  - Aging
  - Mental health
  - Therapeutic hypothermia in rural settings
  - tsRNA as a non-invasive biomarker
  - Targeting cell adhesion
  - Substance abuse-induced bone loss
  - Cardiovascular complications of chemotherapy
  - Neonatal abstinence syndrome
  - Hepatocellular carcinoma surveillance in cirrhosis
  - Shared decision-making in prostate cancer
  - Rural field assessment of stroke triage
  - Non-steroidal hormone receptor breast cancer therapy
  - Growth factor treatment for lung cancer
  - Opioid-induced epigenomic consequences
  - Nutrition and food security
  - Primary care data collection strategies
  - Rural lung cancer screening
  - Breast cancer therapeutic target identification

# Big Data Grant a Big Deal for Big Ideas

The expression “information is power” is soon to take on a special meaning for NNE-CTR researchers. A two-million-dollar grant will allow investigators to organize and learn from previously inaccessible data contained in both publicly available archives and electronic health (or medical) records. This means researchers will be able to ask unprecedented questions to investigate and address health issues specific to the people of northern New England.

To envision the leap this technology will help researchers make, think back to the days of encyclopedias, reference books, and information available only at libraries. Now imagine yourself in the world of online search engines. In the past, researchers in our region could only ask questions with a limited degree of complexity because the computing power and access to vast amounts of data simply did not exist. Within the next year, this will dramatically change.

## New Technology, New Possibilities

Kate Tracy, Ph.D., senior associate dean for research at UVM’s College of Medicine, is the project lead and was one of the primary grant writers. She said, “Harnessing all this data wasn’t even an option before companies came along with standardizing electronic medical records. [Previously] it



Kate Tracy, Ph.D.

was a bunch of small studies that were very much subject to how good a job you did finding the people and getting them to give you the information. I think technology is really positioned to ask questions that we couldn’t ask before. A bunch of things have come together all at the same right time. Data storage has gotten a lot cheaper [and], cloud computing makes it possible to access it from anywhere. It’s given us a unique opportunity, and it’s being driven by technology innovation.”

Susan Santangelo, Sc.D., Director of the Center for Clinical and Translation Science at the MaineHealth Institute for Research is the site lead for

MaineHealth and was also a primary writer on the grant. She is a researcher whose work will directly benefit from this enhanced technology. “For example, my own work in genetic epidemiology is to sift through enormous amounts of genomic data in order to try to find associations between genes and disease states. I wasn’t able to do that here before and in the near future we will be able to. So that that is hugely exciting and satisfying for me.”

The new system will allow researchers access to not only electronic health record data but many other resources as well. “For instance,” said Santangelo, “the Framingham Heart study is a huge multigenerational data set begun in 1948 that marked its 75<sup>th</sup> anniversary in 2023. And we have had investigators here who were attempting to [pull data from it] in the past without great success. The UK Biobank dataset is another very large, detailed study with genomic, environmental, and health data on over 500,000 participants that we would be able to bring in. Those are those are just two examples, but there’s a lot of that kind of data out there.”



Susan Santangelo, Sc.D.

A recent example of the kind of work this new system will be capable of is an ongoing project conducted by members of the NNE-CTR. Santangelo is part

of team who are investigating disparities in [COVID health effects between urban and rural communities](#). The study is analyzing data from over three million patients. The investigators have been using an external data system because, Santangelo said, "this work couldn't have been done in our local data environments. The exciting development made possible by this grant is that it will soon be possible to conduct studies like this on millions of patients [in our region] in the very near future."

Timothy Plante, MD, is a physician researcher and self-described "stats geek" at the University of Vermont Health Network who is eager for the new system to make its debut because, he said, "I love to use powerful tools to answer specific questions." A prime advantage of the new system, he said, is that it represents a significant safety and security upgrade for patient data. "There's been a desire for researchers in the cause of medicine and in the university to use the patient data that is generated during routine care in order to generate new discoveries and advance science but there have been major problems in privacy." These concerns are often related to underpowered computer systems, individual computers, and less uniform ways of obtaining and storing data. The new platform will vastly improve security that while also greatly improving researcher ease of use.

For now, there is an "under construction" sign on the metaphorical door of this project, with hopes that it is fully up and running in about a year. But researchers are already anticipating the possibilities. Isha Agarwal, MD, Ph.D. is a physician researcher at MaineHealth Medical Center. She said, "We are interested in analyzing the free text of clinical notes to identify linguistic cues of bias and stigma using advanced machine learning techniques. This requires enormous computational power and would be enhanced by the proposed tools."

*A prime advantage of the new system is that it represents a significant safety and security upgrade for patient data.*

### **Computing Power + Data = Promise**

In Vermont, this new platform brings together two worlds to create broad possibilities by more closely linking the UVM Health Network and the University of Vermont. In electronic health records lies a vast amount of information on how health conditions affect people of the northern New England region. But, said, Plante, "the hospital [currently] is not set up to support analytical software. The College of Medicine and the University, on the other hand, have an extensive history of using the software for advanced analytics and we have all sorts of licenses for these statistical software [packages] and we have expertise." This combination of data and "compute power" means that soon, local data can be used to propose local solutions.

Tracy said that, once the system is fully operational, interested parties will be welcome to propose projects to researchers at either MaineHealth or the University of Vermont, or both in partnership. This includes a wide variety of topics, including bigger-picture ones, such as the intersection of climate and health.

She said, "Many people wouldn't think about computer scientists necessarily being people who would work with those data [but] there are discoveries that we will make just by virtue of the fact that you can point complex computing capabilities at this reservoir of data. It can see data that the human eye can't see because it's so complex. So, computer scientists, students, trainees [can use it]. Public officials use it, state planners [can] use it. A neighbor could say, 'I noticed that a lot of my neighbors are coming down with cancer. Has anybody looked at the geographical distribution of cancer in the state of Vermont and might there be something going on?' They would share their observation in a way that a researcher might think, 'Oh, we could look at this and we could try to

dig into what might be going on.” Then, said, Tracy, “if we have a discovery and we see this thing affects health outcomes for a group, they can implement it in one hospital and then they can push it out to all the others. It’s evidence-informed practice and it’s the research informing how healthcare gets done.”

### **Implications for a Broader Social Mission**

That the new data science initiative will mean a lot of things to a lot of interested parties is plain. But Tracy widens the lens on the project. “It’s part of our mission to serve the public,” she said. “We pay an enormous amount of money for healthcare and it’s of fairly poor quality and why is that? What needs to change for that to be better? And I think having data assets like this where healthcare systems can use the data to inform clinical care is part of how you get to quality care.”



# Investigator Spotlights

Editor's Note: The NNE-CTR's Pilot Projects Program 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 projects led by from Dr. Elizabeth Scharnetzki of MaineHealth and Dr. Emily Belarmino of the University of Vermont.

## The Power of Partnerships

Researchers and Community Members Go to "Boot Camp" to Improve Lung Cancer Screening Rates

*Lung cancer kills more people in the U.S. than any other cancer, accounting for more than one out of every five cancer deaths, according to the American Cancer Society. And in Maine, residents experience above-average cancer diagnoses and deaths. A team led by Liz Scharnetzki, Ph.D., of the MaineHealth Institute for Research wanted to find out if a community-engagement approach known as Boot Camp Translation could help turn community feedback into effective pro-screening messages. A helpful definition of the Boot Camp Translation approach is supplied by [Norman et al.](#), who write: "By building a community of solution that integrates primary care with public health and community-based organizations, evidence-based medical care can be translated into language and constructs accessible to community members and readily implemented to improve health."*



Elizabeth Scharnetzki, Ph.D.

*Liz and Ericka Buote, a project manager at MaineHealth's Healthy Community Coalition, discussed their pilot project experience. This interview has been edited for length and clarity.*



Ericka Buote

**Matt:** Ericka, the Healthy Community Coalition played a key role in the project in terms of gathering together the community members who were central to this project. So, can you tell me more about what the coalition is and does?

**Ericka:** The Healthy Community Coalition has been around in Franklin County for over 30 years. It was trying to make the community healthier before they had to go to the doctor's office. [Today] we have a mobile health unit that goes out into these rural communities. We have some outreach that we do directly with physicians who can put in a referral to us directly for social

We have a healthy food pantry. We have a recovery center. All these different facets sort of all work together.

**Matt:** Liz, please tell me a bit about your background as it relates to this project.

**Liz:** I am an experimental social psychologist by training and so my program of research looks at different processes [by which] people can be socially devalued. And one of the big social



processes I study is the experience of stigma, which really led me to the lung cancer space because lung cancer is actually more highly stigmatized than all other cancers because of its association with smoking.

Despite a lot of the scientific advancements and efficacy of things like low dose CT screening, our screening rates here in Maine are relatively low. We found that people felt two things were primary barriers. The first was that they felt very stigmatized. And, also, that they just didn't know a lot about what early detection actually was. Why should they do it? Is it effective?

*"Lung cancer is actually more highly stigmatized than all other cancers because of its association with smoking."*

*Neil Korsen, MD, MS, not interviewed here, has been a key partner in the project. Neil is a physician scientist at the MaineHealth Center for Interdisciplinary Population & Health Research. He also is co-investigator for the NNE-CTR's Community Engagement and Outreach Core among his other roles.*

**Matt:** Liz, Neil Korsen played a critical role in your project. Tell me more about that.

**Liz:** Neil and I [talked] about how there's a real need for some translation of scientific evidence to our communities about early detection and just the fact that lung cancer is now such a curable, survivable disease, especially if it's caught at an early stage. [We asked], wouldn't it be cool to develop--with some of our community members--messages about lung cancer screening?

And so, we shopped this idea around to several funders and then finally, the NNE-CTR took a chance on us, and we've been so lucky to connect with Ericka and the Healthy Community Coalition. Ericka was responsible for identifying all of our community group members.

**Matt:** I think that if you study stigma and you're interested in stigma, you're an empathetic sort of person. How do you think about your motivations regarding stigma?

**Liz:** My motivation for being interested in and wanting to change systems so that people don't feel stigmatized by them really boils down to empathy. But I think it also boils down to optimism. I think that this is a people-derived problem and so I think it's fixable by people.

**Matt:** Finish this sentence for me: Boot Camp Translation is ...

**Liz:** Boot Camp Translation is an approach to engaging with community members, and that can be defined in a lot of different ways, so it can be people that live in a particular location and have the shared knowledge of how that place works, or it can be medical professionals, subject matter experts, but [it's] essentially an approach to engaging with diverse communities and stakeholders to co-create usually a messaging intervention to address a priority health topic in their area--creating with full support and collaboration of everybody in the group actionable and relevant messages.

**Ericka:** [A misperception is that] you think that it's a community group that comes together and basically does a marketing campaign to the community, but [with] the researchers that we've involved [and] all of the different people who've come and joined to talk to with us, we've sort of all grown together and it's really been a really great collaborative effort so far.

**Liz:** This tool is particularly special because it flips the script in a structured way. So instead of taking information and communicating it back out into the community, it follows a process for translating that information. And what you get at the other end is something that is super local, super culturally relevant.

*"The researchers that we've involved [and] all of the different people who've come and joined to talk to with us, we've sort of all grown together."*

**Matt:** Social science is a way to address the thorny problems that remain beyond the reach of regulation and mandates. In other words, you can't mandate lung screening. There's so much in that big, gray in-between realm that social science and persuasion and engagement have to address.

**Liz:** Oh yeah, I mean I think that that's the rub. And also what makes this particular field so exciting is that we take things that you can't put a ruler next to or put up on a scale and we figure out creative ways to measure them, to quantify these really noisy, messy human experiences. So, it's hard to package and sell. But I also think that that outcomes are so exciting.

The beauty of Boot Camp Translation (BCT) is that you are able to show that the experience is in and of itself an outcome. And what BCT does is show that if you can address those higher-order upstream factors like attitudes, beliefs and knowledge, [then downstream] you will make meaningful changes on health outcomes.

**Ericka:** I have lived here for 45 years, so seeing the growth [in this sector] has been great and a project like this, I can see how it can truly pique the interest of people who are just looking for good messaging, good things to come out other than from their doctor's office. I'm really excited about what we've come up with.

**Matt:** We have an extremely divided country and so much of that divide, if you ask me, is not political, it's emotional. People just feel very left behind, both on the left and the right. From what I'm hearing from you both, it sounds like you're saying that your work has a bigger, 20,000-foot potential, which is to just start people talking, and you said this a moment ago, Liz, about how there's value just in the process of people being heard.

**Liz:** I think that's an important observation. One of the things that social science is striving to do and has done is place importance on the value of experience because experience becomes reality. Our perceived experiences are our reality, and then that becomes our behavior, and that becomes our health, right? At a certain point, what's the distinction? And I think that this project is a good example of how value is placed on the lived experience of people.

And the other thing that I love about this project--and I think it's just so beautifully showcased in our group--is the diverse expertise. Everybody who walks in the room for BCT is an expert. They're there because they have a really important perspective that's going to be incorporated into whatever we make together, and I think that there's something really empowering about that on a personal level.

**Ericka:** It's a small group, but Liz calls it the small and mighty because there is they all came in for different reasons and with different perspectives and different levels of knowledge. And we all have

sort of learned together and shared, and we trust each other now and so we feel confident that they'll speak to the community because they speak to us so strongly. When people meet in the grocery store or they meet someone and start having these conversations, this might actually come up instead of politics or something. It is something that everyone can talk about.

**Liz:** It would be incredible to be part of the knowledge that gets passed on and to be part of the narrative. So, if we can just change the conversation in any way in any group of people to be more hopeful, to be more optimistic and empathetic, I think that that's exactly what lung cancer needs.

**Matt:** So, I think there's a truism in social science and it has to do with the value of playing small ball. And what I mean by that is single-digit percent improvements can actually be quite meaningful.

**Liz:** I feel like those small changes do have ripple effects, but it's going to be in small increments. And there's a big wave happening in the field, or rather maybe more of a reckoning, that we are moving away from these P values and we're putting more emphasis on, what's the effect? And let's not write off small effects, because we're dealing with things that are so messy [and] that change from moment to moment and space to space.

**Matt:** So, you've engaged with your community group, you've gathered information on their perceptions of the process, and, with help from a local advertising agency, you've developed pro-lung-screening messages. What now?

*"There's a big wave happening in the field, or rather maybe more of a reckoning, that we are moving away from these P values and we're putting more emphasis on, what's the effect? "*

**Liz:** The next step of this project is to roll it out, and we're actually doing a pre-post assessment for the community at large and we'll be able to see, among folks who have seen our messages, whether or not general knowledge and attitudes in the community are changed.

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

**Liz:** We have had an incredible team of mentors and people who have provided us with just so much food for thought and subject matter expertise. Doctor Neil Korsen is the senior mentor on this project and has just been invaluable, both as someone who has worked as a researcher in the lung cancer space as a family medicine physician and as a Boot Camp Translation expert.

And then we had Doctor Jamie Studtz from the University of Colorado come and speak with us about lung cancer stigma and the social experience of stigma and how we make screening equitable. His conversation with us in our group was transformative. We had Doctor Dannell Boatman speak with us about her work in West Virginia on lung cancer communication, and I would say that she was so giving with what they have found and what they have done and lessons learned. And then I would say a thank-you to Doctor Don Nease [from the University of Colorado] who's one of the Boot Camp Translation guys. He has really been sort of the guiding light through all this. And then, of course, all of our group members. Wow, nothing would happen without them. And Erika, you should get a special shout out because you are like the life force behind this project, truly. So, I hope that gets into print.

**Ericka:** I've learned so much. It's been incredible.

**Matt:** Before I let you go, tell me about the role the NNE-CTR played in terms of supporting your work.

**Liz:** I think that value of the NNE-CTR is just immeasurable. Obviously, but it took a chance on us and funded our pilot. I like how clear the support options are. I felt like I knew what supports were available to me and how to access them, and I felt like they were very approachable. We have had the tremendous benefit of working with the Community Engagement Core folks. They have been a tremendous help [including] helping us troubleshoot some of the logistical everyday things that come up.

**Matt:** Is there anything missing that you think would've helped your pilot project?

**Liz:** Community engagement is a growing area of emphasis and focus, and I think that honoring community members' expertise and compensating them fairly is really important. I think to the degree to which it would be possible, budgets that would be able to be slightly more project-tailored would be incredible. I think that could be really it would lower the bar for people that want to do community engaged research because there it's a high bar; sometimes it's an expensive bar. I think that that would be that would be awesome and I know that's a focus of the CTR.



# Investigator Spotlights

## Looking for “Positive Deviance” in Rural Diets

*Emily Belarmino, MPH, Ph.D., is an assistant professor in the University of Vermont's Department of Nutrition and Food Sciences where she teaches and does research on the intersection of food systems and rural public health. She is also a Faculty Fellow at the Gund Institute at UVM.*



*Emily and her co-investigator, Jonathan Malacarne, Ph.D. of the University of Maine, were interested in understanding “positive deviance” trends regarding diet in rural New England communities. According to [Marsh et al. \(2004\)](#), “Positive deviant behaviour is an uncommon practice that confers advantage to the people who practise it compared with the rest of the community. Such behaviours are likely to be affordable, acceptable, and sustainable because they are already practised by at risk people, they do not conflict with local culture, and they work.”*

*This interview has been edited for length and clarity.*

**Matt:** You started your career in environmental studies and then moved to the food realm. I'd love it if you could spend a minute or two talking to me about that journey.

**Emily:** As an undergraduate, I majored in environmental studies, and I did a senior project looking at food systems. It was totally new to me, and I got really interested. I hosted a community dinner, and we had local farmers donate food and then we spent all this time cooking. It was fun and, after, I felt confident that I wanted to go in that direction.

I absolutely loved my graduate studies learning about the food system and how the food system ties in with nutrition and public health and different ways that we can influence what is making it to people's plates through policy.

**Matt:** So, a lot of big-picture thinking is going on here.

**Emily:** I see linkages between what we eat and every aspect of our lives. I see linkages between how we eat and our personal values, links between how we eat and our place in the world. And I think a really important aspect is that how we eat isn't always our choice. There's a huge privilege in being able to choose what we eat because for most people in the world, there's no choice, and that includes many, many Americans.

**Matt:** What would you say about the connections among climate, diet, and planetary and personal health?

**Emily:** I don't think that we can disentangle human health and environmental burdens. Food and planetary health are tied together. If any piece is broken--and it can be broken by an unjust system, it can be broken by individual struggles [or] collective struggles--none of it is going to work optimally, and people won't be able to choose foods that support their health, the environment, the economy, and align with their values.

**Matt:** What thoughts come to mind when I mention the words "diet" and "education"?

**Emily:** Nutrition education is really sticky because it hasn't been very successful. You can go to the most remote parts of the world and ask people what nutritious foods are, and they will tell you vegetables, fruits, whole grains, et cetera. People understand what nutritious foods are. [But] those foods are not always accessible, acceptable, and meet people's needs for a million and one reasons. We'll use dried beans as an example. Yeah, they're incredibly nutrient rich, they're relatively cheap. For the most part you can buy them at the co-op, you can buy them at a mainstream grocery store, you can buy them at some corner stores. But they also require you to be at home for long enough to cook them. They require you to have consistent access to electricity or gas so that you can make that happen.

*"I don't think that we can disentangle human health and environmental burdens. Food and planetary health are tied together."*

**Matt:** Let's talk about your pilot project and the concept of positive deviance.

**Emily:** Rural communities are often viewed as a monolith, and the enormous diversity that exists across and within rural communities is often not considered. Part of our goal with this project is to start to disentangle some of the heterogeneity that exists within rural communities as it relates to what people eat. The other piece is that rural communities are often talked about using deficit terms. So, all the things that are not going well for rural areas are highlighted. But there's actually a lot of really positive, exciting things happening in rural communities and [we're] trying to understand these things in the context of diets. What are the uncommon or unique factors that are allowing some rural communities to do really well? And are there lessons from that that could be leveraged for other communities?

Our ultimate goal for this pilot project is to better understand what sorts of things help certain rural communities thrive as it relates to food and nutrition security. And we know that a rural community in Vermont looks very, very different than rural community in Mississippi, which looks very different than one in Wyoming. We also know that even here in Vermont--I'll just use as an example Stowe and Brattleboro and the Northeast Kingdom--rural communities in these different places look very different; they have different economic drivers, they have different connections to regional hubs.

**Matt:** What are some characteristics of these people or communities that you can share at this point?

**Emily:** We heard quite a bit about universal school meals, which I think is really interesting. Maine and Vermont both have universal school meals. New Hampshire does not. And we've heard from our participants about the real value that they see in no longer subjecting children to means-testing as it relates to whether or not they can get the meal at school for a free or reduced price. We've also heard from our participants about home and wild food procurement. We asked our participants specifically about cultural foods and cultural diets, and that is a piece that kept coming up--

the importance of hunting, fishing, and gardening. And then the other piece that we've heard a lot about is housing. How does the cost of housing impact people's ability to put certain foods on their plates?

One of the things that we're doing now is trying to overlay our data with different frameworks for rurality. [Rural communities] have different cultures and economies and demographics. And so, we're trying to understand how those factors could overlay with some of these things like the social safety net, home and wild food procurement, and housing. Some communities in our region have been much more impacted by in-migration and housing shortages than others. And so, are different factors more important or less important for different types of communities?

*"We asked our participants specifically about cultural foods and cultural diets, and that is a piece that kept coming up--the importance of hunting, fishing, and gardening."*

**Matt:** You mentioned universal school meals. Can you talk a little bit more about that?

**Emily:** If you think back to the standard operation of school meals, most of the country continues to be divided into three groups: you're a full-paying, reduced-price, or free-school-meal person based on your household's income. Universal school meals means that no child pays for their school breakfast or lunch; these meals are available to all for free. During the pandemic, there were federal waivers available for universal school meals, because kids couldn't eat at school. When those waivers came to an end, some states, including Maine and Vermont, passed new legislation to continue universal school meals because it reduces stigma associated with getting a free or reduced-price lunch and reduces the number of children skipping these meals.

**Matt:** What else have you found so far?

**Emily:** I think the economic analysis is going to be really interesting! We are using data from grocery scanners to look at how people's food purchases align with the dietary guidelines and the cost of a healthy diet. We are trying to understand if the cost of a healthy diet is different for people living in different communities.

There are families all across the country who have scanners, and after they purchase their food, they scan it and then all of that data is uploaded, and it creates this enormous database. And so, you have millions of observations--purchases from across the country. And we know exactly what was purchased--the ingredients, the nutrition profile, where it was purchased, how it was packaged, the sizing. I think that the findings from those analyses will be really exciting, but they are still underway.

*"Most dietary data in this country is at a population level and indicators of rurality are not included in analyses. If they are included, it's often rural versus non-rural or rural versus metropolitan versus suburban, which doesn't get at some of that heterogeneity. "*

**Matt:** Are you correlating what people buy with health outcomes?

**Emily:** I think that could be a next step. We actually have very little data on rural diets, so we need to understand that first. Most dietary data in this country is at a population level and indicators of rurality are not included in analyses. If they are included, it's often rural versus non-rural or rural versus metropolitan versus suburban, which doesn't get at some of that heterogeneity. We are also going to do an economic analysis to compare the cost of a healthy diet in different communities. For example, comparing how much it costs to meet the vegetable recommendation here in Burlington versus northern Maine.

**Matt:** Let me shift the conversation to your team for a moment. What would you like to say about the folks who've worked with you?

**Emily:** Oh, this is an awesome team. We bring really different sets of expertise. Jonathan is an agricultural economist with incredible quantitative data skills and he's the one who's analyzing the scanner data. Caitlin Morgan is a research social scientist for the USDA's Agricultural Research Service, based at UVM, and is contributing to all parts of the project. She has lived and worked in New England for most of her life and done very different sorts of research projects to understand food systems in this region. Caitlin's personal and professional experiences bring a lot to the project. And then we have an awesome set of graduate students who are supporting the work.

*"Rural populations make up almost 20% of the US population. They do not get 20% of the airtime."*

**Matt:** Our mission at the NNE-CTR is, as you know, rural public health. So why is it so important for you?

**Emily:** Rural populations make up almost 20% of the US population. They do not get 20% of the airtime and I'm really excited about doing work that elevates some of the fantastic aspects of rural communities as a way of showcasing their assets and also letting them learn from each other and supporting collaboration across rural areas.

One of the things that I enjoy the most about doing translatable research is that everybody that I talk to is able to find connections between the sorts of work that I do and their lives. It's incredibly rewarding to be able to have conversations with people about things that matter to them. And it's nice to be able to do work that has the potential [to] impact policy and programming for my neighbors.

**Matt:** Is there anything else you want to add or you wish I'd asked?

**Emily:** I'm really grateful to the NNE-CTR for supporting this project. It's something that Jonathan and I were excited to pursue, and I think this project will help leverage us to the next step.





# Core Focus:

## Tracking & Evaluation Core

### Making it Real

#### The Tracking and Evaluation Core on Using Facts, Figures, Multimedia, and More to Tell the Stories of the NNE-CTR

*The Northern New England Clinical Translational network is organized around a series of cores, all of which are set up to help investigators in the research process. These include the Administrative Core, the Biostatistics, Epidemiology, and Research Design Core, the Community Engagement and Outreach Core, the Pilot Projects Program Core, the Professional Development Core, the Translational Research Technologies Core, and the subject of this issue's feature, the Tracking and Evaluation Core, or TEC.*

Lord Kelvin, the 19<sup>th</sup>-century physicist and inventor of the absolute-zero temperature scale, reportedly said, "If you can't measure it, it isn't real." The Tracking and Evaluation Core's job is to understand—and so make real—the many outputs, outcomes, and effects of the NNE-CTR's work. As one might expect, this involves a lot of number-crunching. But measuring is just part of the core's efforts. Telling the story in an engaging, creative way is a key aspect of the job as well.

Kelvin may have laid down the terms, but the challenge for the Tracking and Evaluation Core is epistemological, even existential: In a network whose cores supply services as far-flung as research design, community engagement, mentoring, and assistance with advanced research software and machines, what does effective evaluation look like? This is an ongoing conversation at the TEC.

Brenda Joly, Ph.D., is a professor of public health at the University of Southern Maine and the TEC's lead. She says that the core's communication efforts include stories of success, lessons learned, and challenges faced. She said, "We do that both quantitatively and qualitatively. We are the one core that takes a step back and really tries to aggregate across the entire initiative: What are we doing? What are the major successes that we should be sharing with others externally? What do we want to highlight? What is innovative? What are our major accomplishments? What are some of the challenges and how have we handled those?"

When prospective pilot project grantees first interact with the NNE-CTR, their experience might start by talking with one, two or most of the network's seven cores as they assemble their proposal. When their proposals are approved, new investigators often seek help with project design, collaborators, institutional review board approvals, research subjects,



Brenda Joly, Ph.D.

and statistics. During that whole time the researchers most likely won't be chatting with the TEC. But they can rest assured that the TEC is thinking about them.

"We've done a lot of work looking at the investigators in many pilot projects as they've had mentorship [and] have received NNE CTR support across multiple cores," said TEC co-lead Valerie Harder, Ph.D., M.H.S., of the University of Vermont. This is because the TEC is also tasked with understanding how investigators use NNE-CTR core services to advance their research.

In addition, the TEC also thinks about the other cores and how they interact with each other. Harder said, "A lot of our work is helping build relationships and helping communication across the cores themselves because we get the opportunity to interact with all the cores, which is one of the best parts of our [job]."

So, a process that, on its face, would seem to be about numbers is equally about the people behind them. Carolyn Gray, MPH, from the University of Southern Maine serves as project manager and research associate for the TEC. She said, "We've now had the opportunity to build these relationships over a number of years. We meet with the cores on an annual basis to talk about, what are their goals, what are their interests and how can we measure those things that are important for them to attain?" She credits the cores for their interest in creating a stronger NNE-CTR. "[The cores] try to set measures that are good goals for the next year so that we can track those goals over time."



Valerie Harder, Ph.D., M.H.S



Carolyn Gray, MPH

Harder, an epidemiologist and methodologist who leads the TEC's quantitative efforts across projects, said that the conversation is always open. "I would encourage others to come to us with their ideas and to share with us what they're doing to help inform our evaluation."

### **Telling the NNE-CTR's Story in a Variety of Ways**

Joly said, "I think we're an experienced-enough evaluation team to recognize that the numbers will give us important information, but maybe only tell us part of the story. And I think we've realized how to collect the qualitative information we need to present."

The core's outputs come in a variety of formats, from [impact reports and infographics](#) heavy on the numbers to published papers and [multimedia pieces](#) that rely on people and local images to tell the story. Kelly Waters, MPH, is a research associate at the University of Southern Maine who spearheads the core's digital storytelling and data visualization work. Waters has been with the core for about a year and a half. She explained that she was excited to join because "I had Brenda as a professor in University of Southern Maine's MPH program and thoroughly enjoyed being in her classes and knew that she was very innovative with evaluation tools and methods."

As an example, Waters cited the core's presentation of its first collection of digital stories to the American Evaluation Association's conference in the fall of 2023. "The theme was actually about storytelling in evaluation. In our digital stories, we presented a summary of some of the COVID-19 research that took place--and is ongoing--with the NNE-CTR. So, it was an opportunity to really kind of look across all of the cores to check out everything that the CTR has accomplished during the pandemic. I showed [the audience] the link [and] walked



Kelly Waters, MPH

them through our process. They were excited about it, in part because it was engaging.”

Among the core’s many audiences is, of course, the National Institutes of Health (NIH), the organization that funds the NNE-CTR in five-year increments. Joly said, “We have to be able to demonstrate what we’re doing with this grant. So, it really is about quality improvement. It’s about understanding the investment that NIH is making in our region and the impact that it’s having.”

### **Teamwork and Innovation**

Chatting with the members of the TEC, one comes away with two main impressions: One is that the core, spread across two states, enjoys working together; they are quick to give each other credit. And the other is that they are excited to pioneer innovative and creative ways to explain, assist, and measure the work of the NNE-CTR.

*“We really have an incredible team that’s across both institutions. I think we work really well together.”*

*—Brenda Joly*

Joly summed it up: “I’ve been involved in the NNE CTR since its inception, and we really have an incredible team that’s across both institutions (the University of Southern Maine and the University of Vermont). I think we work really well together. We’ve got people that are bringing a lot of different skill sets, and combined we’re I think some of the leaders of evaluation across the country for CTRs (clinical and translational research centers). We’re doing some innovative things that we’re excited to share.” And, indeed, Joly reports, “Others have acknowledged our high-quality products and nationally, we are known for helping to contribute to the science for evaluating clinical and translational research initiatives.”

Innovative evaluation and reporting, of course, go hand in hand with the forward-looking research taking place at the NNE-CTR. One TEC product is the researcher investment tool. Harder explained, “This was conceptualized by Brenda and the team, and we all joined to work on this together. It [assesses] the experiences and perceptions of our young investigators, early career investigators. But we are [also] sampling all of our investigators at any [career] stage to look at their progress over their research career, and it’s really innovative. On my end [I help] to bring psychometric testing, which is testing the validity of the measure with some quantifiable metrics and testing the reliability of the measure using some statistical methods. And you’re going to see this soon because [we have] just submitted it to a journal.”

*Innovative evaluation and reporting go hand in hand with the forward-looking research taking place at the NNE-CTR.*

Another example of the TEC’s innovation is its social network analysis of organizations throughout Northern New England who have an interest in community-engaged research. This analysis, which was a collaboration with the Community Engagement and Outreach Core, used Visible Network Labs’ PARTNER platform to conduct a survey of academic institutions, community-based organizations, healthcare organizations, and government entities. Waters explained that the survey will be repeated throughout this grant cycle. “It’s a validated approach to really track collaborations over time. And also, the cool thing is that it has these network maps that you can create based on different questions from the survey. Hopefully we’ll be publishing something about how you can use this tool to evaluate clinical and translational research networks and how it’s benefited the CEO Core.”

The NNE-CTR was created around the ambitious goal of improving the health of northern New Englanders. Because health is complex, measuring how the NNE-CTR is doing this is complex as well. The challenge laid down by Kelvin over 150 years ago—measuring to make it real—is one embraced by the TEC, but with one important added element. Joly put it this way: “NIH isn't just interested in the successes. They also want to understand, because this is a national initiative, what challenges is our CTR facing and what have we done to overcome them? Because there are others that can learn from that.”

In other words, if you can measure it, you can make it real. And if you can make it real, you can make a difference.



The other members of the Tracking and Evaluation Core include, from left to right, Karen Pearson, MLIS, MA, Policy Associate, Cassandra Cousineau, MA, Research Data Specialist, and Vy Cao, MPH, Research Specialist & Data Manager



# What Are You Up to These Days?

We'd love to highlight you and your research. 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 [matthew.j.dugan@med.uvm.edu](mailto:matthew.j.dugan@med.uvm.edu)

