

The NNE-CTR Quarterly Newsletter

Winter 2024



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Welcome to the NNE-CTR's Winter Newsletter

The central goal of this newsletter is to educate, encourage, inform, and connect. We do that by focusing on story content that:

- Anyone can read (no specialized training required!)
- Encourages collaborations
- Helps people both outside and inside our network better understand what we do
- Provides not just the facts but the human perspective on our organization's activities--that is, content that answers the question, "What does this *feel* like?"
- Takes deeper dives for particular audiences

This can result in lengthy articles. Therefore, you'll find a new "Who Should Read This and Why" explanation at the beginning of the newsletter's longer pieces so that we can give a special heads-up to particular readers.

From January Jan 24 - 26, 2025, the Northern New England CO-OP of Practice and Community Based Research Network (NNE CO-OP PCBRN) will hold their [annual conference](#) at Attitash Grand Summit Resort in New Hampshire. The theme is particularly fitting for these divided times: Effective and Equitable Whole-Person Care. At the conference will be dozens of motivated, interested, caring people from across northern New England who are going to be learning about, discussing, and brainstorming ways to improve patient outcomes by thinking about not only the person but the world around the person.

The conference also just happens to be taking place during [Integrative Health Month](#). So, the time is right for considering how connected everything truly is—and how connected we truly are across all political or perceptual divides—when it comes to our health.

Whole-person care is about ecosystem-oriented thinking and it all comes back to that central desire we all share and that brings us all together: to enjoy the best possible health. When we listen, and when we consider the world swirling around us and its effects on us and those we seek to help, we inevitably come up with better solutions for those we serve. It's empathy at work.

And there, in these challenging times, lies the great hope of building a healthier, happier, more connected, and kinder world.

We hope to see you at the conference.



Clifford Rosen, MD

A Message from Our PIs



Gary Stein, Ph.D.

The Annual Northern New England CO-OP Practice and Community Based Research Network Meeting: **An Opportunity to Strategically Support Northern New England Health and Healthcare**

This coming weekend, January 24 through 26, we will be joining our Northern New England CO-OP PCBRN colleagues in Bartlett, NH for their 45th Annual Meeting. With the NIH commitment to engage primary care practices in clinical investigation and clinical trials, a priority of the meeting will be development of strategic approaches to leverage the resources, expertise and capabilities of our NNE-CTR-NNE CO-OP PCBRN partnership for credentialing rural primary care practices to support clinical investigation and clinical trials, traditionally only available in academic medical centers. Securing an NIH investment to transitioning to electronic health records and development of patient status sharing networks will be explored.

The theme of this year's meeting will be effective and equitable whole person care delivery. Drawing on the broad-based expertise of our NNE-CTR and NNE CO-OP PCBRN members, the increasing appreciation for prevention, detection, treatment and survivorship of chronic disease will be centerpieces of the program. Community engagement and our responsibility to expand health and healthcare literacy, responding to social determinants of health and environmental challenges will be focal points for discussion. The necessity to address our responsibilities to support rural Northern New England health and healthcare throughout the lifetime continuum will be emphasized.

While the meeting provides a forum to identify challenges and opportunities that can decisively enhance effectiveness of primary care in northern new England, it will be important to develop initiatives that provide sustainability and continuity.

Please join us in Bartlett, New Hampshire this weekend.

—Gary and Cliff



Working Way, Way Hopeful Initiatives, Frames, and Good Upstream New Works



Who Should Read This Article and Why

This article is both primer and, hopefully, a spark for those interested in evolving concepts of upstream health. Investigators and physicians will find it of particular interest and will find collaboration opportunities as well.

Part 1: Thinking Broadly to Care for the Whole Person

The term “upstream health” is familiar to most. But how about “planetary health”, “global health,” “one health” or “whole-person health?”

If you feel a bit in the dark, never fear. That’s what this two-part series is for. These evolving concepts are shaping healthcare’s perspectives in exciting ways, with considerable promise.

This series has several inspirations. These include the world climate and health challenges that are an increasing part of daily life, concerns about future [funding for important health initiatives](#), the trend of [increasing distrust in institutions](#), and the exciting, burgeoning conversation about the potential of [upstream health interventions](#) that address people as well as planet. After so much recent media emphasis on our challenges, it’s fitting to concentrate on the many promising developments going on all around us. So, we’re pleased to present news about the innovative, life-changing work that members of the NNE-CTR and beyond are doing every day.

Part One of this series will address the concept of whole-person health. Part Two, appearing in the Spring edition of this newsletter, will delve into planetary health.

And, not by accident, part one also coincides with the Northern New England Co-Op Community and Practice Based Research Network’s [annual meeting](#) the last weekend of January, the theme of which is Effective and Equitable Whole-Person Care.

We hope that what you find here sparks an idea or a new collaboration and helps get your new year off to a hopeful start.

Part 1: Introduction

The 80 and the 20

To properly describe whole-person health, it is necessary to consider other concepts and frameworks, beginning with the social determinants of health. While most people reading this article are well familiar with the idea that at least 80% of our health is determined by factors outside of the medical setting, it's a statistic that never fails to give one pause. Where we live, how we live, policy, local transit, our education, our family situations, and so much more all affect the quality and duration of our lives. The good news is that, while these issues are multifold, they're also like a to-do list; check off enough of them and true progress can be made.

Take, for instance, what we eat. Hippocrates famously said, "Let thy food be thy medicine and thy medicine be thy food." And modern research confirms ancient Greek wisdom. Bruce Barrett, MD Ph.D. from the University of Wisconsin Madison speaking at last November's Healthy People, Healthy Planet Symposium, noted, "As you improve the sustainability of your diet as measured by the Planetary Health Diet Index, you reduce your risk of mortality by as much as 20 or 30%. This is more powerful than almost all medical interventions."

An inexact but somewhat illuminating comparison: Americans spent almost [\\$64 billion on organic food in 2022](#). That's impressive, but, according to one [source](#), they also spent nearly \$500 billion on fast food last year. Further, on any given day, over [36% of Americans eat fast food](#). This indicates that, when it comes to our health, there's a lot of low-hanging fruit out there (pun intended). The trick is how to gather it.

But before we go further, it's time for some definitions.

From Far-Off Forests to Local Air

To properly understand whole-person health, it is necessary to situate it within the ecosphere of health concepts. Here, the "upstream" metaphor falls short because it implies a more or less linear pathway that also grows smaller as it approaches its origin. It's more helpful to think in terms of concentric circles (see Figure 1) that grow larger and more encompassing as more health factors are brought into the conversation. As a helpful analogy, let's consider the Canadian wildfires of a year and a half ago.

Somewhere in northern New England in the summer of 2023, a patient presents with asthma, a **personal health** problem. In addition to prescribing medication for the problem, a practitioner might wonder why this episode occurred and note that local air is impacted by long-distance transport from distant forest fires, and, indeed, that other community members might be visiting their primary care offices with similar complaints. Here, a personal health issue becomes a **public health** one.

It is helpful to think of **global health** as essentially public health across borders. In an era of international travel, pathogens can turn up thousands of miles from their point of origin in a day, and pollution from

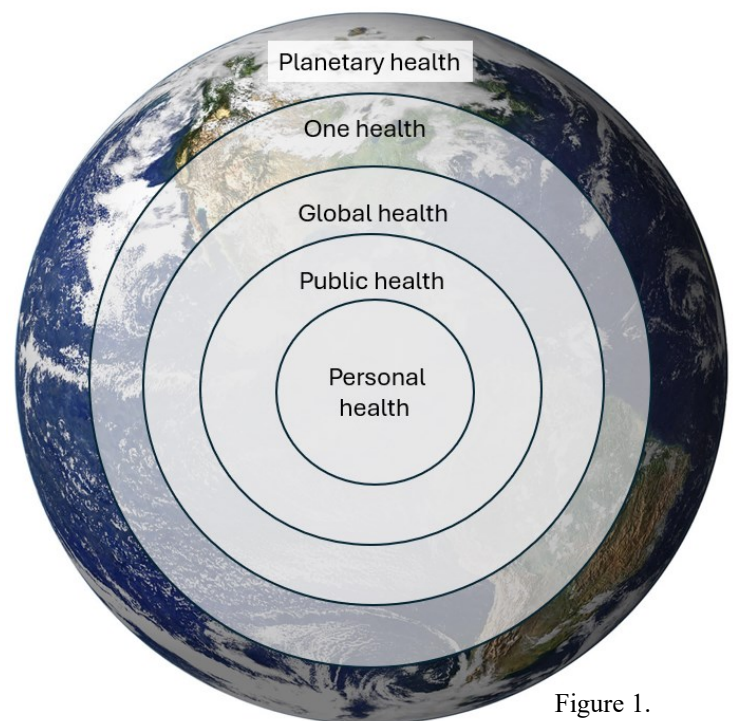


Figure 1.

factories in China takes only about six days to travel the Pacific Ocean where it [contributes to West Coast smog](#). So, the problem of Canadian wildfires is also a problem of global health as these fires affected people across Canada and across large sectors of the eastern United States, with New York City [reporting the worst air quality](#) in the world during this time.

At the risk of oversimplifying, it is useful to think of the **one health** concept as [public health + environmental health](#). It is about the interconnectedness among humans, animals, plants, and all living things. The Canadian wildfires were the result of a perfect storm of events including anthropogenic climate change that resulted in drought conditions. They were also the result of good intentions gone awry. [Poor reforestation practices](#), including a monoculture approach, contributed to workers planting trees that would later become known as “gasoline on a stick.”

“Human health and the health of our planet are inextricably linked, and ... our civilization depends on human health, flourishing natural systems, and the wise stewardship of natural resources.”

—Rockefeller Foundation-Lancet Commission on Planetary Health

Going from the concept of one health to **planetary health** is a matter of expanding one’s concept of the world from that of a series of systems that interact with each other to the idea of the planet as an organism itself. “Planetary health” is the newest concept in this list—not in terms of the idea itself, which is as old as Buddhism, but rather in terms of how the concept is quantified. The [Rockefeller Foundation-Lancet Commission on Planetary Health](#) offers the following: “Human health and the health of our planet are inextricably linked, and ... our civilization depends on human health, flourishing natural systems, and the wise stewardship of natural resources.”

Under the planetary health framework, we don’t improve environmental systems to serve humanity. Rather, we respect the natural systems, including the health of both living and non-living entities because our species co-evolved with them, making us an inextricable part of these systems.

Using this framework, it is possible to link distant Canadian wildfires with a local case of asthma and more than that, this expanded perspective also incorporates a transdisciplinary, [health-in-all-policies](#) perspective. Instead of focusing on one individual and an inhaler in a town in northern New England, upstream thinking now involves addressing asthma, in part, by growing healthier, more resilient forests in Canada, which, in turn invites the inclusion of silviculturists, botanists, soil experts, hydrologists, mycologists—the list goes on. And one might even add in the physician prescribing one inhaler over another because the former uses a propellant that is more climate-friendly. Imagine the opportunities for [conversation](#).

So, where does whole-person health fit in?

Whole-Person Health

According to the [NIH’s National Center for Complementary and Integrative Health](#), the whole-person health framework considers “multiple factors that promote either health or disease. It means helping and empowering individuals, families, communities, and populations to improve their health in multiple interconnected biological, behavioral, social, and environmental areas. Instead of just treating a specific disease, whole-person health focuses on restoring health, promoting resilience, and preventing diseases across a lifespan.”

If that sounds like planetary health, here are some ways to think about the differences. Whole-person health is a human-focused perspective that prioritizes improvements in the ecosystem's elements that demonstrably affect human health. It is likely that not every entity on the planet, if existing in health and harmony, will have a positive effect on human health. Planetary health views human health through the lens of environmental health and so does not directly account for social determinants such as housing, income, and community safety, etc.

Finally, money makes for a short leash. In other words, to date it has proven at least somewhat feasible to create nonprofits and funding mechanisms for social determinants that are related to whole-person health. In contrast, despite groundbreaking work from almost 30 years ago that valued worldwide "ecosystem services" at [\\$33 trillion](#), pay models haven't yet fully accounted for the value of a healthy planet.

If you perceive the gap between whole-person health and planetary health as vanishingly small, that's not so far from the truth. According to [Kondo et al.](#), "Healthcare providers are increasingly looking to incorporate knowledge about environmental influences on health into therapeutic interventions." The largest challenge at present remains quantification. For example, it's well-established that nature exposure has multifold health benefits, but studies on the effectiveness of nature prescriptions are [few and inconclusive](#).

But practitioners and researchers alike are making progress, and models exist. Consider that the benefits of the Clean Air Act exceed costs by a ratio of more than 30:1, and the Act prevents around 230,000 early deaths per year [according to the EPA](#), all while [creating millions of jobs](#). In addition, the Clean Air Act has helped restore waterways and benefit wildlife through reduction of [acid rain, ozone, mercury and more](#).

Another of these mechanisms, perhaps surprisingly, is the health insurance industry. With climate change having an increasing effect on both physical and mental health, a sector that is built on making more than it pays out is an eager stakeholder. An [industry report](#) from February 2024 states, "The insurance sector is uniquely positioned to help prevent and manage climate-related risks."

For a variety of reasons, forces across sectors are working toward the same thing. With that in mind, we'd like to introduce you to some people right here in our region who are working on the issue of whole-person health from variety of angles.

Part 2. Whole-Person Health and Voices of Change

Earlier, we mentioned how using a social determinants framework is helpful because it helps turn a variety of issues into a to-do list. In the hands of dedicated practitioners and researchers who are seeing the issues in their communities on a daily basis, this to-do list becomes local, and, as lessons are learned and conclusions are drawn, results can be shared nationally and beyond.

Below, voices from the NNE-CTR network and discuss their thoughts and work in their own voices as they ponder and research local issues with global implications. As you read, take note of how much overlap there is: Individuals from very different perspectives, doing very different kinds of work, are thinking in similar ways.

The following quotes are selected excerpts taken from extended interviews.

Changing Norms and Reducing Stigma to Improve Health: Dr. Elizabeth Scharnetzki, Ph.D.

Liz Scharnetzki is a social psychologist and a faculty scientist at MaineHealth's Center for Interdisciplinary Population & Health Research

“When I [think about] whole-person care, I think about considering broader social context as part of [the patient’s] care, because I heard the analogy that you can have the healthiest fish in the world, but if you put it in a dirty fish tank, it's not going to do well.

“I'm particularly interested in some of those upstream factors--things like people's beliefs, their attitudes, the norms in our society or culture, how all of those things--those really, really upstream factors—set people down a particular trajectory. And so, time and time again, what we see in health services research is really cool. Interventions will be developed that target a specific outcome that will be designed to help promote some sort of health promoting behavior. And they won't work—not because it's not a fantastic idea, but because it's targeting the behavior that is associated with an outcome. And really what we need to do is scoot that intervention up a couple steps to address those extreme factors to create and disrupt somebody's social context that doesn't support them engaging in behaviors that are going to lead to that positive health outcome.



“Failing to take into account somebody's broader social context, how they interact with the people or entities around them, how the structures that set up the overarching socio-political climate for them--failing to take into account those things is going to really confound anything you're able to design and so then we kind of get in the self-perpetuating cycle where our methods are confounded and our outcomes are parameterized. And then on a broader level, we get into this scientific issue where then we have to have a study to test in each and every context and then science takes, I don't know, 150 years to do anything.

“One thing I'm really excited about right now that we're doing in my lab [is] a clinical trial that is testing the efficacy of a social psych intervention on feelings of stigma for folks who have type 2 diabetes. There's stigma associated with diabetes, and then there's also stigma associated with weight and body size because, regardless of somebody's actual weight or body size, they have become linked.

“And so, we really chose an intervention not geared on condition management behaviors, not geared on [for example] blood glucose control, not geared on any of those health outcomes. We wanted to intervene on that upstream factor and then see if we can change people's experiences with stigma. So, we're testing whether or not this intervention decreases feelings of stigma and whether or not that in turn will have a positive impact on condition management behaviors and their blood glucose control.

“So many of our social norms really constrict the degree to which we perceive we have agency to engage in whole person care. There's a lot of feelings of shoulds and oughts, and it's all socially constructed. So, I think that the more that we move away from those shoulds and oughts and change our norms, I think will be more effective in delivering whole person care.

“If you don't have a sense of belonging and connection, it's a fundamental need that's not being met. And when we don't have our fundamental needs met, there are significant consequences. If you're talking about an individual person not feeling any kind of sense of belonging, [there are] significant mental and physical health outcomes. I think that there are potentially some negative attitudes that could be correlated with not feeling any kind of sense of belonging or connection, which then has consequences for broader social decisions that get made.

“I really am excited about the potential of taking some of these lab-tested interventions for things like stigma or these upstream factors, and I want to put them in the real world.”

“I really am excited about the potential of taking some of these lab-tested interventions for things like stigma or these upstream factors, and I want to put them in the real world. I want to figure out how to make them accessible and usable in all of our messy, noisy social contexts, because we see that they work in the lab. So, let's get them out in the world. “

Community as Inspiration and a Call for Convening: Dr. Sally Kraft

Sally Kraft is Assistant Professor of Medicine and Assistant Professor of The Dartmouth Institute

“We talk a lot at Dartmouth Health in our population health group about the link between health of the individual and economic prosperity of the community, and the Surgeon General Jerome Adams a couple years ago really made that link between community health and economic prosperity. So, I do think that there are multiple sectors that do care about your health.

“In the healthcare [field], as we are progressively moving away in theory from fee-for-service pay, [we are] rewarding health systems based on their health outcomes. And those health outcomes are twofold: quality of care, but also cost. And this is what the accountable care organization or value-based payment model are doing. And the extreme of that would be a capitative payment system. ‘I'll pay you \$35.99 a month to insure [a person, without any extra payment no matter whether] you have an abdominal aortic aneurysmectomy or you're perfectly fine and you never come to the office.’



“I am deeply humbled by the skills and the knowledge that we need to acquire. It's how do we work in partnership with different people coming at the same problem from different directions, an employer or a government, an individual, a family unit, a doctor, a healthcare system, a school? I think we all are willing to say I would like the people around me and in my community be healthy and to live with dignity and to be as productive and present and engaged in their community as possible, I think we would all agree with that.

“I get excited about where we are [because] I think rural communities have an opportunity to make a really unique contribution. We are dealing on a daily basis with real live constraints right in our face when you're pregnant and your labor and delivery unit just closed. You are dealing with finding a solution now before [you] have to deliver. So, I think we are like the canary in the coal mine where we're really dealing with finding a

solution now before [you] have to deliver. So, I think we are like the canary in the coal mine where we're really dealing with those constraints right now. And there's a resiliency and a sense of accountability in rural communities that I think come from the fact that the communities are so small and we tend to know a greater proportion of the people with whom live than in an urban area. While I would characterize New Englanders as very proud and really proud of that self-reliance, there is a need to take care of my neighbor. They are my neighbor. I know them.

"I get excited [because] I think rural communities have an opportunity to make a really unique contribution. "

"We share a community together and I think that's what makes working in this northern New England area exciting. I'd like to see us bring people together in effective partnerships to achieve shared goals. I would love to see a rigorous convening of economists and anthropologists and healthcare providers and civic leaders and employers and educators coming together--health insurance payers should be in there too--to set up enough of a learning health system that we can more rapidly learn what's working and what's not working. We could have a conversation that would end with, what are the foundations? How will we work together to continue to learn to find the data systems, to find the communication systems, to build the capacity to make changes? I really do think we could do it."

From Planetary Perspectives to Provider Action: Andrew Rosenfeld, MD

Andy Rosenfeld is an associate professor in the Department of Psychiatry and the Department of Pediatrics at the University of Vermont Medical Center

"I'm [working] with (UVM's) Christine Vatovec on whether we can get a little grant to create some kind of Earth RX or planet RX program. There's a lot of evidence, broadly, that nature contact has a lot of human health benefits, including mental and physical health. [Nature's effect on] blood pressure or anxiety or depression or diabetes risk--it's new enough and broad enough that we're not sure. Our goal is to add that to the list of offerings for some conditions or scenarios. So, imagine a time when a primary care provider may say, 'Oh, I have many patients with mild to moderate depression, and I've learned that contact with nature has an effect size for mild to moderate depression that's comparable to our antidepressant medicines. And so, I'm giving my patient more evidence-based options because flexibility is important.' "



"[A physician could say], 'Something you could do for your depression is get outside. Grow a plant in your home. Start a garden.' There are lots of ways to have nature contact. Even in the office we could do some of those things that may help their nature connectedness and their depression simultaneously, with or without talking about planetary health and the nature, connectedness, and it reciprocally helps the planet, because it's fewer antidepressants prescribed in this scenario. Then there's less carbon footprint for manufacturing them, and there's less getting into the water supply and potentially the food chain and the effects of that. So, we're actually elevating the care because we're saying here's another evidence-based option [a patient] could use."

“Maybe we do group medical visits where five or ten people come to talk about their mild to moderate depression, which is pretty common. And in that visit, when they're checking in about symptoms, they go for an hour walk together or they listen to nature sounds or they learn about where [turmeric](#) comes from as a spice for their food.”

“[Regarding] big pharma and all their advertising, I think probably we don't fight it. We look for the opportunities where [there is] a better environmental impact or somebody has said, ‘This pill is giving me a side effect. What else do you have?’ And we could say, ‘You know, we have the slower, maybe more enduring benefit of nature exposure or mindfulness practice. Are you interested in trying that with the both/and approach? It's not pills or skills. You can do both and if your skills allow you to take fewer pills or have fewer side effects, it doesn't have to be no pill.’”

Informing Policy to Improve Healthcare: Erika Ziller, Ph.D.

Erika Ziller is the director of the University of Vermont Larner College of Medicine Health Services Research Center, where her research is focused on public health and health policy in rural areas. She and her team were recently awarded a \$2.8 million grant from the Federal Office of Rural Health Policy to study the effect of federal policy on rural health care.

I started out in social work and got really convinced after about seven years in the field ... that policy was probably the big lever that that would help people the most. So, I got a master's in health policy and then ultimately my Ph.D. in public policy.

“I've always been really interested in health systems and health equity and so how do we make sure that we're getting the right care to the right people at the right time in a way that meets their own stated and not stated needs and I think that's fundamentally what whole-person care is.

“I think it gets back to this this distribution question. I don't think anybody is happy over-consuming resources. Things are really just out of balance and at the end of the day, nature, systems, humans strive for equilibrium in some way. But you can also just see the power of community and resilience and groups coming together to solve problems. And so, my first days in Vermont were right after the first flood [of 2023], and then we had the second flood--these back-to-back hundred-year floods--watching how people responded to that made me feel very hopeful--even people who don't necessarily agree politically or socially. That's something that I always felt growing up in a rural community as well. If somebody got sick or their barn caught on fire, there'd be dinners there, people would have jars out at the corner store. For them, it just was ‘We're in this together.’”

“[When you're designing policy briefs], it seems like it's all numbers. Yeah [it's about] the data, but there's always a story in every bit of research, at least from a policy perspective. There's a villain, there's, a conflict, a challenge, right? There's a problem, otherwise you wouldn't be doing the research. And I feel like probably our biggest challenge is communication.

“So if we want to make sure that these super important, very relevant critical scientific discoveries—I'm never going to undersell bench science--but if we want to make sure that it is moving the needle, then we need to make sure that we know how to talk about it. When he was leaving the NIH, [former director] Francis Collins was asked



if there was anything that he would have done differently and he said, “I would have funded much more social science and social and behavioral research because here we are in the middle of this pandemic. [and] we have the scientific knowledge, and we can't get people to use it. And I never imagined that we could get to a place where we would offer a vaccine and people wouldn't take it.’

“How do you do knowledge transfer with policy makers? How do you make sure that the law actually makes it through the bureaucracy and is implemented in a way that is functional for the people trying to be served? It's the same concepts and things in dissemination and implementation science. And of course I'm a public health person, so I want to know, how do we make sure that populations are able to take advantage of the resources that they need? The social sciences are critical in my opinion.

“I would love to hire some more faculty to work in the center with me. Vermont is really in an interesting and unique place to be one of these centers because we are so small population-wise, and yet so rural at the same time. In some ways ... we are a perfect microcosm of all the stresses and tension [in the system]. I get excited [because] I think rural communities have an opportunity to make a really unique contribution. “

“We have four years of funding. I definitely intend for us to reapply in four years if the program is still going. And I would love to hire some more faculty to work in the center with me. Vermont is really in an interesting and unique place to be one of these centers because we are so small population-wise, and yet so rural at the same time. In some ways ... we are a perfect microcosm of all the stresses and tension [in the system]. So, I'm really excited to have this resource here in Vermont and to be able to both learn what other states are doing in terms of rural health and also being able to be a resource and share what we know.

“There's a lot of discussion within the field of public health [about] how do we do precision public health? What can we do using big data? What are the biggest predictors? How do we get the best bang for the buck in delivering a public health intervention?

“You know, that's ultimately the goal of health services research as a field discipline, to kind of find the balance between access, cost, quality to this place of value, right? I mean, you can save a lot of money in healthcare if you stop delivering it. But that's not the outcome that we want. This is really where the harmony between whole-person care and health system reform [is so critical].”

Look for Part 2: Thinking Planentially, Working Incrementally in the Spring edition of the newsletter.



Core Focus



Biostatistics, Epidemiology, & Research Design Core



Who Should Read This Article and Why: Current and potential investigators will learn about how the BERD Core can help them with a variety of services including research design in the process of applying for Pilot Program grants. Other CTR core members will learn how the BERD Core works with investigators and other NNE-CTR cores to foster great research and to make the whole process easier and more fulfilling.

Welcome to our ongoing Core Focus series where we chat with the NNE-CTR's cores about how they work with investigators and with each other to create strong projects that result in solid research. This issue features the Biostatistics, Epidemiology, and Research Design (or BERD) Core. This core is composed of 11 individuals, four in Vermont and seven in Maine, with a variety of skills from biostatistics to research navigation, or the process of helping investigators through the research process. Here, team members explain how they work with investigators. Quotes have been edited for length and clarity.

Q: The BERD Core is more than just compiling data at the end of a project, isn't it? What do you do for researchers that they might not know about?

Peter Callas, University of Vermont Core Co-Lead: I think the perception is often that what we do is [just] data analysis. And the reality is biostatistics, epidemiology, and research design really covers the whole gamut. We help investigators come up with a testable hypothesis [and] design the study, especially the analytic part and the sample size, which is what they expect from us. But we can [also] help with all sorts of aspects of it. Once the study is being conducted, there's sometimes quality control we can help with by looking at the data to look for missing values or inconsistencies. Then the analysis and interpreting the findings.



Peter Callas, Ph.D. of the University of Vermont is the BERD Core Co-Lead

Matt Williams, Cloud Engineer, MaineHealth: We're just now getting into the cloud and my role supports the researchers in providing them with more powerful and agile capabilities to do their work. It's something that we've been working on for a while now and I'm excited now that we have the infrastructure to keep going forward with it. So, we can do things like genomic sequencing in the cloud and that type of more compute-heavy research.

As time has moved on, we're getting researchers who are more familiar with machine learning and AI. We've had requests for researchers to do things like build a machine learning model to reduce sepsis rates in the ER. And then additionally, the other component that's pretty exciting and we've been working for towards is the collaboration piece with other research institutes.

It's much easier and you can share data much quicker and much more efficiently in the cloud with other research institutes with common data models. And if they are working with a different analytic platform, it's not as big of a

deal because the way that we are able to store the data is agnostic for the type of technology that you might use. So being able to have that capability is something that we're very excited about.



Melissa Graham, RN, from MaineHealth's Center for Clinical and Translational Science, is a research navigator and regulatory spe-

Melissa Graham, Research Navigator & Regulatory Specialist, MaineHealth: I am the IRB liaison. My role is really to help investigators who are writing their research protocols and assisting them with logistical aspects, but also with the regulatory focus.

Susan Santangelo, Core Lead, MaineHealth:
We're here to help people do their best research.

Wendy Craig, MaineHealth: I think that says it all, and we are a really good team. We all work together very, very well. We all recognize and respect everyone's different niches and expertise, and we leverage that as best we can to help people.

Q: What's enjoyable to you on a personal level about your job in the BERD Core?

Wendy: I think pretty much part of my everyday work as a navigator is mentoring. It's something we all do, just a part of who

we are.

Deanna: I agree with Wendy. I feel like as navigators, mentorship is kind of like the gift wrapping that we provide that is wrapped around all of the support we provide because we're always kind of teaching and consulting and kind of showing folks best practices.

Jonathan Emery, Biostatistician & Research Navigator, UVM: The big thing for me is the researchers will have a question they're trying to answer. They have data and [they're] trying to align the question to the data. In reality, is this question actually within the scope of what the data can answer? And how much can I clean this data and get it aligned with their question?

Q: That must lead to some interesting conversations with researchers.

Shamima Kahn, Biostatistician & Research Navigator, UVM: When I work with researchers, I do suggest alternative ways of looking at the data or maybe follow-up studies. That's something I feel is a value added. I mean, instead of just taking the data and crunching it, I offer my suggestions, and I don't expect them all to be accepted, but I just want them to be heard.

Peter: That's a good point because we have some areas of expertise beyond just data analysis just based on projects we've worked on in the past. [For instance], Derek, with a master's in computer science, has some other skills that he brings in that the rest of us might not.

Q: When you're working with a researcher's results, do you think about the story they tell?

Wendy: I help with the analysis, but I typically also help with dissemination, whether it's a manuscript and abstract or presentation. And it's always, always, always about the story and it makes it more fun for people to

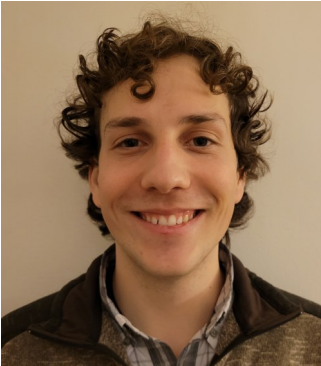


Susan Santangelo, ScD, of MaineHealth is the BERD Core Lead

realize that. You know, often they want to talk about everything. Well, no. Let's see what the storyline is. It's not that you're being nontransparent by leaving things out; there's only so many tables you can present, right? What are the most important things to them that they want to tell the world?

Jonathan: I do agree that that it can be thought of like a story.

Peter: Clearly when people do projects, they have a hypothesis in mind or they wouldn't be doing it, but we try and help make sure that it's objective. Like yes, you can say that. No, you can't say that. You know, sometimes we have to pull in a little bit [when it's] really not an appropriate interpretation.



Jonathan Emery, MS, of the University of Vermont is a biostatistician and research navigator

Susan: I would just add to that that there are some times when you need to reign in some of the data interpretation. That happens because sometimes people want to say things that really may not be fully supported by the data and you need to make sure that that doesn't happen too, right? So, there's a story, but you don't want the story to be overly embellished or not supported.

Shamima: Yeah, I like the saying, "Numbers don't lie, but they're made to."

Jonathan: It's tough. You can go too far with it sometimes. You don't want to just make the story be an anecdote. We're trying to answer a general question, but, yeah, trying to still keep it a story that you can learn from [is valuable]. It's a bit of a line there.

Shamima: Another thing I would like to add here is [the importance of] putting statistical analysis in plain English language so that everybody can understand. I make it clear that my job is not just to analyze the data, but make sure it is in line with, of course, what the research question is, [and] also what is the existing literature showing right now and how does our study either agree or disagree? It can go both ways, so that's kind of a big part to make sure that the statistical analysis is properly explained and put into the context of the existing literature.

Derek Devine, Biostatistician, UVM: The thing that I see as a potential and a plus about [computer programs such as] R and Python is that there are newer plots that are being used in a lot of papers and publications, for instance, not just a box plot but a violin plot that shows density. That's where you can add creativity and points within a plot that also has a shape to it so there is more than one point of reference. I can see a lot of potential for more information being communicated.

Q: Your work spans all kinds of projects. How does that feel?

Shamima: I do enjoy the work in terms of the diverse projects and for me it's like having an opportunity to kind of work with direct patient-oriented research, which I couldn't do myself because I'm not a clinician, I'm just a researcher, so that's kind of enjoyable for me.

Derek: I've worked with Meredith Niles (Ph.D., associate professor in the Department of Nutrition and Food Sciences at the University of Vermont) on some hunger-related things. And it's got me interested in studying those



Shamima Khan, Ph.D. of the University of Vermont is a biostatistician and research navigator



Derek Devine, MS, of the University of Vermont is a biostatistician

ideas in different ways that aren't really being done here. For instance, using social media to try to [examine] hunger rates in general and things like that. So yeah, I like the exposure to different things, like working on COVID or air quality and wood stoves, cancer studies. I enjoy the diversity because I don't know if homing in on one specific area would I keep it as novel and fun.

Peter: Career-wise, the best thing to do is to carve out your niche in one specific area and be the expert in that. [But] I find I much prefer working on a variety of topics and helping other people get their research done. I enjoy the different topics that come along and learning about them myself. So, some mornings I might feel like I have whiplash going from one study to another because they're on such different topics, but I can adjust. So, for me

it's a positive.

Wendy: On the team we have people with a wide array of expertise and different niches so if there's things that we don't understand [we can] bring someone in to help us with it. Also, many of us have been here for quite a few years so we've seen a quite a lot of these things come through in their different forms.

Q: It seems there's a customer-service aspect to what you do, or perhaps it's that you have customer relationships to manage.

Peter: Yeah, it comes up sometimes, both in the analysis, but also in the interpretation and reading a manuscript. And you know, sometimes you make suggestions and then you get the next draft, and they didn't take the suggestions and that's fine; they weren't that big of a deal. But other times they're like, "No," [and] you have to be more forceful, like, "Well, no, that's actually an incorrect interpretation, and it really needs to be changed." So, it's a balance; some suggestions are minor and take and leave it, but others are important things where you have to make a stand a little bit more forcefully. In a nice way.

Shamima: Diplomacy comes in.

Wendy: You have to really be careful and respectful in your dealings with people, but sometimes their ideas are too big and too feasible to do all at once, and their experience isn't there. So, you have to help them shape a project that is right-sized and feasible and with a high probability of success that they can build upon. You never shut an idea down. You just sometimes give them an alternative path of getting there.

Susan: Many times their scope is much too large, and you have to help them bring it down to a feasible size. Without squashing their dreams, right?

Wendy: For the most part, people are incredibly receptive, and particularly the younger or less experienced investigators who have this massive idea, "Ohh, I'm going to cure XYZ and I want to go straight and do this randomized control trial." I find I spend a lot of my time putting the brakes on and convincing people that really, they want to take this as a logical stepwise progression, building knowledge and expertise as they go and cut things up into manageable chunks so that their project will be



Wendy Craig, Ph. D., from MaineHealth's Center for Clinical and Translational Science, is a research navigator

feasible, successful. And they'll have more fun with it, you know? And it's particularly important when you're working with the trainee who's got a limited time frame in which to work on their project. They usually quite relieved to learn that there's a lower hanging fruit that they can start with. It's less overwhelming.

Matt: Yeah, I agree with Wendy on that. I had a student researcher who is currently trying to build a small app that guides surgeons through picking out the right device for cardiovascular stints. He doesn't have a lot of experience but was very receptive in learning about tabular data sets, how you would get that set up. He's currently working with the manufacturers to get all that data compiled and then we'll be able to put that in our data warehouse. And then from there you can go on to building the tool that he wants to use for our surgeons at [Maine Medical Center] so they can quickly pick out what they need for that patient.



Matt Williams, BS, of MaineHealth is a cloud engineer

And when you take the time to show [researchers] what is possible with technology, they get very excited about it. It's something that I enjoy doing and I think researchers are pretty apt to think outside the box and be receptive to new technologies and new ways of doing things.

Q: What projects or type of work do you especially enjoy?

Jonathan: I've really enjoyed working with Planned Parenthood of Northern New England. They've had some a couple of really interesting questions that they need help answering. Most recently, they did a study where, when you test positive for an STI, you're supposed to get retested and historically, those retest rates are pretty bad. So, they're just, they're trying to up those rates. And one of the ideas was mail-in test kits. And so the question is like did this work? That project's been really fun to work on.

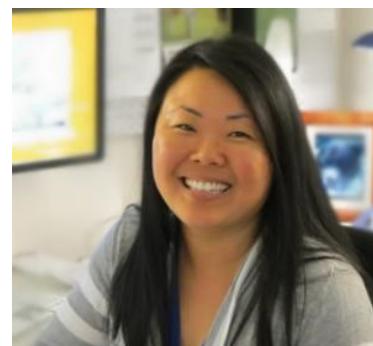
Peter: One thing I've really enjoyed is working with on the pilot projects and really both sides of it--the helping when people come with questions or help in trying to make it be a competitive application and then the other side of it, which is actually reviewing the projects and trying to weigh the strengths and weaknesses.

Derek: For me, just working on a COVID project with [David Kaminsky] has been one of the most fulfilling things and fun things. Just being able to add to the literature out there about COVID and long-term effects having to do with shortness of breath and whether or not there's other things associated like neurological [issues], I think it's just exciting and I think he's going to have a really good paper. I just feel privileged to be able to help him.

Deanna: I fell in love with data in design and so I started doing that kind of work, helping people transform data and best practices with data collection and things like that. I love it because you're always learning new things. You're meeting new people. It's just it's a really rewarding position

Q: What's your advice for people who want to put together a great Pilot Project proposal? When should they be in touch with you?

Peter Callas: The sooner the better. I think we all have stories about, well, mine



Deanna Williams, BA, of MaineHealth's Institute for Research, is a research naviga-

from this week was an email Monday afternoon for something that somebody needed Thursday. And that's why it's nice to be involved early in the project, like in the design phase rather than the, you know, "Here's the data, what can you do with it?" phase. Working with the pilot project applications is great and is a really strong function of BERD. That's what we're here for.

Some things we get involved in when they're just in the conceptual phase and or are vague. And then as you get closer to the letter of intent or the actual application, we get more specific with the details. But it's always nice to have some time to think about things so, at least a month ahead of time can be helpful. I always try to point out that the shorter the time frame, the more likely that errors will crop up because we don't have time to think it through.

Derek: I would second what Peter was saying about as soon as possible, because [if a researcher waits too long] it increases the chance of an error being introduced.

Q: What do you like about your job?

Matt: I've been doing data engineering and cloud engineering since 2014. I was a consultant before I came to Maine Health Institute for Research. Susan told me about her goals for the future state of our technological infrastructure. And I've found that fascinating. It's not as much fun programming machine learning models for, you know, drywall at Georgia Pacific or cargo. I'd rather support research that goes to help people and benefits their health.

Wendy: There's always something new and fun to learn about and it's not a burden; it's a privilege, really, to work with a big variety of subject areas. It's all about the person. It's all about the investigator and lifting them up, guiding them, helping them. It's wonderful to watch how people come along.

Susan: Yes, it's very stimulating. We do get a lot back. It's not that we're just giving; we're getting, too.

Deanna: Being able to consult and mentor and show someone best practices, for instance with data and then also have them teach me about some of their best practices in terms of their expertise, it really is a full-circle thing for me. And so I feel like I get as much as I give, and it's a really it's just a really fulfilling role.



Emmaline Ashe, MPH, of MaineHealth's Institute for Research, is a research navigator

Emmaline: Within this core there is that culture as well. [For example], Deanna and I have a lot of overlap in the work that we do and she has been so great in teaching me things and helping me, and I would say that about all of the navigators. That culture exists and it's really nice. So, thank you all.

Melissa: I have a very similar relationship with Wendy. She's always very generous about sharing her knowledge and what she does, but I think that the culture actually comes from the top down. So, this is an environment that I think has been created and it just grows because we have such a wonderful group of people.

Wendy: We do love each other. I'll just put that out there.



Pilot Projects Program



Meet Our Latest Round of Funded Researchers!

The Northern New England Clinical & Translational Research Network is pleased to announce our Round 7 Pilot Project recipients. As a result of their funding, these researchers are engaged in research to help improve the health of the residents of northern New England. Co-PIs of the NNE-CTR Dr. Gary Stein Dr. Cliff Rosen said, "Each year, through a competitive application process, projects are chosen based on their potential to make our region healthier and safer, and we are proud and excited about this year's recipients." The NNE-CTR's Pilot Project program funds a wide range of research topics. The application process opens each summer and closes in September.

Christopher Turner, MD, MPH, Director of Pediatric Trauma, Maine Medical Center

Dr. Turner's project is entitled, *Assessment of Firearm Owners' Opinions on Safe Storage in Northern New England*. Firearms are not always stored safely, resulting in injuries and fatalities, including suicides. Turner's project explores firearm owners' storage practices with the aim of guiding community-based strategies to create a safer gun culture in northern New England.



Meagan Stabler, Ph.D., Dartmouth Health

Dr. Stabler's project, *Northern New England Provider Insights and Participatory Engagement (NNE PIPE) Survey* has several goals, including understanding the needs of rural northern New England patients, promoting collaboration among clinicians, strengthening the NNE CO-OP Practice and Community Based Research Network's research capabilities, and better understanding the challenges and opportunities facing clinical practices.



Benjamin King, Ph.D., University of Maine

The basis for Dr. King's project, *Genetic Factors of Non-Diabetic Chronic Kidney Disease in Maine* is that while diabetes and hypertension are primary risk indicators for chronic kidney disease,, genetic factors may also contribute. This study will help answer this question.



Bikki Tran Smith, Ph.D., University of Vermont

Dr. Tran Smith’s project, *When Formal Supports End: Picturing Health Access for Afghan Refugees in Small Town Refugee Resettlement Communities in Vermont* explores “how race and ethnicity, class, politics, and immigrant status intersect within rural geography to produce health disparities and inequities among Afghan refugees living in small town resettlement communities in Vermont.” Tran Smith hopes to identify and shed light on the barriers to health access that result in poorer health

Niccolo Fiorentino, Ph.D., University of Vermont

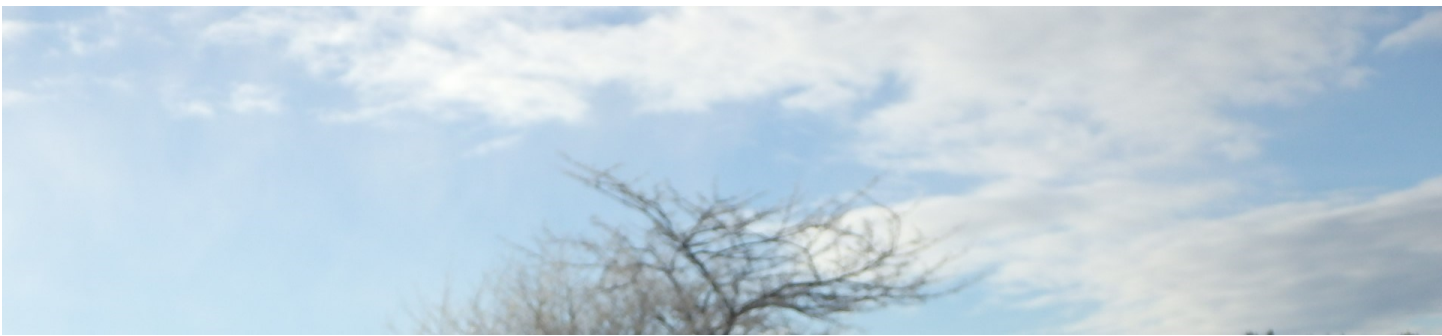
Dr. Fiorentino’s project is *Development and Evaluation of ErMo™, an Affordable DIY Power Mobility Device for Children with Neuromotor Disabilities*. Fiorentino’s team has developed a power mobility vehicle that helps children with cerebral palsy and other disabilities gain mobility at a critical time in their development. The goal is to provide a device that costs in the hundreds—versus thousands—of dollars to all caregivers.



Kahsi Pederson, Ph.D., MaineHealth Institute for Research

Dr. Pederson’s project is *Assessing a Mobile App-based Mindfulness Training to Improve Mental Health of Caregivers of Children with Autism Spectrum Disorder in Rural Areas*. She and her team are seeking to learn if a mindfulness app—requiring little time or investment of funds—can help decrease caregiver stress and lead to improved mental health.





What Are You Up to These Days?

Your work, your perspectives and your voice matter as we build our NNE-CTR community and seek to improve the health of our neighbors in northern New England. Do you have a story to share or work you would like us to write about? Let's put it in our newsletter. Email matthew.j.dugan@med.uvm.edu

