The Wisconsin Network for Research Support
Innovative patient and community engagement services for researchers

Stakeholder Engagement Inventory for CAIRIBU

July 2021

NIH-NIDDK
CAIRIBU

School of Nursing
UNIVERSITY OF WISCONSIN-MADISON

Institute for Clinical and Translational Research
UNIVERSITY OF WISCONSIN-MADISON

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ALBERT EINSTEIN COLLEGE OF MEDICINE

[Harold And Muriel Block Institute for Clinical and Translational Research at Einstein and Montefiore](#) (ICTR): Founded on the partnership between Albert Einstein College of Medicine and Montefiore Medical Center, the ICTR has helped cement that collaboration in clinical and translational research since 2007. The ICTR is a member of the nationwide Clinical and Translational Science Awards (CTSA) consortium, funded by the National Institutes of Health (NIH). The CTSA is designed to break down barriers that inhibit cross-disciplinary, bidirectional research from the laboratory to the clinic and back again.

Specific Services and Programs:

- Community Engagement Consultation & Collaboration Core: The Core is closely allied with the new Health Research Implementation Core to enhance community engagement with research that impacts health care. The Core works with The Bronx Health Link to expand collaborations and engagement with the Bronx community and healthcare partners. It helps advance life span, child health, and aging research across genders and special populations, by working with the Bronx Community Research Review Board. Finally, the Core innovates methods and processes that advance clinical research by linking with the Community Engagement Research Academy (CERA) to advance team science. Contact email: ictr@einsteinmed.org

- Health Research Implementation Core: The health research implementation core provides resources for designing and implementing research programs that efficiently translate effective strategies to improve health into practice in clinical settings and the community through expertise in patient centered outcomes research (PCOR), comparative effectiveness research (CER) and dissemination and implementation science (DIS). The core partners from the Montefiore CMO, the Office of Community and Population Health, and the Montefiore Medical Group. The HRIC also works with our practice-based research network (PBRN), and train clinicians in scientifically sound quality improvement and patient safety research. Contact email: ictr@einsteinmed.org

- [Trial Innovations Network](#): The Trial Innovation Network is a collaborative initiative within the CTSA Program and is composed of three key organizational partners – the CTSA Program Hubs, the Trial Innovation Centers (TICs), and the Recruitment Innovation Center (RIC). Email any questions or inquiries to Zoe Tsagaris, TIN Liaison Point of Contact: zoe.tsagaris@einsteinmed.org, 718-430-8804

CHILDREN'S HOSPITAL OF PHILADELPHIA (CHOP)

[Research Family Partners](): Research Family Partners assists study teams with writing community engagement plans for grant proposals; recruiting, training and supporting families serving on research teams or in advisory council roles; providing experience incorporating the patient and family voice in research; document review; helping with providing feedback in all stages of research including dissemination to the community. Specific services include:

- Assistance with writing engagement plans for grant proposals

- Access to families who are trained and interested in partnering with researchers

- Recruitment of families with specific backgrounds who are interested in collaborating with research teams, advisory councils, etc.

- Onboarding, training and support for patients and families to participate on the research team

- Support for meeting study community engagement requirements

- Experience providing the "family voice" to research

- Innovative ideas related to recruiting and engaging family partners and research subjects

Families participate on the research team as co-investigators or serve in a consultant/advisory role and help with:

- Providing feedback from the family/parent/child perspective

- Reviewing documents

- Providing input for all stages of research including:

  o Study design

  o Recruitment strategies

  o Study conduct

  o Dissemination of study outcomes

Training:

- Research family partners are trained using FYREworks *(Family, Youth, and Researcher Education)*, a set of interactive, web-based training modules and resources that prepare youth, parents, and collaborating researchers to establish, maintain, and operate PCOR partnerships.

- FYREworks is available to researchers, patients and families and can be found via [fyreworkstraining.com]()

The Recruitment Enhancement Core (REC): is a free service providing study teams with additional recruitment support. Services include recruitment strategy consultation for protocols and grant writing, recruitment strategy consultation for studies already in progress, writing and editing recruitment documents, IRB regulatory support related to recruitment, deploying recruitment emails/letters, tear pad advertising around CHOP's campus, submissions to This Week at CHOP and CHOP social media tools, utilization of Clinical Trial Finder advertisement and other resources to support study enrollment. We also support enrollment in the community and maintain a participant registry list of families who have indicated that they are interested in participating in research at CHOP.

COLUMBIA UNIVERSITY

CTSA: Irving Institute for Clinical and Translational Research:

The institute provides over 60 services and programs to Columbia University researchers and study teams, our community partners in upper Manhattan, and collaborators from other academic institutions, industry, and local and regional government. These offerings span all stages of the translational science spectrum from basic research to public health, and cover six broad categories including research support services, core facilities, funding opportunities, community engagement, seminars and workshops, and education, training and mentoring. The Irving Institute's main partners are New York-Presbyterian Hospital and the New York State Psychiatric Institute.

Leadership:

> Rafael A. Lantigua, MD
> Director; Professor of Clinical Medicine
>
> Elizabeth G. Cohn, RN, PhD
> Co-Director
>
> Alejandra N. Aguirre, DrPH, MPH
> Assistant Director

1. **Community Engagement Core Resource** (*services free – at least initial consultation*):

   > The Community Engagement Core Resource (CECR) promotes academic-community partnerships and public engagement in translational health research through outreach, education, informatics, training, and funding programs.
   > The Columbia Community Partnership for Health (CCPH), CECR's off-campus physical home in Washington Heights, provides free activity space for health-related programming to Columbia University researchers and not-for-profit organizations serving upper Manhattan. In addition, CCPH connects residents to health and social services, organizes health lectures, operates a bilingual health library, and facilitates access to health research.
   > CECR collaborates across Irving Institute resources, as well as with other CUIMC centers and multi-sector stakeholders in New York City.

   a. Off-Campus Activity Space in Washington Heights
      > The Columbia Community Partnership for Health (CCPH), is a unique and inviting, multipurpose space for conducting health research, health promotion activities, and research education and dissemination. CCPH is wheelchair accessible. In addition, CCPH connects residents to health and social services, organizes health lectures, operates a bilingual health library, and facilitates access to health research. The health library carries a wide selection of bilingual health information, reference books, and interactive materials. Starting in March 2020, we are also providing support for COVID-19 research.

b. <u>Consultations in Community-Engaged Research</u>

The Irving Institute's Community Engagement Core Resource (CECR) provides technical assistance to support Columbia University researchers and community stakeholders in carrying out community-engaged research, community-based participatory research, and dissemination and implementation science. Technical assistance includes:

- o Partnership Facilitation: Introductions between academic and community stakeholders for possible research partnerships.
- o Participant Recruitment: Assistance with potential sources for participant recruitment, including ResearchMatch, the data warehouse, RecruitMe, and our own research registry, which are all available to Columbia University researchers. We also post flyers and advertise research studies at the Columbia Community Partnership for Health.
- o Communications: Assistance with event promotion and research recruitment through digital signage, our email newsletter, and ad hoc email to community residents.

Starting in March 2020, we are also providing consultations for COVID-19 research.

c. <u>Study Promotion and Recruitment</u>

The Community Engagement Core Resource (CECR) provides assistance with research study promotion through potential sources for participant recruitment, including ResearchMatch, the data warehouse, RecruitMe, and our own research registry, which are all available to Columbia University (CU) researchers. We also post flyers and advertise research studies at our off-campus space, the Columbia Community Partnership for Health (CCPH).

CCPH Research Registry: CECR assists CU researchers with participant recruitment through the CCPH research registry. Individuals who are members of the CCPH research registry will receive information about studies that are recruiting in Harlem, Washington Heights, and Inwood. If they are interested in participating they may contact the researcher recruiting for the study and ask questions, check their eligibility and/or volunteer to participate.

Starting in March 2020, we are also providing support for COVID-19 research.

2. <u>Implementation Science Initiative</u>: *(services free – at least initial consultation)*

There is a well-documented gap between research (what we know) vs. practice (what we do), with only a fraction of evidence-based practices, interventions, and research findings routinely applied in real-world healthcare and community settings. Translating new public health and healthcare knowledge and research among practitioners, healthcare providers, patients, and the general public is complex, but critically important. The Implementation Science Initiative at the Irving Institute for Clinical and Translational Research, Columbia University's CTSA Program hub focuses on: 1) increasing awareness of and capacity for implementation science; 2) providing opportunities for education and training; and 3) facilitating research and collaborations in implementation science. We provide the Columbia Implementation Science seminar series with the New York State Psychiatric Institute, Working Group meeting, training and symposia, consultation services, pilot funding, and help build research capacity and connections.

a. <u>Implementation Science Consultation</u>
The Implementation Science Consultation service is provided by experts on dissemination and implementation science (D&I) and is available to inform research ideas, grants, papers, and abstracts. This includes consultation on D&I measures, study designs and methods, frameworks, strategies, and general tips for successful implementation science consultations. Consultation may also be provided on training opportunities and applications. Depending on the request, you will meet one-on-one for an hour with an implementation science expert and also have the opportunity to get feedback as 'work-in-progress' session with a group of D&I experts.
Starting in March 2020, we are also providing consultations for COVID-19 research.

3. <u>The Herbert Irving Comprehensive Cancer Center's (HICCC) Community Outreach and Engagement Office</u> (*Services provided at a fee, including translation to researchers outside of cancer*)
COE brings together a team of experienced researchers, clinicians and community health educators lead by Dr. Mary Beth Terry and managed by Ms. Kimberly Burke.

DUKE UNIVERSITY

The Duke Clinical Research Institute, part of the Duke University School of Medicine, is the world's largest academic clinical research organization. We conduct innovative research to deliver on our mission to share knowledge that improves health around the world. DCRI projects are led by physician scientists whose grounding in patient care helps to inform their research, and supported by staff who have deep expertise in operationalizing global studies.

Our Vision
To be the leading academic clinical research organization that:
- Generates world-class evidence to improve health;
- Creates novel methods that accelerate clinical research;
- Shares and implements knowledge widely;
- Develops the next generation; and
- Improves health equity through our research.

Our Values
At the DCRI, our values honor our history and guide our actions and daily decisions. Our values and our mission help us define what it means to be successful—as an organization, as individuals, and as a partner to our sponsors. Together, we are making tomorrow better than today—one patient, one question, one innovation at a time.

Stakeholder Engagement
All people – including patients, caregivers, community partners, and other stakeholders – bring value to clinical research and should be involved as partners in every stage of the research process. These stakeholders have the potential to impact every stage of the study life cycle, including design, funding, recruitment, protocol development, monitoring, data analysis, and FDA approval.
Our philosophy extends to the DCRI Research Together™ program which provides sponsors and investigators with access to DCRI thought leaders who understand the science of engagement.

Email DCRI-ResearchTogether@duke.edu or call 919-668-9210 to discuss your research needs and reach the appropriate engagement team.

- Incorporating Patient Perspectives to Create Valuable Research
- A Scientific Approach to Thanking Patients
- Redefining Outcomes with Input from Patients

Community Engaged Research Initiative (CERI): *Fostering community-ready researchers and research-ready communities*

Our Goals:
- Prepare researchers and diverse community stakeholders to cultivate meaningful and equitable collaborations on research opportunities to achieve better population health outcomes.
- Provide programs and tools to enable stakeholder-engaged research and spark collaborations and innovation.
- Improve knowledge and information-sharing to foster trust and transparency in research

Consultation Service:
- Assesses and addresses client needs and capacity to engage in stakeholder-engaged research via individualized consultations. Consultations are the entry point to all CERI programs and services.
- Provides recommendations to match stakeholder needs with resources, tools, and trainings that enhance capacity to partner in stakeholder-engaged research.
- Works with teams to make research more delightful and efficient for participants, and research innovations more sustainable and meaningful for those implementing research findings.
- Connects and facilitates partnerships between researchers and diverse stakeholders within and outside Duke, if needed.
- Offers guidance to researchers on how to conduct community tours that focus on the strengths and capacities of the neighborhoods served by Duke Health.

Community Consultation Studio (CCS):
- Facilitates stakeholder-influenced research by convening panels of community experts who resemble a study population to encourage targeted feedback about the study that will enhance feasibility and acceptability of study procedures.
- Leverages guidance and lived experience of stakeholders who help shape research by giving feedback on research protocols, recruitment materials, data collection procedures and instruments, web-based material, smart phone apps, retention plans, and dissemination of results.
- Compensates community experts for their time and expertise, while researchers receive detailed, written recommendations based on community consultant feedback.

e-Library of Community and Researcher Resources:
- Provides a curated list of searchable national resources for both community and academic research partners and advisors on stakeholder engagement practices, principles, and research.
- Includes trainings, videos, and other evidence-based resources to build capacity for research teams and communities to equitably engage in partnered research.
- Visit guides.mclibrary.duke.edu/CEnR.

Sparks Studios:
- Facilitates discussions convened with community groups, patients, researchers, and other stakeholders who work together around a single health topic in order to foster innovation.
- "Sparks" new and innovative ideas for stakeholder-engaged research that may be used to form partnerships to impact policy decisions or to develop research proposals that can be submitted to various funders ranging from private foundations to governmental opportunities.

Population Health Improvement Pilot Award Program:
- Promotes academic-community partnered research through an annual, multi-tiered competitive funding program designed to identify, support, and promote population health improvement research.
- Provides up to $25,000 in pilot project funding to foster community and academic partnerships to generate pilot data for future population health research proposals.

African Methodist Episcopal Zion Health Equity Advocates and Liaisons (AME Zion HEAL) Partnership:

18 North Carolina AME Zion churches and their pastors serve as partners, co-learners, and advisors to Duke Health's research programs to ensure that clinical trials participation accurately reflects all communities of North Carolina. The partnership is designed to:

- Foster health equity, reduce health disparities, and improve health in the African American community.
- Cultivate trust among people of color via dispelling myths and negative perceptions of clinical trials.
- Increase knowledge and minority participation in health research, and increase engagement in clinical research.
- Bridge the gap between medical development and community needs.
- Provide consultation and feedback on research protocols, design, implementation, and dissemination of research.
- Partner with researchers to enhance opportunities for HEAL-affiliated congregations to participate in research studies that align with partnership vision and health priorities.

CERI Stakeholder Advisory Council:

- Provides thought leadership and expertise on stakeholder engagement and research initiatives.
- Comprises diverse and engaged patient and community members, researchers, and leaders of community-based organizations and the broader health system.
- Acts as a think tank of community advocates and partners who assist in planning, advising, and enriching research.
- Increases awareness and education to diverse community stakeholder groups about research that affects the lives of the communities they serve.

Request CERI Services

MEDICAL COLLEGE OF WISCONSIN (MCW)

MCW Office of Community Engagement

The Office of Community Engagement at the Medical College of Wisconsin (MCW) is dedicated to leadership and excellence through community engagement and partnering with public and private organizations to enhance learning, research, patient care and the health of the community. Quick links to:
- Community Engagement Conference
- Community Engagement Resources
- Community Engagement Poster Session
- President's Community Engagement Award

Clinical and Translational Science Institute (CTSI)

The CTSI is an innovative infrastructure to support and advance education, collaboration, and research in clinical and translational science.

- **VISION**: To create a borderless, complementary and synergistic research environment in southeast Wisconsin to translate Office Odiscoveries into better health of our citizens while simultaneously providing comprehensive educational and training programs to develop the next generation of Clinical and Translational Researchers.

- **MISSION**: The mission of the CTSI, a unique academic-community partnership between four area academic institutions (Medical College of Wisconsin, University of Wisconsin at Milwaukee, Milwaukee School of Engineering, Marquette University; three hospitals (Froedtert Hospital, Children's Wisconsin; Zablocki VA Medical Center); and Versiti Blood Center of Wisconsin, is to develop an integrated, shared home for clinical and translational research, education and training, hallmarked by a borderless, collaborative, synergistic, and investigator/community/patient-friendly environment that is functionally integrated into local, regional and national CTSA networks.

Community Engagement Program

A primary focus of the Community Engagement Program is to overcome obstacles to community involvement in translational research, such as difficulty engaging the community in setting research priorities that affect patients; absence of trust of medical research by the community; lack of systematic methods to inform research of community perspectives before, during, and after the research process; and lack of coordinated recruitment for clinical and translational research through an informed community.

Specific programs and services:

- Community Engagement Consultation Service: Consultation is available with community engagement faculty to discuss meaningful engagement and inclusion of community in the research process.

- [Citizen Advisory Council](#): The Citizens Advisory supports interrelated, collaborative relationships between the key functions of the CTSI structure and provides new opportunities for faculty and students to expand work with communities
- [Citizen/Scientist](#): Working together, scientists, clinicians, and community advocates can improve the health of our community and bring research discoveries to the patient bedside and community.

UNIVERSITY OF MASSACHUSETTS – BOSTON

Our research, academic programs, and partnerships focus on addressing the many faces of health disparities—from access to undergraduate and graduate education to translational research centers. In addition to campus-specific strengths and talents, we work closely with our four sister campuses to combine and leverage our collective expertise when competing for grants from the National Institutes of Health, National Science Foundation, and the U.S. Department of Education, to name a few.

Below are details on just some of our biomedical, health, and life sciences successes and ongoing collaborations with our external partners. To learn even more, contact the Office of the Vice Provost for Research and Strategic Initiatives & Dean of Graduate Studies at 617.287.5614 or 617.287.5608.

- College of Science and Mathematics

- College of Nursing and Health Sciences

- Center for Personalized Cancer Therapy

- UMass Boston-Dana Farber/Harvard Cancer Center Comprehensive Partnership Program

- UMass Center for Health Equity Intervention Research

- UMass Center for Clinical and Translational Science

- UMass Boston Venture Development Center

UMass Center for Clinical and Translational Science

In 2010, the UMass Medical School received a prestigious $20 million award from the National Institutes of Health to create an academic home for clinical and translational science across all five UMass campuses—the UMass Center for Clinical and Translational Science.
UMass CTSA Community Collaboration and Engagement Core

Mission: To improve health in Massachusetts by developing and nurturing community engaged research that is fostered through equitable partnerships between our UMass campuses and their communities.

Resources include:

- The Community Engagement Research Section of the UMCCTS supports researchers and community partners in a variety of ways.
- Community Engagement Studios: A structured guidance session that engages community members, patients, and other non-academic stakeholders in biomedical and clinical research, where they may serve as expert consultants and provide feedback from a community perspective to enhance the relevance and utility of research projects.
- Resources for Community-Engaged Research: Offers links to a variety of resources and information related to community-engaged research.

UMass Medical School: Community Engagement Partnerships

Provides an overview of partnerships and resources to support community engagement.

UNIVERSITY OF ALABAMA AT BIRMINGHAM

Center for Clinical and Translational Science (CCTS)

The Center for Clinical and Translational Science (CCTS) was established in 2008 and is funded by a Clinical and Translational Science Award (CTSA) from the National Center for Advancing Translational Sciences (National Institutes of Health grant UL1TR003096). We are one of more than 50 CTSA programs nationwide and the only CTSA in Alabama.

The CCTS supports the development of authentic partnerships between researchers and the populations we serve.

- Engagement of Communities: Through our Engagement of Communities domain, we provide learning and collaboration opportunities to a wide variety of community stakeholders. Our aims are to foster trust, explore and establish shared research goals, and speed the translation of knowledge into health improvements for all. Specific programs and resources include:

  - One Great Community (OGC): Building on relationships fostered since the Center's inception, the OGC Community Action Board is a joint partnership with UAB's Center for the Study of Community Health and its CDC-sponsored Prevention Research Center. OGC provides a bidirectional flow of information among a broadly engaged team of academics, patients, health advocates, organizational leaders and residents in an effort to champion a shared mission and to guide scientific priorities that reflect community needs. OGC works with scholars and young investigators to shepherd community engaged and community based participatory research. It also works with project leaders to consider how to effectively integrate community input and involvement in future opportunities.

  - Community Health Innovation Awards (CHIA): The CHIA program supports community-led research projects led by organizations in the greater Birmingham area that fosters novel ways of thinking about challenging local health issues. Participants work collaboratively with local leaders, neighborhood groups, and the UAB community to develop their ideas into fundable project development proposals.

  - Community Engagement Institute (CEI): CEI represents a coordinated series of discussion venues that collectively strive to foster broadly engaged teams to build trusting relationships and to participate in respectful exploration of seminal and timely topics related to health equity, bioethics, and social justice. CEI has multiple options for interaction and learning. One event is an annual day-long symposium featuring panel discussions, plenary speakers, roundtable conversations and poster sessions. Recent symposia have embraced themes of intergenerational communication, inter-sectoral collaboration, and civil inclusion & empowerment. CEI also includes the CCTS's annual bioethics forum, which brings together researchers, bioethicists, students, community members, front-line research staff, and clinical staff to discuss ethical issues in research. Topics have included COVID-19, Respect in Research, Genomic Investigation &

Population Health, to name a few. CEI will also encompass the Community Heath Research Pipeline (CHRP), which is regular one-hour discussions surrounding topics related to current issues and research needs. Collectively, the CEI examines the importance of why and how community engagement and collaboration are effective in social/behavioral research and essential in community building practices. Drawing diverse participation from across the region and beyond, CEI provides an engaged venue and safe space to share perspectives and find common ground to work together.

- o Southern Commonweal: Our regional organization, integrates community engagement efforts across the CCTS Partner Network, a region that includes Alabama, Mississippi, and Louisiana, to define common challenges, share best practices, and align goals and activities whenever possible.

- o CCTS Training Academy: The CCTS Training Academy offers interdisciplinary, educational programs and enrichment activities for broadly engaged research teams. Topics include Diversity, Equity & Inclusion, Team Science and Clinical and Translational Research.

For more information, please contact:
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UNIVERSITY OF CA – SAN FRANCISCO/KAISER

USCF Center for Community Engagement (CCE): The CCE coordinates and facilitates UCSF community-academic-health/healthcare partnerships to promote civic engagement and foster health and well-being.

Specific services and programs:

- Consultation Services: We connect people with experts in order to develop research, health policy, interventions, evaluation design, and more. The timing and depth of the assistance we provide depends on many things, including the interest of partners and the resources available. Some examples of assistance we've provided include: helping policymakers develop health policies grounded in science and informed by community perspectives, and helping a community-based coalition develop an evaluation plan for a transportation and health services program. (First hour of consultation service is free.)
- Partnership Grants Program: Offers partnership grant funding to support projects that strengthen partnerships between San Francisco Bay Area communities (including Fresno) and UCSF partners to address health and healthcare inequities. All grants are intended to fund partnership projects and programs where community-based organizations and UCSF affiliates work together.

Clinical and Translational Science Institute (CTSI): The CTSI facilitates clinical and translational research to improve patient and community health. We do this by providing infrastructure, services and training to enable research to be conducted more efficiently, effectively and in new ways.

Specific programs and resources:

- The Community Engagement & Health Policy (CE & HP) Program supports research that investigates, plans, applies and evaluates solutions to pressing public health problems. It focuses on bridging academic research, health policy and community practice to improve public health.
- The Participant Recruitment program aims to bolster UCSF research by implementing programs and creating tools that allow research teams to meet recruitment goals with ease and efficiency. The programs aims to connect with campus and community stakeholders to assure programs meet the needs of our diverse research enterprise.
- Community-Engaged Research Consultation: Get advice on community based participatory research (CBPR)

UNIVERSITY OF MICHIGAN

Office of Patient Experience: The mission of the Office of Patient Experience is to promote and sustain the ideal patient experience through excellence in patient and family centered care. As a leading healthcare provider in the nation, Michigan Medicine seeks to improve the experience for our patients and families. We know that patients who have an ideal patient experience also have better outcomes. When they are listened to and understood, they are more likely to be engaged in their care planning and adherence to their plan. Better outcomes also result in lower overall costs and improves overall health of the population.

- Learning and Communication resources
- Patient and Family Advisory Councils: Patient and family advisors, volunteer patients and family members, share their stories, experiences, opinions and perspectives to help champion initiatives that create more patient-centric programs, operations, services and research.

UW Institute for Clinical and Translational Research (MICHR): MICHR is here to enable & enhance clinical & translational research at U-M and across the CTSA (link is external) consortium. We do this by being a catalytic partner who educates, funds, connects, and supports research teams here and beyond. Think of our helpful and knowledgeable staff as your extended research team.

MICHR offers 360° support for every stage of your research study. Research management services include: biostatistical design and analysis, multi-center project management, regulatory assistance, data management, informatics support, biorepository storage and specimen processing, and the Michigan Clinical Research Unit (MCRU) facility. MICHR has awarded more than $10M in pilot grants and offers free grant writing consultation, links U-M clinical researchers to the community and recruits volunteers for clinical studies, and offers a comprehensive curriculum of pre- and post-doctoral education programs for the next generation of clinical and translational researchers.

Specific services and resources

- Community Engagement Studios: The Community Engagement (CE) Studio provides an opportunity for researchers to enhance their research project during an interactive session with patients, caregivers, health care providers, community members, and other non-researcher stakeholders. A panel of stakeholders, whose characteristics are defined by the researcher, will be assembled to provide feedback to enhance your research project. The stakeholders who participate in studios are members of the population or community that the researcher wishes to involve in his/her research study. They are experts in their community's culture, literacy levels, translation needs, history, and past experiences with research.

During the CE Studio, researchers can gather input from his/her community of interest or patient group about:

- o Research project design
- o Informed consent development and the consent process
- o Incentives for research participation
- o Participant recruitment processes

- Developing culturally and linguistically appropriate study materials
- Understanding and interpreting research results
- Sharing research results with the community

Who can use this service?

- Anyone looking to strengthen their research idea and application as well as those currently conducting research with human subjects at U-M can use this service. This includes principal investigators, study teams, post-docs, K scholars, etc.

Community Partners: Our Community Engagement Program promotes new collaborations and projects that positively impact the health of communities. This is done through research focused on community-identified and defined priorities with community and academic partners.

What is Community-Engaged Research (CEnR): Are you a researcher looking to conduct studies that demonstrate clear impact on the health of local communities? Or maybe you're part of a community organization fighting for better health for you and your neighbors? What you need is each other—a reliable partner you can go to for resources and expertise, an equitable relationship based on trust and mutual goals. This is a key facet of what we call community-engaged research (CEnR), where academic institutions and community organizations come together to make real and lasting change in the form of practices, programs, and ultimately policies that mobilize resources and influence systems. Community-engaged research is a spectrum, and our Community Engagement program caters to the researchers, community organizations, and members interested in learning about or already conducting research inclusive of these values. Check out their virtual platform, M-REACH, and reach out to one of their experts for a consultation today.

Michigan Research Engaging the Academy and Community in Health (M-REACH): Information available on M-REACH is not limited to MICHR-sponsored activities; rather, it is meant to be inclusive of all major CEnR happenings across the state.

Features include:
- "Matchmaking" program for community organizations, members, and researchers
- Educational and funding opportunities
- Checkpoints with MICHR team members
- Calendar of CEnR-centric events hosted throughout Michigan

Sign up for MREACH here

Participant Recruitment & Retention Consultation: Whether you are in the planning stages of a future study or are struggling to recruit for a study that is already underway, MICHR can help you develop and review recruitment materials, identifying obstacles that may affect participant recruitment and retention. We can review existing recruitment material or help you create new material.

Who can use this service?

- Anyone conducting research with human subjects at U-M can use this service. This includes principal investigators, study teams, post-docs, K scholars, etc.

When should I contact MICHR about this service?

- o You may contact MICHR whenever you need recruitment help, but the best time is during proposal development

How much does this service cost?

- o There is no cost for this service. The cost pricing/recharge rates for this and other MICHR services are available here.

UNIVERSITY OF PITTSBURGH

The University of Pittsburgh Clinical and Translational Science Institute (CTSI) is an integral part of the National Institutes of Health (NIH) nationwide network that provides the support necessary to bridge the gap between innovative approaches to research and effective clinical and public health practice and policy.

- Get in contact with CTSI to learn more about research services, guides and tools, funding opportunities, and more.
- Stakeholder Engagement Resource Guide assists investigators in obtaining community feedback for their research projects.

Other resources:

Community Engagement

The Community PARTners Core supports nearly 200 ongoing member and organizational partnerships that encourage scientific findings to better human health and mental health. These relationships bring people together to collaborate, foster public trust, and ultimately promote health equity for all. For researchers, the community engagement team helps develop studies that address the complex health questions about which community partners state are most concerning. We provide training, as well as funding for research development and partnered data collection. For community organizations, we assist with providing evidence-based research interventions and practices. We assist communities with getting the word out on health research awareness and education.

Community Health Series Partnership

CTSI's Community PARTners Core, the Urban League of Greater Pittsburgh, the New Pittsburgh Courier, and the UPMC Center for Engagement & Inclusion collaborate on a monthly printed and online health page in the Courier, a Lunch and Learn series in the downtown Urban League location, and a newly launched quarterly Dinner and Dialogue series held in the University of Pittsburgh's Community Engagement Centers. Aims for this unique, ongoing partnership between academics, the community, a health system, and local media include community health education and advocacy, increasing minority participation in clinical and translational research, and encouraging individuals to become empowered and actively engaged in their own health.

CPRET

The Community Partners Research Ethics Training was designed to help Principal Investigators to tailor research ethics training for their specific studies and to encourage dialogue with community members who will participate on the research team. This training is particularly relevant for investigators engaged in clinical and translational research involving community stakeholders. Investigators have the opportunity to create and discuss scenarios that may arise in the course of their specific study while ensuring that Core research ethics principles are defined and reviewed.

E-Newsletter

The bi-monthly electronic newsletter highlights CTSI programming, community partnerships, internal and external events, and leadership profiles. To be added to the mailing list, please e-mail bee.schindler@pitt.edu.

Stakeholder Advisory Board

The CTSI Stakeholder Advisory Board is comprised of diverse stakeholders from the community who serve for a minimum of two years. The SAB serves as a forum for bidirectional communication between researchers and the community in every phase of the research process. The SAB will guide investigators in understanding the challenges and gaps that can lead to disparities in research participation, especially for diverse populations. The group works together to inform design of participant engagement strategies, including awareness and education; and advise on enrollment strategies to reach and retain broad spectrum of the community with emphasis on diverse populations and marginalized communities.

Stakeholder Engagement Resource Guide

Community PARTners and Comparative Effectiveness Research Core leaders have developed a Stakeholder Engagement Resource Guide to assist investigators who are interested in community-engaged research.

Urban League Health Advocate Program

The Health Advocate provides a link between the Urban League of Greater Pittsburgh staff and clientele, the local community and researchers of health sciences in the Pittsburgh region. The Advocate carries out the daily tasks associated with the Urban League's health outreach and education efforts, and prioritizes community health needs in programming, to ensure that the priorities of the community are conveyed to CTSI partners. To facilitate connections and partnerships, this position is located at the Urban League of Greater Pittsburgh where the Health Education Office provides information to their clientele across the lifespan, care navigation services, and information about and connection to relevant health research.

WORDOUT Grant

Annual grant funds awarded to community organizations to engage in research dissemination by working with researchers to spread information and knowledge gained through research that many people can understand. Research findings can take up to 17 years to reach communities. This is too long! By partnering together, communities can hear about the latest research and best practices that affect the health of those they care about. This understanding can encourage people to use the best practices and make the best decisions about their health. Ultimately, this can build healthier communities.

Youth Research Advisory Board (YRAB)

The Youth Research Advisory Board (YRAB) is a diverse group of 15- to 26-year-old teens and young adults who meet monthly to offer a youth perspective to interested researchers and community partners about adolescent research. Members provide feedback on how to engage young participants in research and offer suggestions to help researchers communicate efficiently and transparently with youth participants.

For researchers:

The primary purpose is to provide insight and feedback for researchers investigating questions that pertain to the health and well-being of adolescents and young adults. The group typically meets during the school year on the first Thursday of every month from 6-8 p.m. in the second-floor conference room at the UPMC University Center. It starts with dinner and introductions, and then the researchers have 60 to 90 minutes to present and receive feedback from members.

Contact Shiva Rahman (rahmansa@upmc.edu) if you are a researcher interested in presenting.

CTSI Recruitment Services

CTSI recruitment facilitators are available to meet with study teams to develop participant recruitment strategies, provide an overview of recruitment tools, resources, and methods, and assist with using social media to promote research studies.

Learn more about the CTSA Recruitment Services, including Pitt+Me (a recruitment program designed to engage potential participants in research. The centerpiece of Pitt+Me is a research registry with over 200,000 potential participants who have signed up to learn about research studies through the Pitt+Me website and email.)

UNIVERSITY OF TENNESSEE HEALTH SCIENCE CENTER (HSC)

The Tennessee Clinical and Translational Science Institute (TN-CTSI) stimulates the discovery and translation of biomedical research into clinical practice to improve population health through a diverse set of services and resources. By providing critical education and training, funding opportunities, resources, and interdisciplinary expertise, TN-CTSI helps clinical and translational researchers advance their discoveries and develop novel therapies aimed at improving health care for all.

Contact the CTSI for more information:

> Phone: 901-448-CTSI (901-448-2874)

> Email: tnctsi@uthsc.edu

Recruitment Innovation Center

We are dedicated to supporting recruitment and retention of research participants through a variety of mechanisms including use of Electronic Health Records (EHRs). With our strong community connections and positive regard for conducting clinical and community-based programs, we have been extremely successful in previous research studies in recruiting and retaining diverse underserved population groups. We understand the importance of community engagement for successful recruitment and retention, and relying on a multifaceted approach using novel tools and methods to reach the whole population of our catchment area. Our plan to support recruitment and retention of participants will be using enhanced continuous improvement methods while aligning with our community engagement initiatives

Patient/Community Engagement

There is limited information available through either the HSC or CTSI about services or resources specifically intended to support patient or community engagement.

UNIVERSITY OF TEXAS SOUTHWESTERN

UTSW Center for Translational Medicine

The Center for Translational Medicine (CTM) provides services that promote a vibrant translational research and training environment at UT Southwestern. Since 2007, resources provided by the CTM have facilitated the training of 1,105 translational scientists who published more than 3,976 original manuscripts and successfully competed for more than $137 million in extramural funding from federal and non-federal sources.

Our programs accelerate the integration of research into practice locally, regionally, and nationally. Examples of our services include:

- Clinical Research Unit (CRU)
- Community Engagement and Population Science
- Participant Recruitment and Retention
- Pilot Funding
- Study Design and Data Management Tools
- Research Education and Workforce Development

We seek to support research teams in their efforts to develop, demonstrate, and disseminate best practices that improve replicability and efficiency of clinical and translational research and multisite clinical trials. The CTM strongly believes in the importance of team science to improve our nation's health in a safe, ethical, and responsible manner that ensures an individual's well-being and the public's trust.

Center for Patient-Centered Outcomes Research

Based at UTSW CTM, the Center for Patient-Centered Outcomes Research provides a wide variety of services, including:

Stakeholder Engagement: The Stakeholder Engagement Cluster provides assistance with stakeholder engagement, the process of soliciting knowledge, experience, judgment, and values of those interested in an issue.

The cluster is led by Simon Craddock Lee, Ph.D., M.P.H., Associate Professor in the Department of Clinical Sciences. Dr. Lee is a medical anthropologist with expertise in qualitative and mixed methods research. Dr. Lee's own research focuses on cancer health disparities in safety-net settings.

The Center for Patient-Centered Outcomes Research has also partnered with Johns Hopkins University to provide expertise to trainees and faculty in one of their areas of strength – stakeholder engagement – as well as systematic reviews, meta-analysis, and pharmacoepidemiology. We will present a video conference of the monthly Johns Hopkins University Evidence-Based Practice (EPC) journal club and DeCIDE/Center for Health Services Research and Outcomes research conference.

The PCOR center also coordinates meetings with a [Community Advisory Panel.](#)

In 2015 the PCOR Center established the Community Advisory Panel (CAP) as a resource to UT Southwestern researchers for soliciting patient stakeholder engagement in their projects. The CAP is a 12-member group of Parkland Health & Hospital System (PHHS) patients and patient stakeholders who meet *ad hoc* to help researchers explore design, implementation, and interpretation of their projects from the patient's perspective. Active patient stakeholder engagement in research is a core commitment of the PCOR Center.

Any researcher may meet with the CAP. While they are not a scientifically representative sample of communities served by PHHS, the group includes diversity across race, culture, age, and healthcare utilization. Meetings are scheduled as needed. The CAP has advised researchers on a broad range of studies and projects.

To further explore meeting with the CAP, contact Bryan Elwood, by [Email](#), or Phone: 214-648-8487.

[Community Engagement & Research](#)

As another CTM resource, the Community Engagement Program's focus is to develop means of reducing disease causality in under-served communities by integrating, supporting, and expanding existing and developing new collaborative relationships between researchers and communities. This includes the following activities.

Partnering with various community constituencies to identify and address health needs by:

- Helping community-based organizations assess needs among their constituencies;
- Providing technical assistance for planning interventions and evaluation designs;
- Partnering with new organizations to expand community-engaged work, especially reaching out to English- and Spanish-speaking Hispanic populations; and
- Setting up mechanisms to share research results with community members while continuing and extending our ongoing partnerships and projects.

Linking community members' need for health promotion with community-based health care services by:

- Facilitating members' access to sources of primary care;
- Enabling community clinics to participate in health promotion efforts such as vaccine promotion or smoking cessation interventions; and
- Providing follow-up care for people whose research participation may lead to identification of a medical problem.

Enhancing fair and equitable opportunities for community members' participation in translational research by:

- Launching new initiatives to expand a [community-based research registry](#), including under-served groups in research; and
- Deploying a [Spanish Language Validation Resource](#) ** to expand research participation opportunities.

Building capacity for culturally sensitive, community-engaged research by:

- Expanding training for Clinical Scholars;
- Enhancing opportunities for pre- and postdoctoral students' summer research and practica;
- Facilitating and funding pilot applications for community-engaged research; and
- Providing consultation and technical assistance for investigators seeking to conduct research which addresses the three above-listed goals.

For more information about Community Engagement & Research, contact Robert D. Toto, M.D., Associate Dean, Translational Research and Education; Phone: 214-648-2600; Email.

Spanish Language Translation Support

The Spanish Language Validation Committee uses a multistep, systematic process to review Spanish-language study materials, ensuring they are culturally appropriate, accessible to low-literacy populations, grammatically correct, and conceptually equivalent to the English versions.

The Committee places a special emphasis on making sure the literacy level of materials is basic enough to be accessible to a wide range of participants. Though translation agencies provide a good starting point for Spanish-language materials, the Spanish Language Validation Committee ensures these translations are delivered accurately and use "broadcast Spanish" that can be understood by Spanish-speakers from different countries/backgrounds. This is particularly important given the socio-demographic characteristics of patients participating in many studies at Parkland Hospital and UT Southwestern Medical Center.

For more information contact: Magalis (Zamantha) Tijer; Spanish Language Validation Resource Coordinator; Phone: 214-648-7971; Email.

Recruitment and Retention Resources

Recruitment of clinical trial volunteers can be one of the most challenging and time consuming parts of a research study. The Research Recruitment and Retention Resources team at the Center for Translational Medicine strives to work with study teams to develop and implement innovative recruitment strategies to recruit clinical trial volunteers in North Texas by utilizing recruitment best practices.

Our no-cost services include:

- Assistance with developing a recruitment plan
- Creating and implementing study advertisements
- Cohort identification
- Recruiting participants from the Volunteer Research Participant Registry

Learn how we can help you facilitate participant recruitment and retention by calling 214-648-5005 or Email.

UNIVERSITY OF WI-MADISON

UW Institute for Clinical and Translational Research (ICTR)

The goal of the University of Wisconsin Institute for Clinical and Translational Research (UW ICTR) is to create an environment that transforms research into a continuum from investigation through discovery and to translation into real-life community practice, thereby linking even the most basic research to practical improvements in human health.

Through the interdisciplinary nature of the ICTR (Schools of Medicine and Public Health, Nursing, Veterinary Medicine, Pharmacy) and the College of Engineering, the mission is to change the UW culture from "silos" to collaborations among ICTR members and within the entire university. With this UW team and ICTR's northern partner Marshfield Clinic, our Institute expects major advancements in clinical and translational research.

ICTR Community-Academic Partnerships (CAP)

The Community-Academic Partnerships (CAP) core is organized as a federation; 41 UW and Marshfield programs and centers currently participate. CAP mobilizes resources across UW and Marshfield by:

- **Centralizing and organizing access for investigators and communities** to diverse community- and practice-based research networks and an array of research and training resources.
- **Creating new community- and practice-based research networks** where there is a strong interest from community partners, a critical mass of investigators, and opportunities for grant funding.
- **Creating or adapting research and training resources** targeting gaps in methodological and content expertise identified by communities and investigators.
- **Implementing incentives (primarily via pilot funding)** for community-partnered research, for investigator/community use of research resources, for senior investigators to mentor new investigators, and for collaborative and interdisciplinary research.

Stakeholder Engagement Resources

Several CAP Programs & Affiliates provide research resources to support engaging patient and other stakeholders in their research. Detailed information on the resources these CAP programs provide for stakeholder engagement in translational research is available on our Stakeholder Engagement Resources page.

For help determining which ICTR stakeholder engagement program is the best fit, please contact Kate Judge, MSSW, kjudge@wisc.edu.

The Community Advisors on Research Design and Strategies (CARDS)®

is a unique service available at the UW-Madison and is an exciting way to get valuable, candid feedback on how to make research materials clearer, more engaging and easier to read for people in your project. Community center staff recruit CARDS® members from center programs such as senior meals,

women's groups, food pantries, and parenting programs. Members complete an orientation program and draw on their lived experiences to offer researchers actionable feedback on any public- or patient-facing materials, including recruitment letters/brochures, consent forms, smart phone apps, website, focus group/interview questions and more. The CARDS® bring valuable perspectives from diverse racial, socioeconomic, and educational backgrounds.

For more information about the CARDS service, contact Kat Phelps at kephelps@wisc.edu

Stakeholder-Engaged Research

ICTR offers an array of funding opportunities, including awards for investigators interested in patient- and stakeholder-engaged research. These pilot funds support development of strong stakeholder engagement strategies needed for grant applications to PCORI or AHRQ. Previously funded projects are described here.

Tools & Toolkits

Our team of UW experts has developed several downloadable toolkits for engaging patients and other stakeholders in research. Click here to explore the *Tools for Stakeholder Engagement in Research* available on **HIPxChange**, an ICTR-CAP dissemination portal.

VANDERBILT UNIVERSITY

Vanderbilt Institute for Clinical and Translational Research (VICTR)

VICTR functions to help researchers and clinicians do their jobs better by providing tools and support to improve the quality of research, publications, grant writing, and training for future doctors and researchers. This is accomplished using a multi-faceted approach:

- Through collaboration with a wide variety of research partners

- By training, nurturing and rewarding participating researchers

- By funding research

- By developing new and innovative ways to involve the community in research

- By developing new informatics and biostatistical systems

- By making available the latest technologies and sound research results affecting patient care

The Community Engagement and Research Core (CERC) is a partnership between Meharry Medical College and the Vanderbilt University Medical Center which brings academic and community partners together to improve community health and healthcare through research. CERC shapes and supports innovative and translational community-engaged research by preparing scientists to impact the public's health, building the capacity for communities to engage in research and creating transformative strategies and structures to support academic-community partnerships

CERC offers a wide range of consultative services to support researchers conducting community engaged research. Assistance is available for all phases of community engaged research including project planning, study design, implementation, data collection, data analysis, translation and dissemination.

Community Involvement Resources:

To request resources, please complete our resource and consultation request.

- CERC Mini-Grants
- Community Engagement Studios
- Consultations on Community Engaged Research
- Communityresearchpartners.net
- Community Scholars
- Research Training for Community-Based Organizations
- Research Training for Community Members

Training and Education Resources:

- [Training Modules](#)

- [Qualitative Research Core](#)

VICTR also offer support for effective dissemination ("getting research results to the people who can benefit from those findings.") Find out more about VICTR dissemination resources [here](#).

Other useful resources:

[The Office of Health Equity (OHE)](#) serves as an institutional home for coordinating and catalyzing health equity initiatives across VUMC and in the community. We prepare future health leaders to promote health equity. Contact us at **OHEinfo@vumc.org**.

Community & Population Health: We create partnerships to improve community and population health and advance health equity. [Learn More](#)

Research: We foster research that addresses health inequities, facilitate academic/community partnerships, and provide trainings around community-engaged research. [Learn More](#)

Education & Training: We prepare future health leaders to promote health equity. [Learn More](#)

Recruitment Innovation Center (RIC) is focused on becoming a successful, evidence-based Center in recruitment and retention strategies in order to improve both the quality of future clinical trials and to raise awareness of the value of research thereby increasing trial enrollment and health outcomes across America. We work in partnership with researchers/study teams to provide tailored support and advice. Investigators and study teams can either submit for initial consultations or specific RIC resources. During an initial consultation, we will work with the study team and the relevant experts to troubleshoot, provide advice, guidance, and recommendations. Contact us at [info@trialinnovationnetwork.org](#)

RIC core resources:

- [Community engagement studio](#);

- [Recruitment planning and feasibility assessment](#);

- [Recruitment materials](#);

- [EHR-based cohort assessment](#);

- [Expression of Interest (EOI)](#).

We will tailor our support around your needs – this includes agreeing on specific areas of focus and basing our recommendations/advice on the specific recruitment and retention challenges associated with your study.

RIC Community Advisory Board (RIC CAB) is comprised of 12 members who represent various urban and rural geographical regions across the U.S. The CAB members also represent a broad spectrum of communities they have worked with closely over many years. They offer perspectives of diverse

populations, including those who are underrepresented in clinical and translational research (e.g., African Americans, Native Americans, Hispanics/Latinos, Asian Americans, LGBTQ, immigrants, persons with disabilities). Read more about the RIC CAB.

The RIC Download brings together all the latest news in recruitment and retention, conference proceedings, papers, and training events, this online bulletin is a quick and easily accessible summary of what is happening in the world of clinical trial recruitment. The bulletin is published every two weeks. Past Issues of The RIC Download