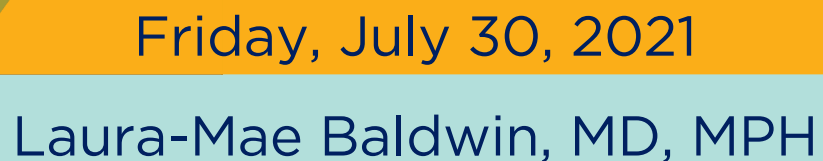


An illustration of a black funnel pouring into the top of a stylized orange head. The funnel contains various mechanical and scientific symbols: gears, wheels, arrows, a lightning bolt, a flame, and a triangle. The background is divided into three horizontal bands: light green at the top, yellow in the middle, and light blue at the bottom. The head is positioned in the lower left, with its eyes closed and a serene expression.

Introduction to Clinical Research **Boot Camp 2021**

Investigators
July 26-30
12:00-1:00pm PDT

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*With thanks to Linda K. Ko, PhD; Tumaini Coker, MD, MBA;
Kimlin Tam Ashing, PhD; Larkin Strong, PhD, MPH*

Learning Objectives

1. Identify different levels of community engagement and the benefits and challenges of engaging community in research
2. Name best practices and available tools for establishing a community partnerships
3. Connect with different types of ITHS-supported community networks

Agenda

1. Define community engagement
2. Discuss the spectrum of community engagement in research
3. “Chat” about the benefits and challenges of community engagement
4. Present best practices for partnering with communities in research
5. Share ITHS-supported resources to jumpstart partnerships with communities for your research
6. Questions and further discussion

Poll Questions

Understanding your
research and your
experience with
community
engagement



Credit: University of Washington- Bothell/KWA partnership, Lynnwood, WA

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What is Community Engagement?

- The process of working collaboratively with and through groups of people affiliated by geographic proximity, special interests or similar situations to address issues affecting the wellbeing of those people (CDC)
- Community: any entity outside of an academic institution

Why Engage Communities in Research?

- Effective interventions often don't get translated into practice
- Health disparities have been persistent across populations and settings
- Research teams lack expertise in working with the communities their interventions aim to serve



Spectrum of Engagement

Increasing level of community participation in research



Adapted from CDC, Principles of community engagement, 2nd ed. 2011

Chat Discussion!

Use the chat box to share your ideas about questions I'll pose regarding benefits and challenges to engaging communities in research

Benefits and Challenges to Engaging Community in Research

- What are the benefits to investigators of engaging a community in a research study?
- What are the benefits to communities of engaging in research?
- What is challenging about engaging a community in a research study?

Benefits of Engaging Communities in Clinical and Translational Research

“Better Science”

- *Improve the research design, reach, efficacy and effectiveness*
 - *Ensure researchers meet the needs of diverse research participants*
-

“Better Answers”

- *Improve translation of evidence to practice*
 - *Enhance relevant, effective, scalable interventions*
 - *Bring about health improvement and community activation*
-

And...

- *Increase community trust in academic/scientific institutions and research receptivity*
-

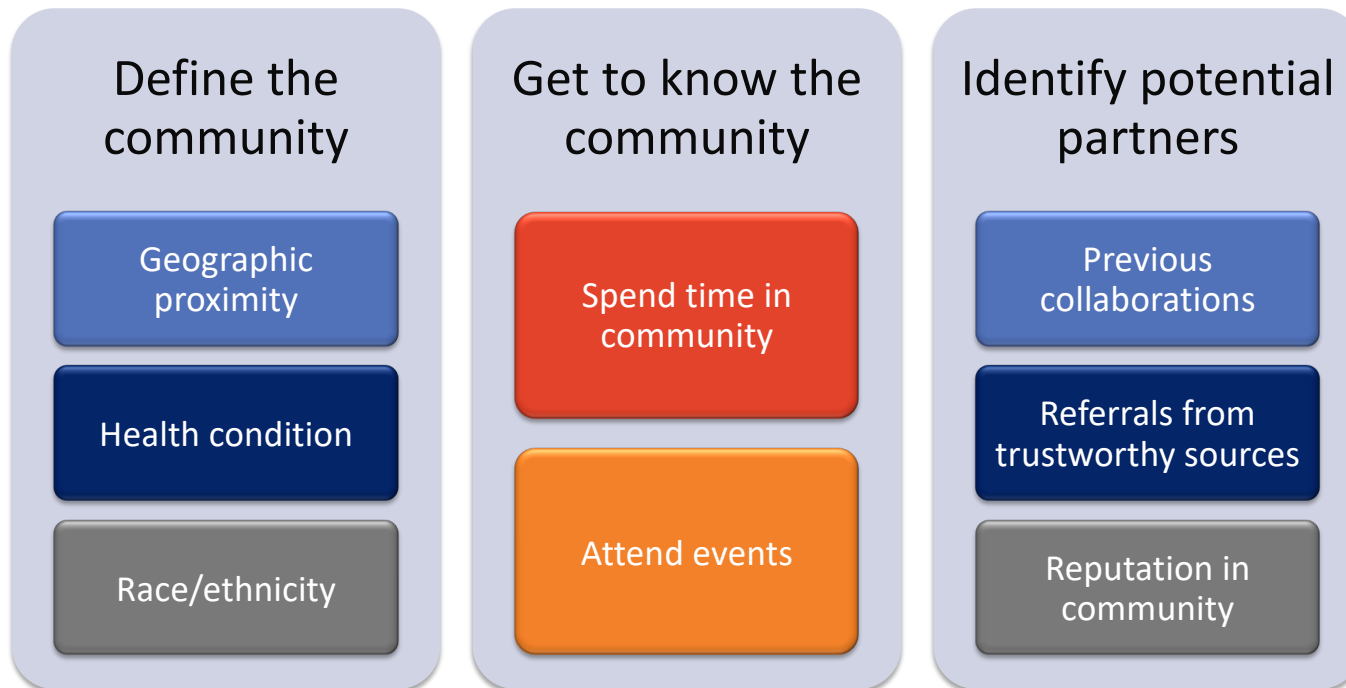
Best practices for partnering with communities in research

- Identify and engage a partner
- Make sure your project fits with the partner's vision and mission
- Create structures, policies, and processes to support and maintain the partnership



Credit: Korean Community Services of Greater Washington DC, Annandale, Virginia

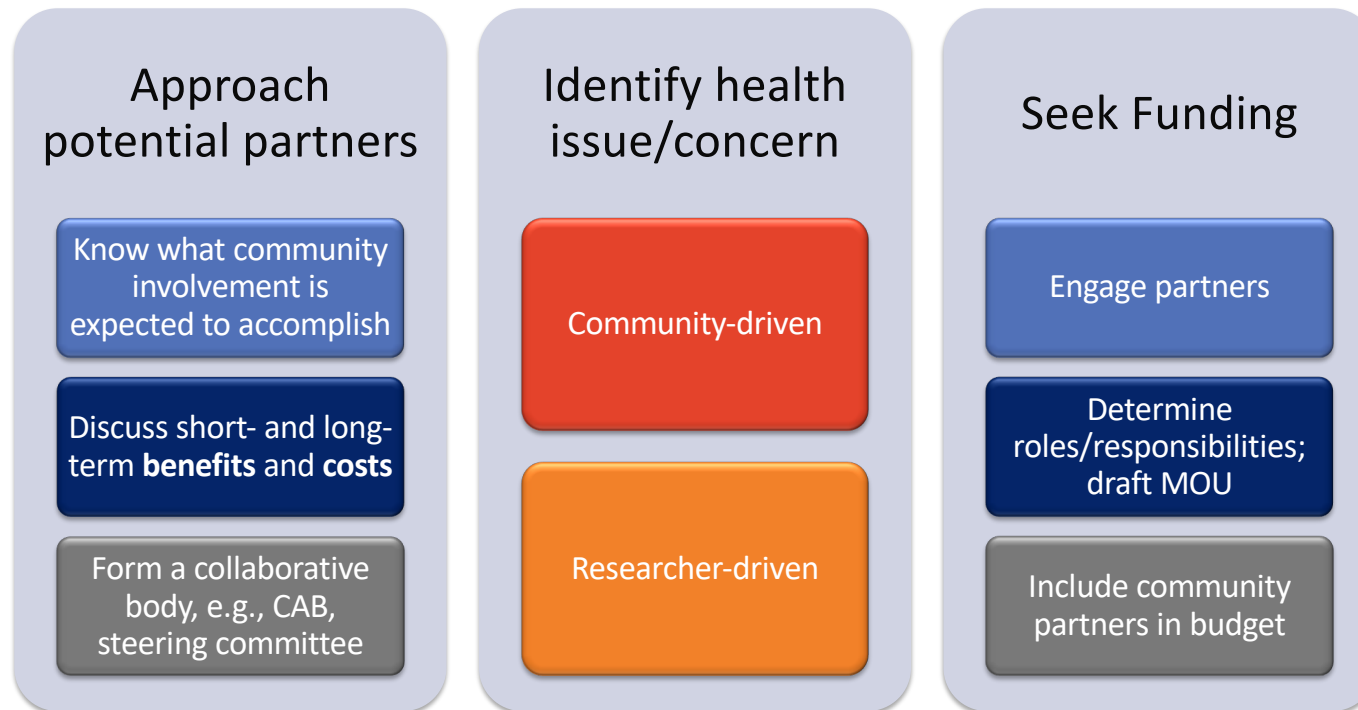
Where to Begin



Characteristics of Effective Partners



Moving Forward



Best Practice Resource for Communities



Step 1: Decide which projects to learn more about

Step 2: Plan your Research Project Engagement

Step 3: Create a Memorandum of Understanding

<https://www.iths.org/community/partners/isp/>



Best Practice Resource for Investigators: Working with Clinical Settings

ABOUT PRACTICE-BASED RESEARCH NETWORKS

Guidance for Researchers Developing and Conducting Clinical Trials in Practice-based Research Networks (PBRNs)

*Rowena J. Dolor, MD, MHS, Kristine M. Schmit, MD, MPH,
Deborah G. Graham, MSPH, Chester H. Fox, MD, and Laura Mae Baldwin, MD, MPH*

Background: There is increased interest nationally in multicenter clinical trials to answer questions about clinical effectiveness, comparative effectiveness, and safety in real-world community settings. Primary care practice-based research networks (PBRNs), comprising community- and/or academically affiliated practices committed to improving medical care for a range of health problems, offer ideal settings for these trials, especially pragmatic clinical trials. However, many researchers are not familiar with working with PBRNs.

Methods: Experts in practice-based research identified solutions to challenges that researchers and PBRN personnel experience when collaborating on clinical trials in PBRNs. These were organized as frequently asked questions in a draft document presented at a 2013 Agency for Health care Research and Quality PBRN conference workshop, revised based on participant feedback, then shared with additional experts from the DARTNet Institute, Clinical Translational Science Award PBRN, and North American Primary Care Research Group PBRN workgroups for further input and modification.

Results: The “Toolkit for Developing and Conducting Multi-site Clinical Trials in Practice-Based Research Networks” offers guidance in the areas of recruiting and engaging practices, budgeting, project management, and communication, as well as templates and examples of tools important in developing and conducting clinical trials.

Conclusion: Ensuring the successful development and conduct of clinical trials in PBRNs requires a highly collaborative approach between academic research and PBRN teams. (J Am Board Fam Med 2014; 27:750–758.)

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Best Practice for Creating Partnership Boards

- Many Academic-Community Partnerships may choose to establish a “Board” to oversee and guide the work of the Partnership, such as a Community Board, Advisory Board, or Steering Committee
- Include key representatives of the institutions and community organizations and/or communities involved



WHAT IS A COMMUNITY ADVISORY BOARD?

A community advisory board (CAB) is a group of individuals who are brought together to guide, respond to, and make recommendations for projects that influence a community. Each CAB member brings unique knowledge and skills to the CAB.

The **mission** of the CAB is to identify problems, develop solutions, and assist, where possible, in the implementation of programs that address community problems. CABs are generally formed of people who are concerned about a community problem and may be working together to help address the problem.

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Best Practices in Funding Community-Engaged Research

1

Share the funds!

2

Be mindful of the operations costs incurred by community organizations

3

Consider utilizing community resources for staffing

4

Be transparent with your community partner

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ITHS Community Engagement Program's Community-affiliated Research Networks

Community Health Network



A collaborative group of community-based organizations

Patient Advisory Network



Patients and families

Northwest Participant and Clinical Interactions Network



Specialty inpatient and outpatient clinicians and clinical organizations

WWAMI region Practice and Research Network



Primary care providers and clinics

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Community Health Network

A collaborative group of community-based organizations committed to addressing community health priorities



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Community Health Network

Collaborative Community Based Organization Partners

- 6 Hospitals/Clinics
- 27 Social & Health Services
- 5 Recreation/Gyms
- 4 School Districts
- 3 Churches/Ministries
- 1 Radio/Outreach
- 2 Food Banks/
Farmer's Markets



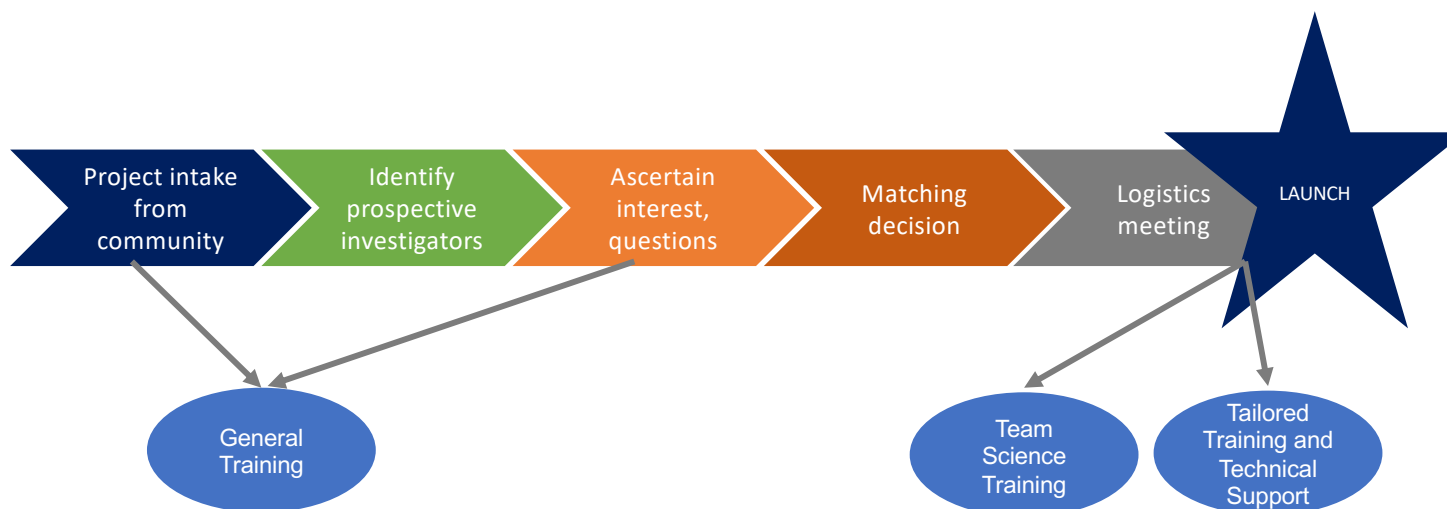
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Examples of research affiliated with the Community Health Network

- Community Needs Assessment among the Hispanic Community
- Adaptation of the delivery of the Check, Change, Control Blood Pressure Control intervention from in-person to telephone-based for Asian Americans
- Implementation of the Healthy Eating Healthy Aging Project among community-based organizations serving older Asian Americans
- Feasibility and acceptability of the Thirsty for a Smile - Dental Caries Project among Hispanic children
- Recruitment of community representatives for a rural cancer coalition.
- Longitudinal study to examine food environment, diet, and physical activity in King, Pierce, and Yakima Counties
- Impact of COVID-19 on community-based organizations' ability to provide services to older AANHPI adults

Community Voices: Community-driven health needs and ideas



Community Voices:

- Solicits project ideas and needs from community partners
- Maintains a list of academic investigators interested in collaborating with community partners
- Facilitates matches between communities and their projects and interested investigators at academic institutions

Connect with the Community Health Network if you are interested in:

- Seeking assistance in developing collaborative relationships with community-based organizations for specific grants or projects
- Learning about community engagement methods
- Looking for opportunities to meet and explore partnerships with community-based organizations
- Gaining access to tools and resources for conducting research in community-based organizations

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CERTAIN Patient Advisory Network

A network seeking to improve research by providing a way for **patients, caregivers, and family members** to work in collaboration with researchers throughout the research process



PATIENT
ADVISORY
NETWORK

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Online library of resources for patients and investigators

PATIENT ADVISORY NETWORK
CERTAIN

Home About Find Resources Create an Account/Login

INSPIRE Research Portal

Strengthen Diversity in Research Partnerships
Explore best practices in developing partnerships with under-represented individuals and communities in research.

Learn More

Find Resources

Search

Keyword(s)

Resource Type

- Organization
- Reference Materials
- Training Materials

Topics

- Advisory Panels
- Budgeting
- Communication/Dissemination
- Engagement Experiences
- Engagement Recommendations

Audience

- Caregivers/Family Members
- Community/Advocacy Organizations
- Patients/Consumers
- Researchers

Condition

- Alopecia Areata
- Asthma
- Cancer
- Celiac Disease
- Heart Disease

Format

- Video
- Website/Webpage
- Written Document (PDF, etc.)
- Other

Organization

Resource Contributor

Rating (click to filter)

★★★★★

Search Clear

www.inspireresearch.org

Examples of research affiliated with the Patient Advisory Network

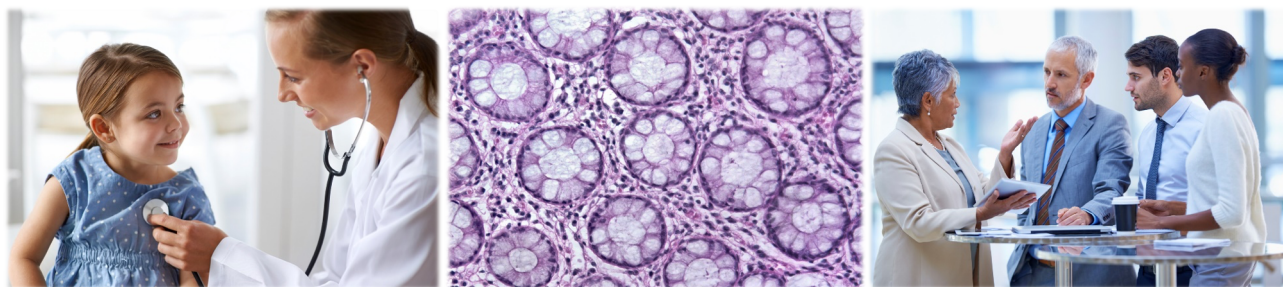
- Clinical Trials
 - Current projects in appendicitis, diverticulitis, bladder cancer
- Engagement Infrastructure-Building Projects
 - INSPIRE, Vascular Ehlers Danlos Syndrome (vEDS) Collaborative
- Initiatives to Inform Research
 - COVID-19 project proposal review panel

Connect with the CERTAIN Patient Advisory Network if you are interested in:

- Tailoring patient engagement strategies to fit your research
- Identifying tools or resources to get you started
- Identifying patients with whom to partner in research

Northwest Participant & Clinical Interactions (NW PCI) Network

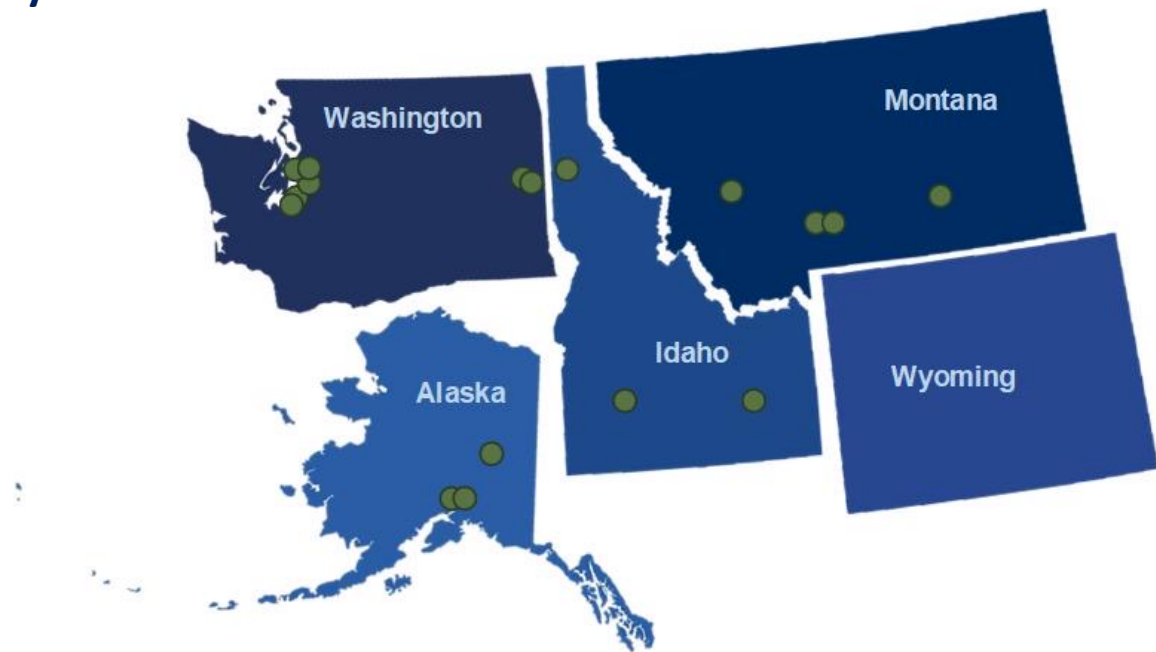
A **collaborative** group of **clinical and translational research centers**, affiliated with medical centers, health systems, clinics and universities across the WWAMI region, that is committed to **connecting diverse populations** to local, high-quality research



Northwest PCI Network

Links 17 regional translational research hubs in WWAMI region hospitals and health systems

- 8 Health Systems
- 4 University Based or Affiliated Centers
- 1 Specialty Institute
- 1 Clinic
- 1 Managed Care Organization
- 1 Medical Center



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Examples of Research in the NW PCI Network

- COVID-19 Clinical Trials
 - Six clinical trials testing new and existing medications (e.g., Remdesivir, dexamethasone) and interventions (e.g., convalescent plasma) for treatment of moderate to severe COVID-19
- Kidney Precision Medicine Project
 - Project to evaluate human kidney biopsies, create a kidney tissue atlas, define disease subgroups and identify key cells, pathways and targets for novel therapies
- Getting Genomic Testing to the Public
 - Randomized trial to assess implementing cancer genetic testing into ongoing clinical practice
- Undiagnosed Diseases Network
 - Network to improve diagnosis and care of patients with undiagnosed diseases

Connect with the NW PCI Network Coordinating Center if you are interested in:

- Collaborating with NW PCI Network sites on a study
- Learning more about how to conduct research in regional health settings
- Accessing tools and resources to build multidisciplinary teams and collaborate with regional partners
- Returning study results and findings to collaborating sites

WWAMI Region Practice and Research Network



A **collaborative** group of **primary care** practices in the **WWAMI** region committed to **research** and **practice improvement**

*University of Washington – Seattle, WA
Institute of Translational Health Sciences and Department of Family Medicine*

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WWAMI Region Practice and Research Network



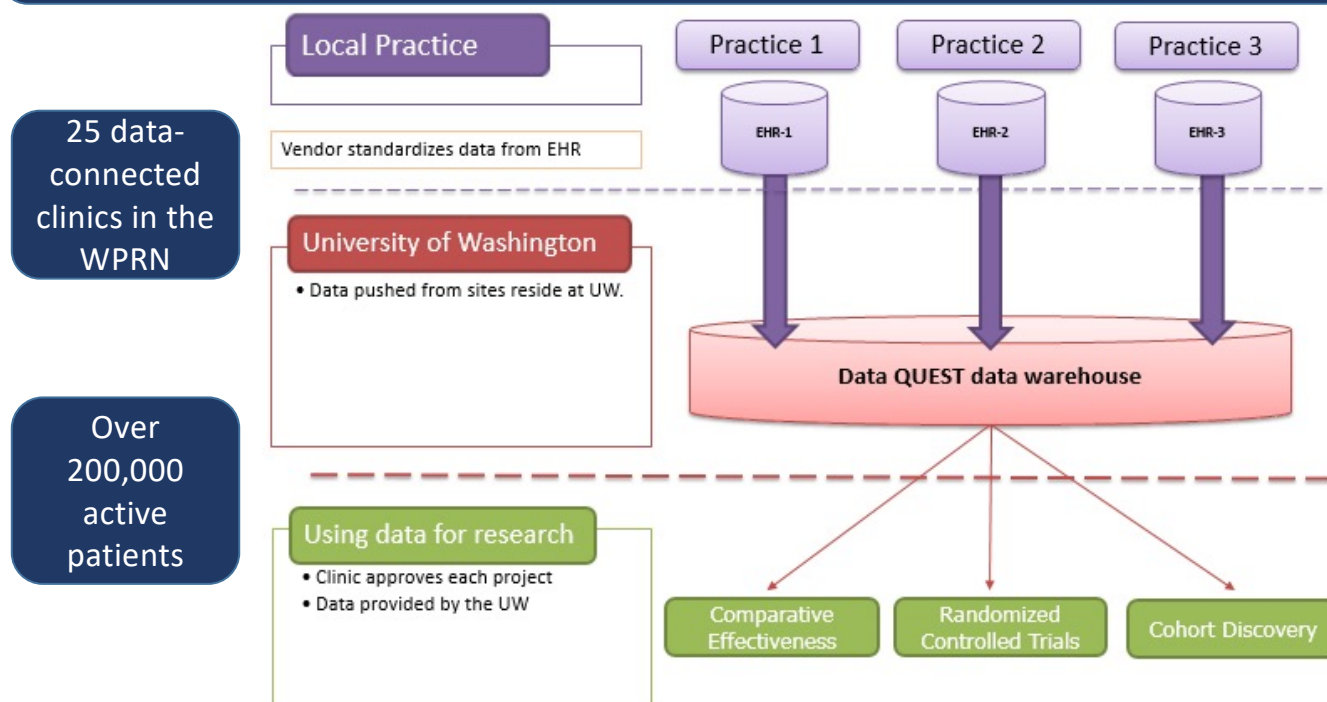
- Over 90 clinics across 34 organizations
- 25 Data QUEST connected clinics

Data Quest



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An electronic health data-sharing architecture across community-based primary care practices in the WPRN



Examples of Research in the WPRN

- **Pragmatic Clinical Trials:**
 - Integrating Behavioral Health and Primary Care
 - Rural Expansion of Medication Treatment for Opioid Use Disorder (RMOUD)
- **Implementation Research:**
 - Improving Rural Primary Care Practices' Capacity to Implement Evidence-based Cancer Screening Interventions (ProCRCScreen)
 - Implementing Innovations in Clinical Settings - A Toolkit for Investigators
- **Observational Studies:**
 - **Using EHR Data:**
 - Longitudinal Evaluation Assessing Diabetes Risk (LEADR)
 - **Using other methods:**
 - A Low-Intensity Technology-Enhanced Intervention for Geriatric Depression (Interviews)
 - Impact of the COVID-19 Pandemic on WPRN Practices (Survey)

Connect with the WPRN Coordinating Center if you are interested in:

- Collaborating with the WPRN for your research/grants
- Meeting to explore partnerships with primary care clinical sites
- Gathering primary care provider perspectives and input via the WPRN Provider Survey Research Panel
- Accessing WPRN electronic health record data through Data QUEST
- Accessing tools and expertise to effectively build multidisciplinary teams and collaborate with community-based research partners

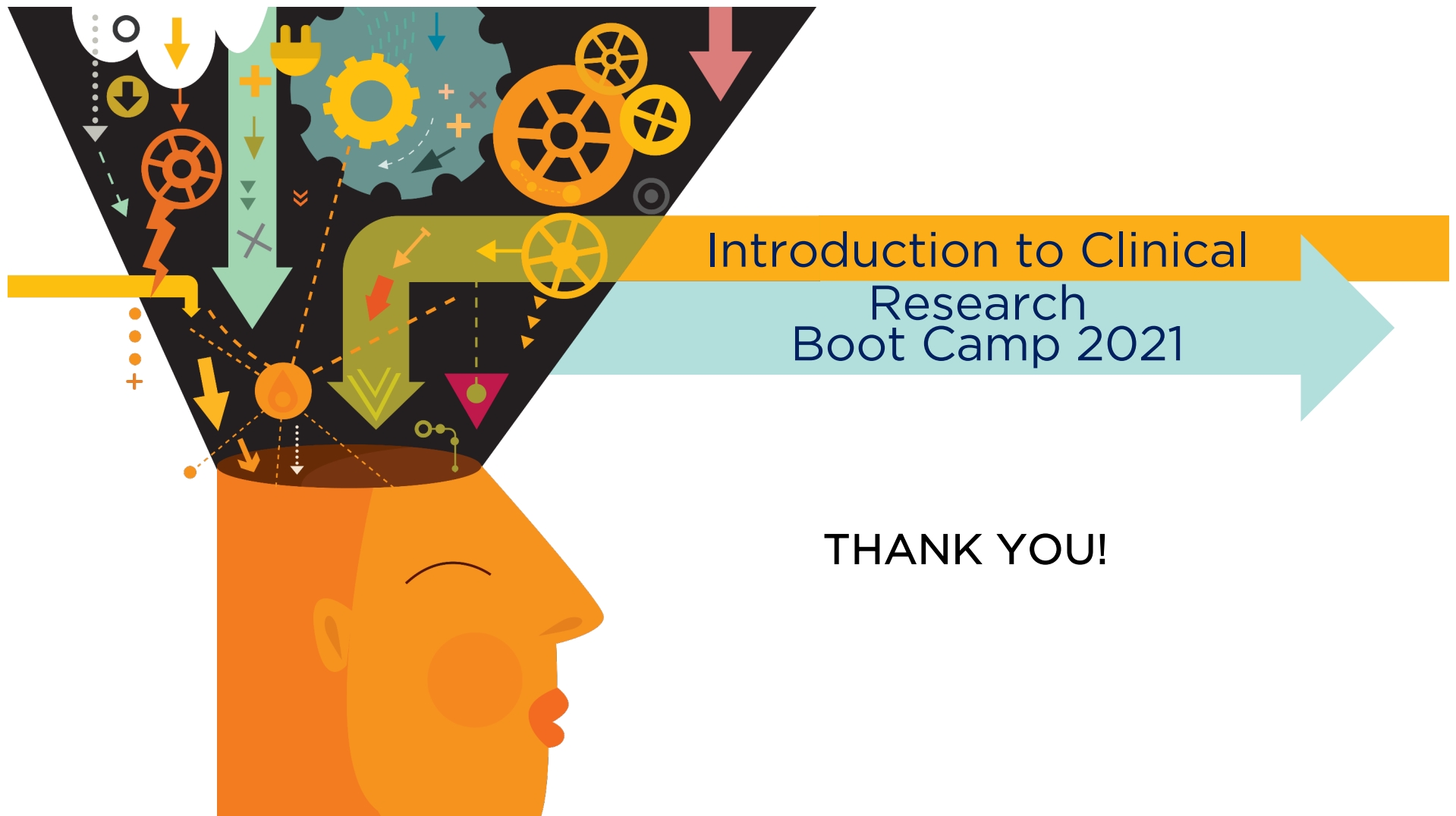
Connecting with Community Engagement Programs

- **ITHS Research Navigator**
 - ithsnav@uw.edu
- **Web site**
 - “Contact Us” form on the ITHS Community Engagement web page –
<https://www.iths.org/community/partners/iths-community-engagement/>
- **E-mail Community Engagement**
 - Jenny Wool, jwool@uw.edu



QUESTIONS and DISCUSSION

Laura-Mae Baldwin, MD, MPH
imb@uw.edu



THANK YOU!