

# Introduction to Clinical Research Boot Camp 2020

## INVESTIGATOR TRACK Day 5

Friday, July 31, 2020

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# Introduction to Clinical Research Boot Camp 2020



## Best Practices and Resources for Engagement of Diverse Communities in Clinical and Translational Research

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*With thanks to Linda K. Ko, PhD; Tumaini Coker, MD, MBA;  
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# Goals and Outline

**Goal:** To provide an introduction to best practices and share ITHS-supported resources for partnering with diverse communities in translational research

- 1 Define community engagement
- 2 Discuss the spectrum of community engagement in research
- 3 “Chat” about the benefits and challenges of different levels 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

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Understanding your  
research and your  
experience with  
community engagement



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



# What is Community Engagement?

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- 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

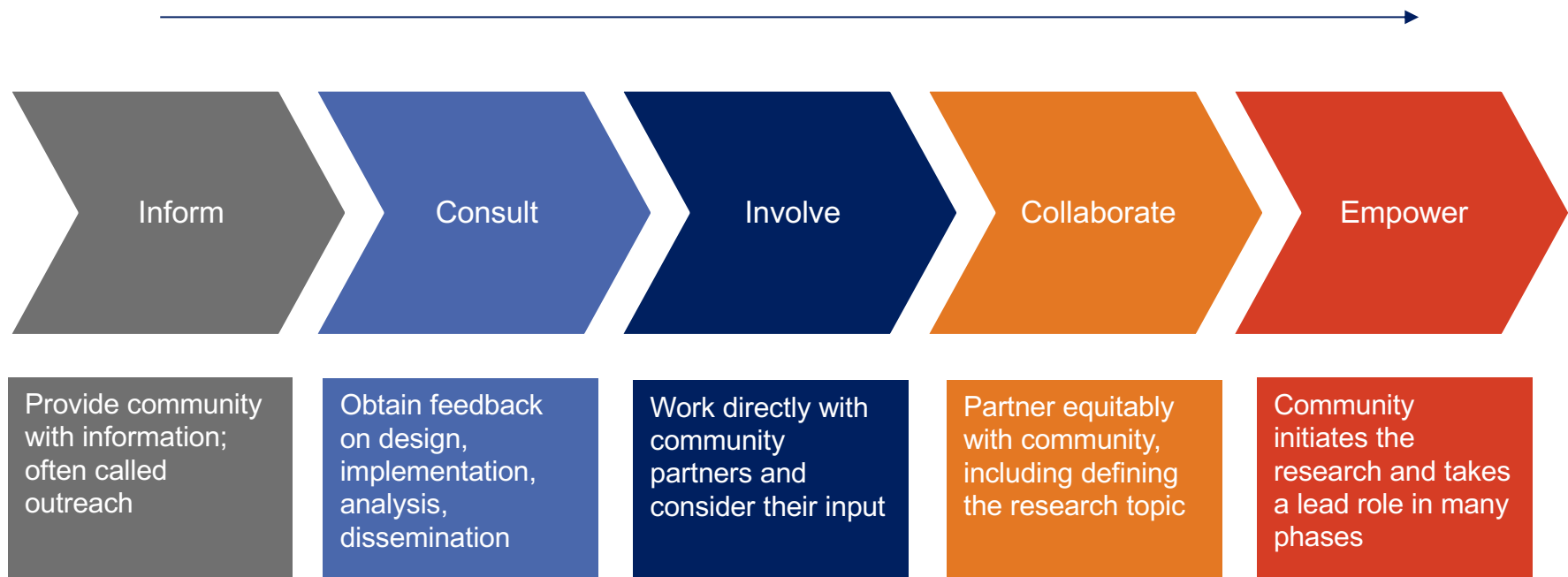
# Why Engage Communities in Research?

- 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

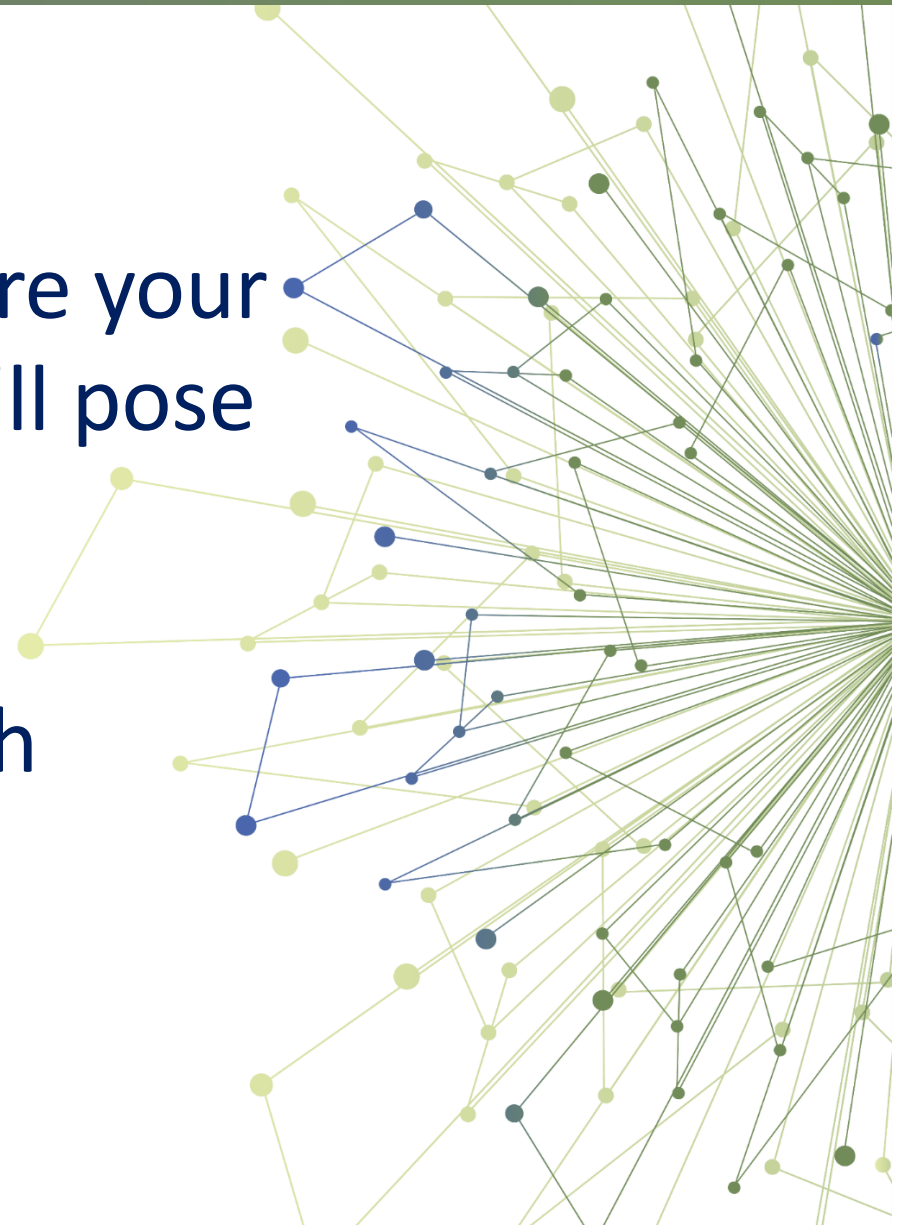


Adapted from CDC, Principles of community engagement, 2<sup>nd</sup> ed. 2011



# 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

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- 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

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## “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
- Create structures, policies, and processes
- Bring it back to their vision and mission



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

## Where to Begin

### Define the community

Geographic proximity

Health condition

Race/ethnicity

### Get to know the community

Spend time in community

Attend events

### Identify potential partners

Previous collaborations

Referrals from trustworthy sources

Reputation in community

# Characteristics of Effective Partners

- Alignment with organizational mission
- Support and involvement from leaders
- Commitment and connections to the community
- Knowledge about the community
- Trust and history of engagement in community
- See value in research



# Moving Forward

## Approach potential partners

Know what community involvement is expected to accomplish

Discuss short- and long-term **benefits** and **costs**

Form a collaborative body, e.g., CAB, steering committee

## Identify health issue/concern

Community-driven

Researcher-driven

## Seek Funding

Engage partners

Determine roles/responsibilities; draft MOU

Include community partners in budget

# Community Partnership Guide for Engaging with Academic Researchers

STEP  
1

Screening  
Questions



STEP  
2

Plan Your  
Engagement



STEP  
3

Memorandum of  
Understanding

**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/>

# 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*

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**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.)

# Partnership Boards

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- 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



## Funding: what you need to know

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



# 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*

# 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



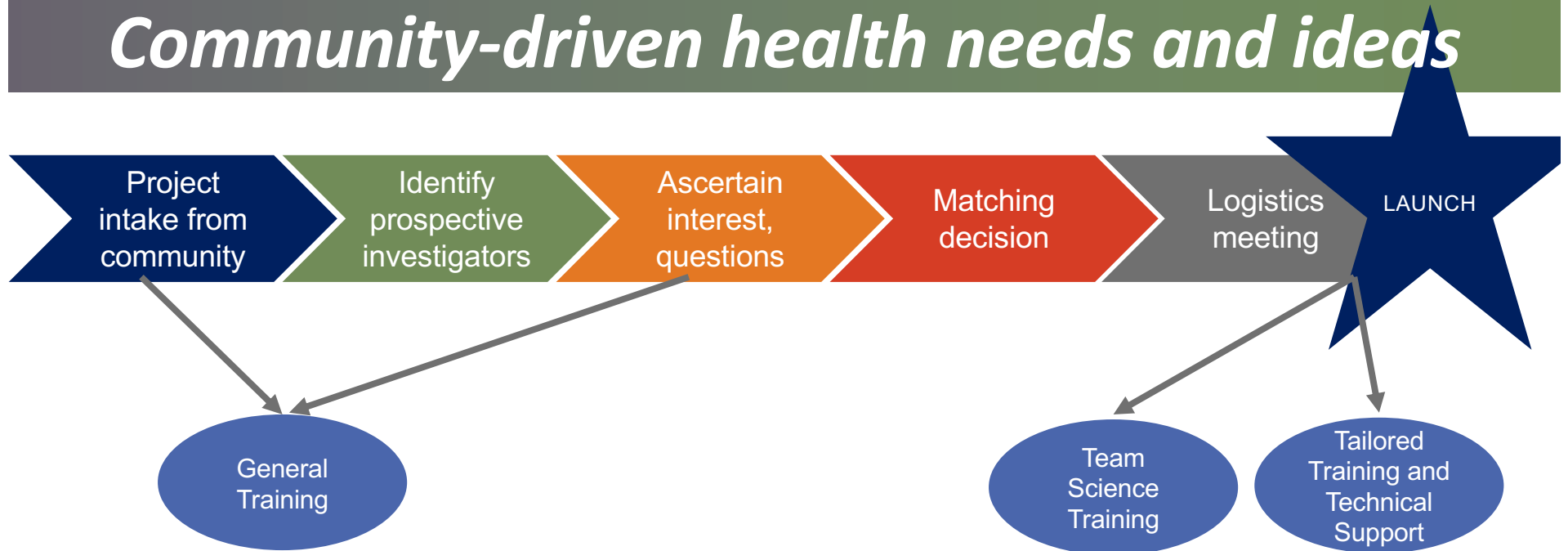
# Examples of research affiliated with the Community Health Network

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- 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

# 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:

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- 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



# 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

**CERTAIN** PATIENT ADVISORY NETWORK

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)

Search

Keyword(s)

Resource Type

Organization  
Reference Materials  
Training Materials

Topics

Advisory Panels  
Budgeting  
Communication/Dissemination  
Engagement Experiences  
Empowerment 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](http://www.inspireresearch.org)

# Examples of research affiliated with the Patient Advisory Network

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- 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

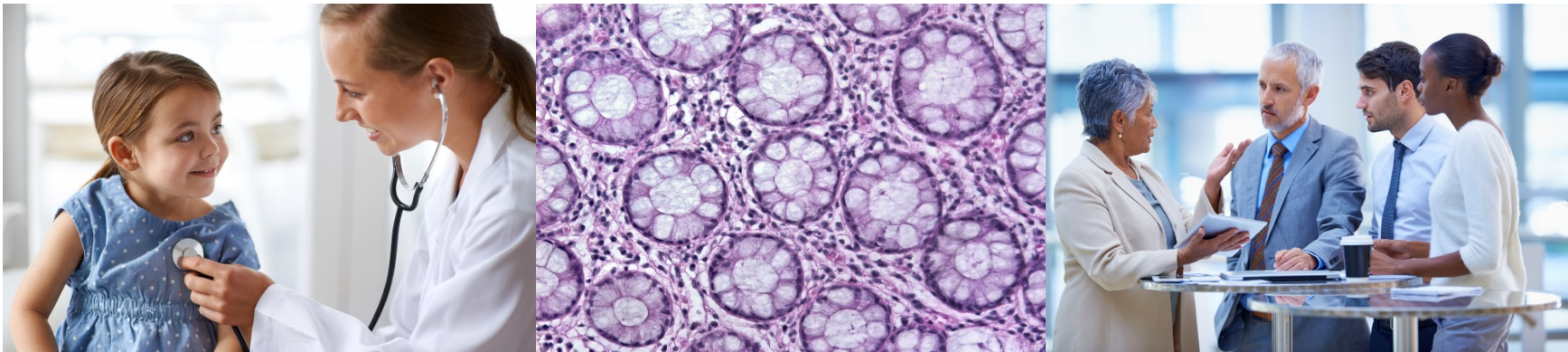
# Connect with the CERTAIN Patient Advisory Network if you are interested in:

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- 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, that is committed to **connecting diverse populations to local, high-quality research**

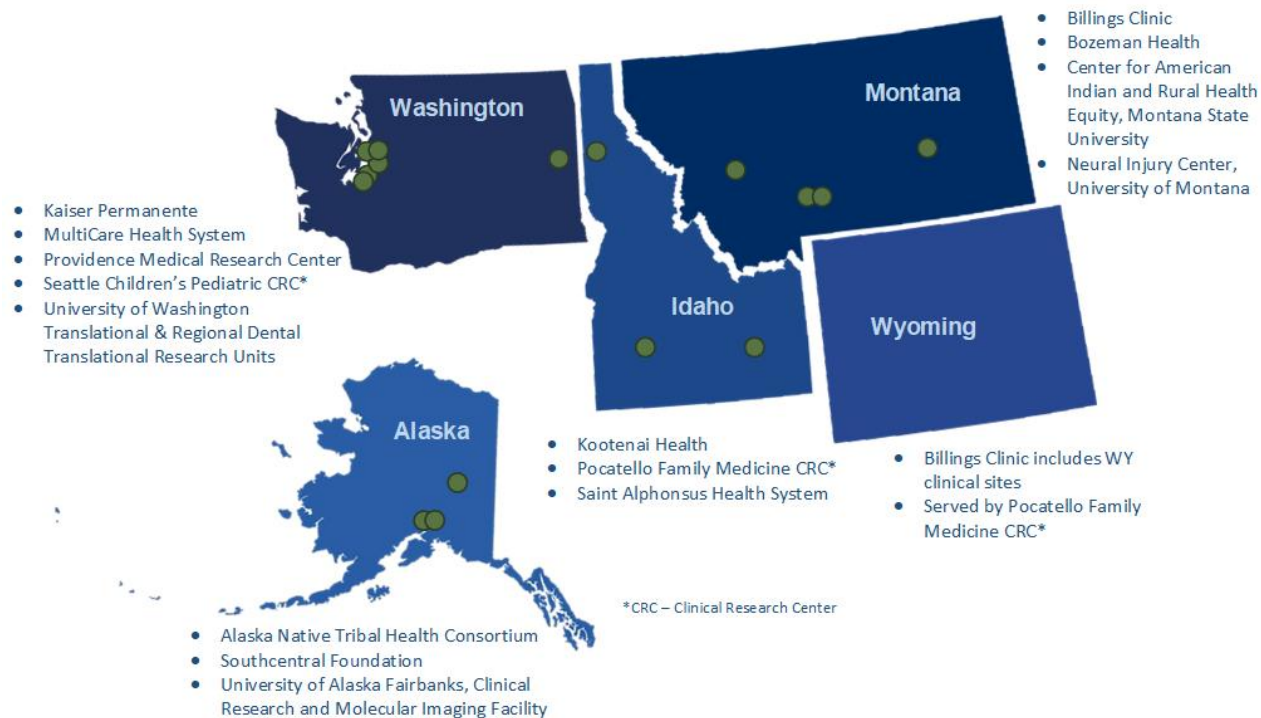


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# Northwest PCI Network

Links 16 regional translational research hubs in WWAMI region hospitals and health systems

- 7 Health Systems
- 5 University Based or Affiliated Centers
- 2 Clinics
- 1 Managed Care Organization
- 1 Medical Center





# Examples of Research in the NW PCI Network

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- 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
- Undiagnosed Diseases Network
  - Network to improve diagnosis and care of patients with undiagnosed diseases
- Getting Genomic Testing to the Public
  - Randomized trial to assess implementing cancer genetic testing into ongoing clinical practice
- Clinician Engagement in Research
  - Survey to identify barriers and facilitators to clinician engagement in research
- Streamlining Research Operations
  - Multiple initiatives to assess research operations

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

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- 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



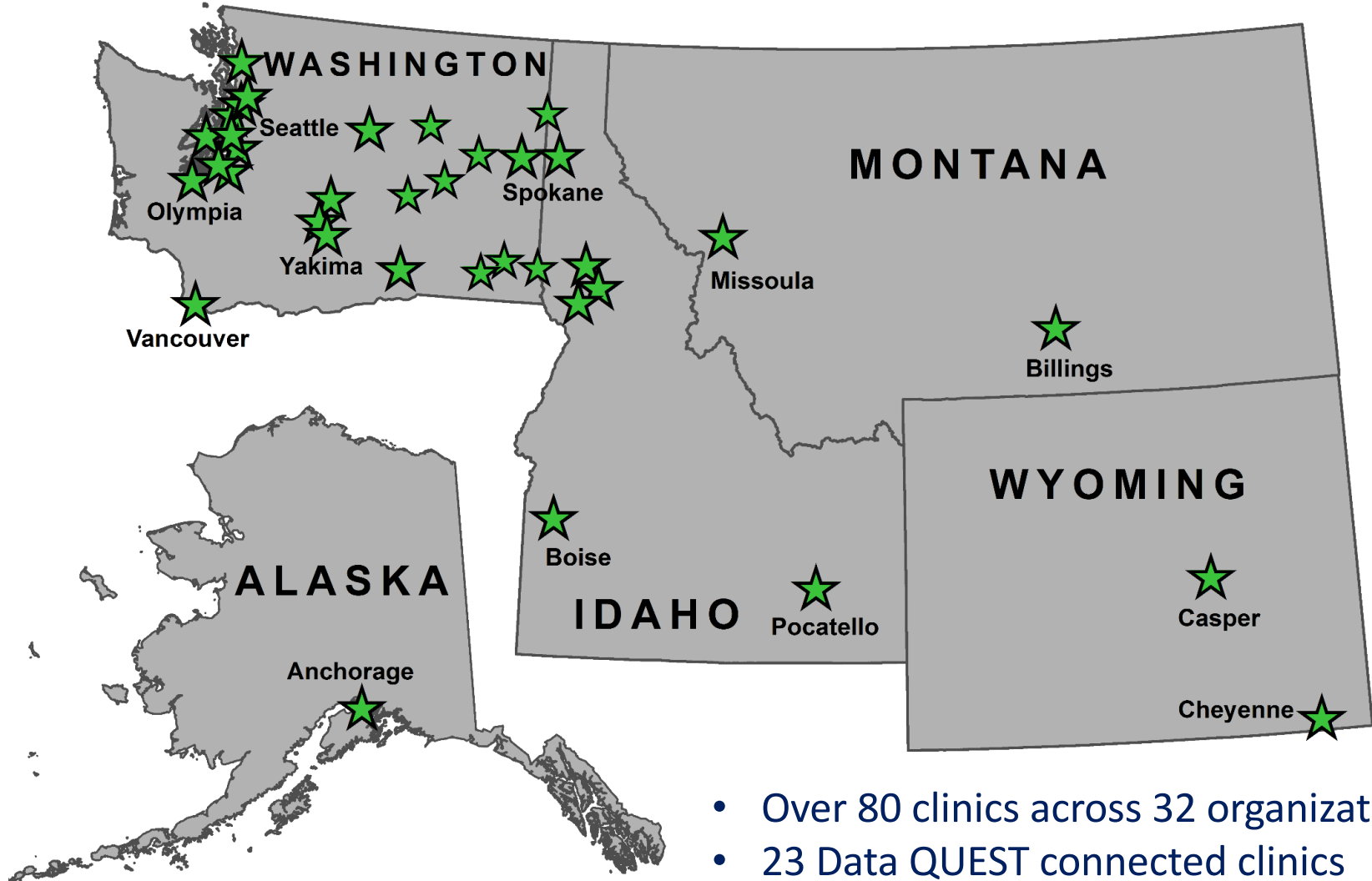
**A collaborative group of primary care practices in the **WWAMI** region committed to research and practice improvement**

## **WWAMI region Practice and Research Network**

*University of Washington – Seattle, WA*

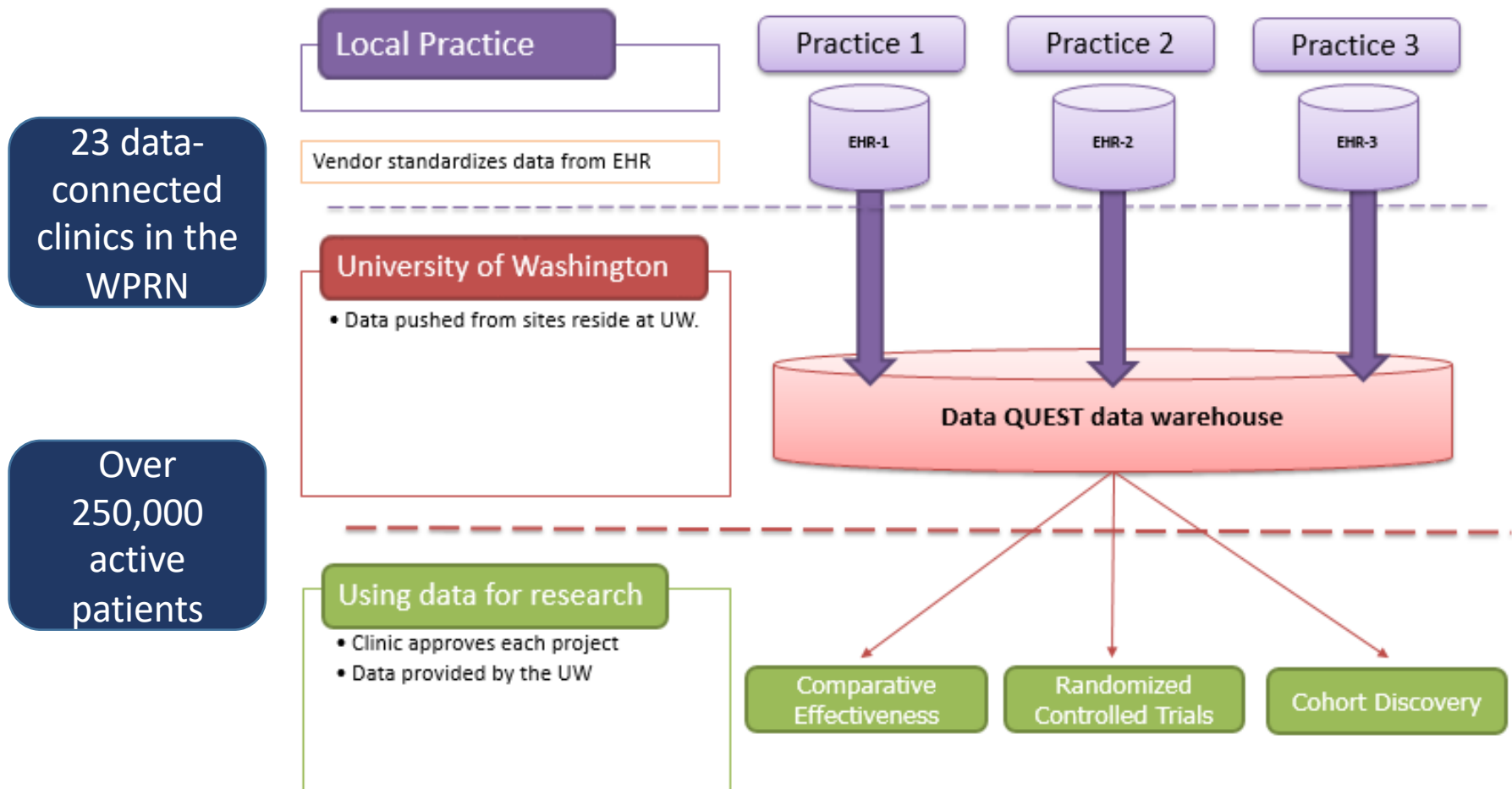
*Institute of Translational Health Sciences and Department of Family Medicine*

# WWAMI region Practice and Research Network



# Data Quest

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



# Examples of Research in the WPRN

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- **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:

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- 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

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- **ITHS Research Navigator**
  - [ithsnav@uw.edu](mailto: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](mailto:jwool@uw.edu)

# Questions and Discussion

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lmb@uw.edu



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# Online Evaluation Survey

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- You will receive an evaluation link to the email address you used to register.
- After you've finished the survey, don't forget to click on "Submit."

**CONNECT WITH ITHS: [www.iths.org](http://www.iths.org)**



**@ITHS\_UW**



**/ithsuw**



**ITHS:InstituteofTranslationalHealthSciences**

**ITHS**

# Become a Member!

Register at [ITHS.org](https://ITHS.org)


The logo for ITHS, consisting of the letters 'ITHS' in a white, bold, sans-serif font, positioned on the right side of a dark green horizontal bar that spans the width of the page.

# What we offer:

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- 1 Access:** Members gain access the different research services, resources, and tools offered by ITHS, including the ITHS Research Navigator.
- 2 Education & Training:** Members can access a variety of workforce development and mentoring programs and apply for formal training programs.
- 3 Funding:** Members can apply for local and national pilot grants and other funding opportunities. ITHS also offers letters of support for grant submissions.
- 4 Collaboration:** Members can connect with collaborators across the CTSA consortium.





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# THANK YOU!

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