



Building patient partnerships and engagement for large, data-focused research networks and projects

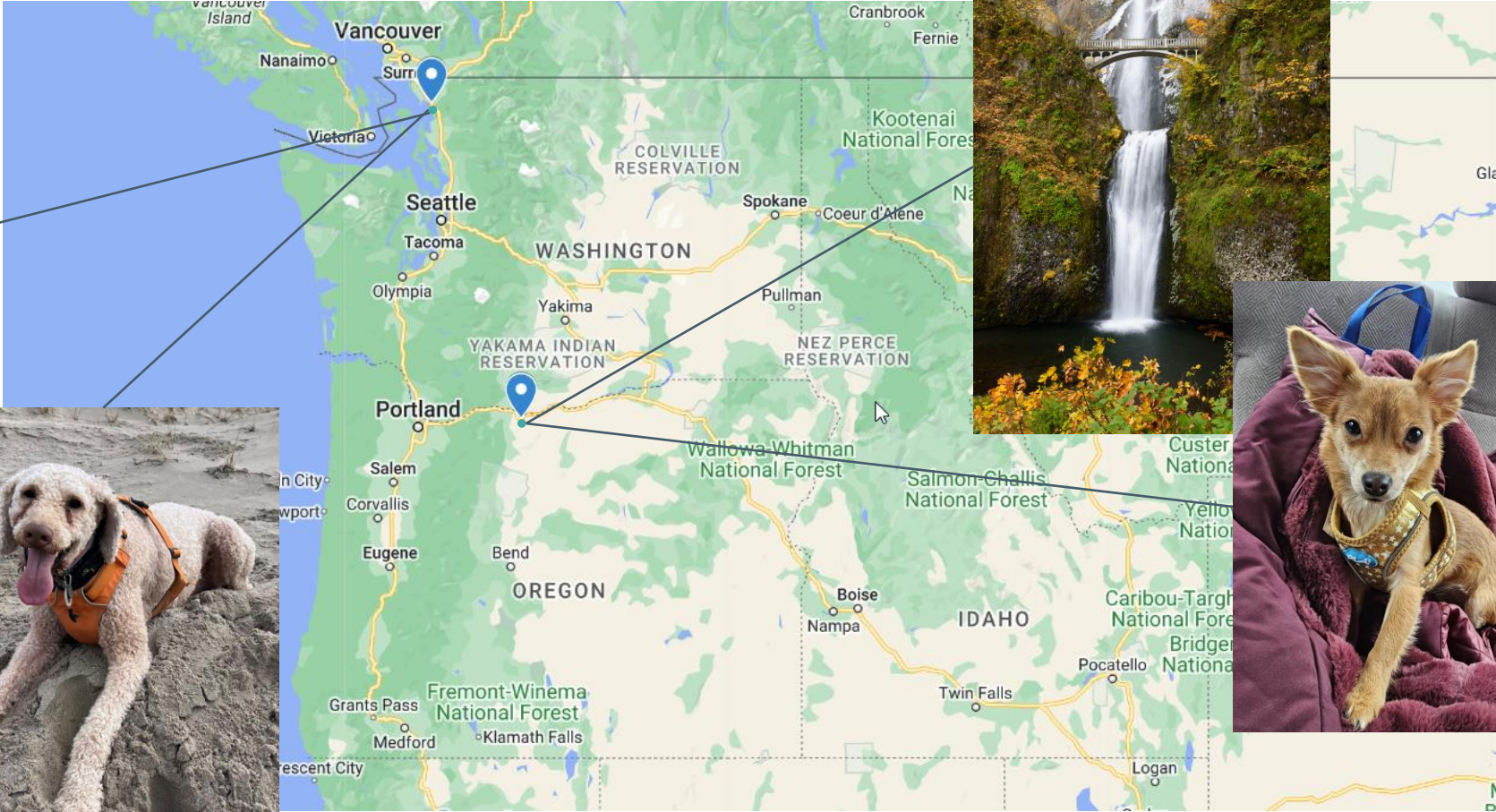
Susan Lowe & Anna Templeton
PaCE TeaTime, 10 September 2024


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Hello from Susan & Anna





Who we
are

What we
do

How it
works

What's
next

A cup of tea later, see where the conversation takes us!

Meet some of our networks



Non-profit health innovation and technology company. Leading US network for health services, outcomes, and policy research with community-based health centers and people they serve.

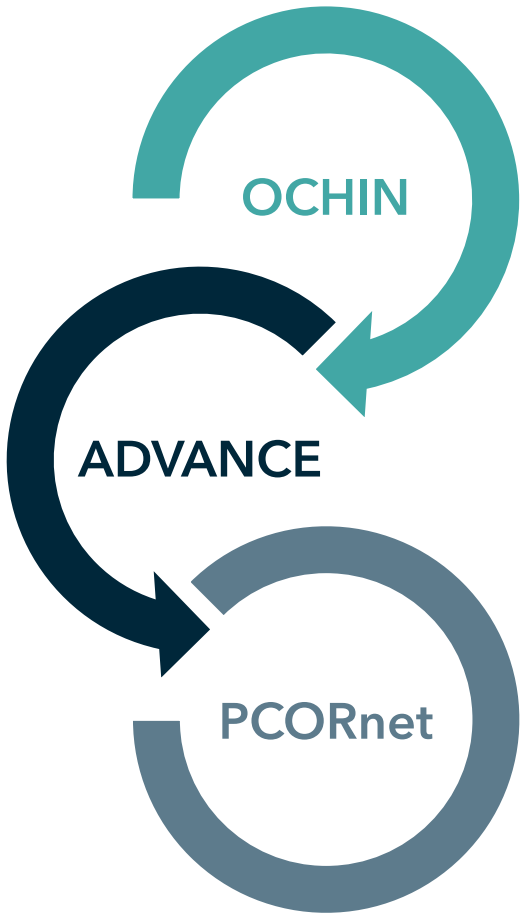


PCORI-funded, health center-focused network led by OCHIN in partnership with Fenway Health, Health Choice Network, Oregon Health & Science University, and the University of Washington.



PCORI-funded “network-of-networks” using a common data model to enable fast, trustworthy insights from high quality health data, patient partnerships, and research expertise.

Different kinds of networks building large data resources for health care and outcomes research



OCHIN Practice-based Research Network & Research Data Warehouse
8.1 million patients, 240 health systems, 37 states
Includes health record and federally required reporting data from community-based primary care centers using OCHIN-hosted Epic EHR

ADVANCE Clinical Research Network & ADVANCE Data Warehouse
13.2 million patients, 263 health systems, 40 states
OCHIN-led initiative bringing clinical EHR data from 5 organizations into the standardized, validated ADVANCE data warehouse

PCORnet - PCORI's "network of networks"
Over 30 million patients, 8 Clinical Research Networks
ADVANCE is the only community-based primary care-focused, non-academic CRN in PCORnet; providing essential inclusion of people and care settings underrepresented in health research

Different kinds of engagement needs and capacity

- Dispersed networks
- Diverse membership
- Convened around data sharing & use
- Communities and care settings underrepresented in research
- Reliant on remote engagement
- Research recruitment and patient participation is mediated by individual partners and member organizations

Collaborate with health center, academic, organizational, and community partners to:

- Build **systems and infrastructure** to strengthen inclusion of people historically underserved and underrepresented in research and support research in primary care settings
- Conduct **practical, applied research** for equitable, evidence-based practice and policy

Strategy 1: Adapting established approaches

PCORI

Equitable partners
Involved throughout research process
Produce more patient centered, relevant, useful results
Improve uptake and use of results

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Community health center settings
Communities, populations, care settings underrepresented in research
Practice-based, pragmatic research

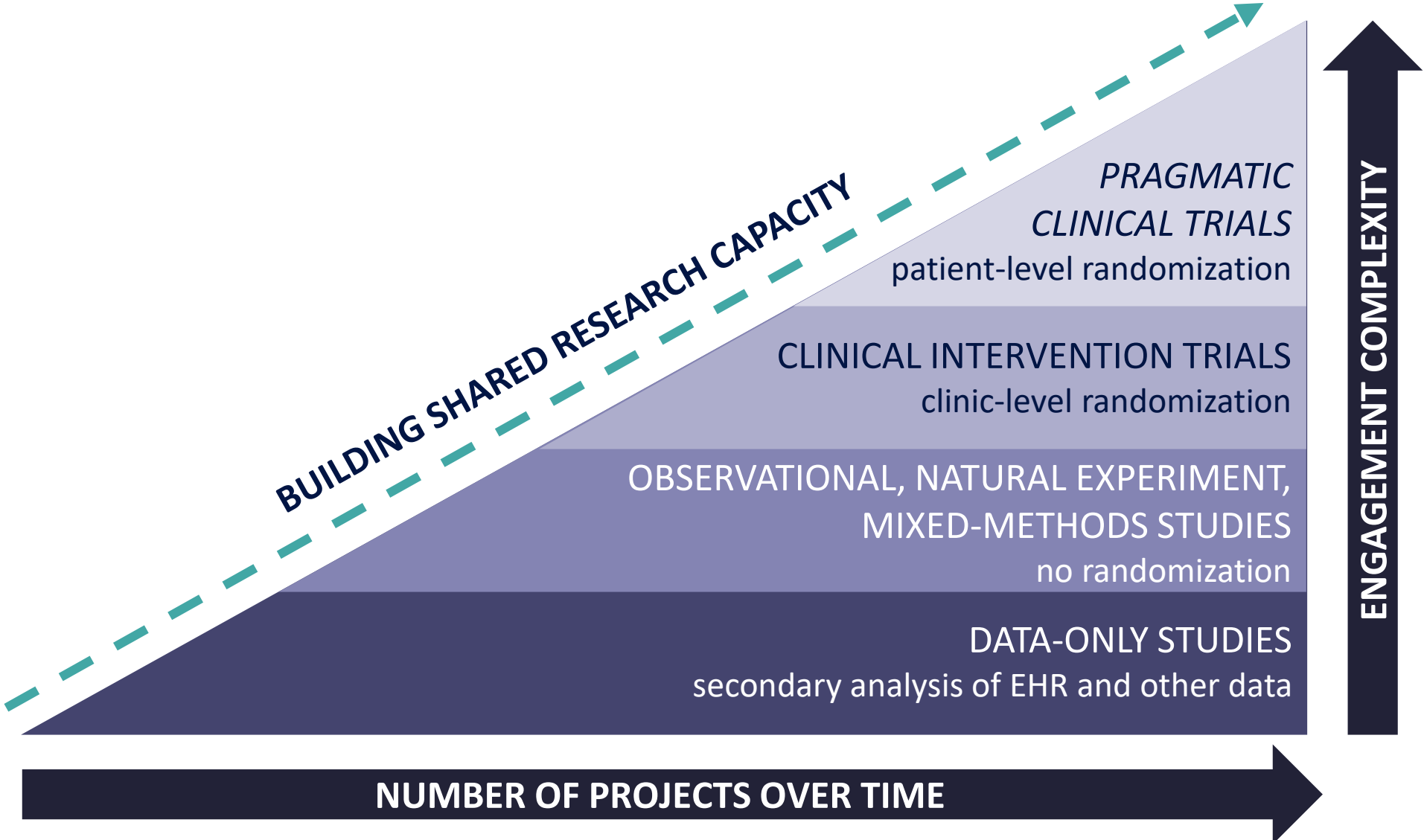
Develop equitable, sustainable, adaptive systems for patient, provider, and health systems engagement

Maintain an integrated approach to engagement from proposal development through study dissemination

Increase capacity, skills, and opportunities for complex, durable engagement across diverse projects

Share learning and contribute to the advancement of engagement science and practice

Strategy 2: Building capacity & complexity over time



Strategy 3: Differentiating roles to support engagement throughout the research cycle



Strategy 4: Long term relationships with patients, caregivers, and community members

“We use our lived experiences as patients, family members, caregivers, community members, and advocates to improve all aspects of research from development through dissemination, to deliver equitable, feasible, and sustainable outcomes for community health centers and the people they serve.”

Patient Engagement Panel – PEP Letter of Support

Engage patient and caregiver collaborators with relevant lived experiences

Integrate and elevate patient and caregiver experience and expertise

Collaborate on research development, conduct, interpretation, and dissemination

Measure engagement and demonstrate impact together

The OCHIN-ADVANCE Patient Engagement Panel (or PEP)



Ashton Varner, Cece Beckwith, Danya Blankenship, Jennifer Martin, Jessica Silva, Jim Gaudino, Laura Williams, Leticia Amador, Marissa Salgado, Meghan Marren, Mickie Bowe, Patience Bixby, Trish Divine Wilder, Patty Poston, Shirley Stowe, Susan Lowe, Tony Hoke

A brief history of the PEP

PHASE I

Convened 2012

8 members, local

Monthly in-person

Panel development,
orientation, training,
connecting members to
individual project
opportunities

PHASE II

2017 – 2018

7-12 members, local

Quarterly in-person

Increased experience,
most serving as individual
project panelists or patient
investigators

PHASE III

2019 – Present

13-16 members, national

Bi-monthly remote

Experienced panelists,
nearly all serving as
individual project panelists
or advisors

PHASE IV

2024 forward!

18 members, national

Bi-monthly remote

**Patient partner role
development, ADVANCE**
patient investigators,
project panelist or advisor
role opportunities for all
PEP members

Examples of recent PEP consultations and collaboration

Over 50 projects and proposals

At any point in the research lifecycle: research development, proposal, study set up, conduct, analysis and interpretation, dissemination

PROPOSAL DEVELOPMENT

PEP consult on a proposed trial comparing the effects of breathing tube size on shortness of breath after a critical illness. Reviewed patient-centered outcomes and provided a Letter of Support to the study team.

USER REVIEW AND REFINEMENT

PEP consultation to refine assessment questions and patient-facing materials for risk-based cardiovascular care resulting in revisions to improve wording, accessibility, and organization of study questions and informational materials.

PATIENT PARTNER

A PEP member joining the DEDICATE study team to provide patient perspective and direction on patient-centered processes and outcomes for social risk screening, referral pathways, and connecting to community services.

Working to set patient-led, values-based engagement goals, practices, and infrastructure across our networks

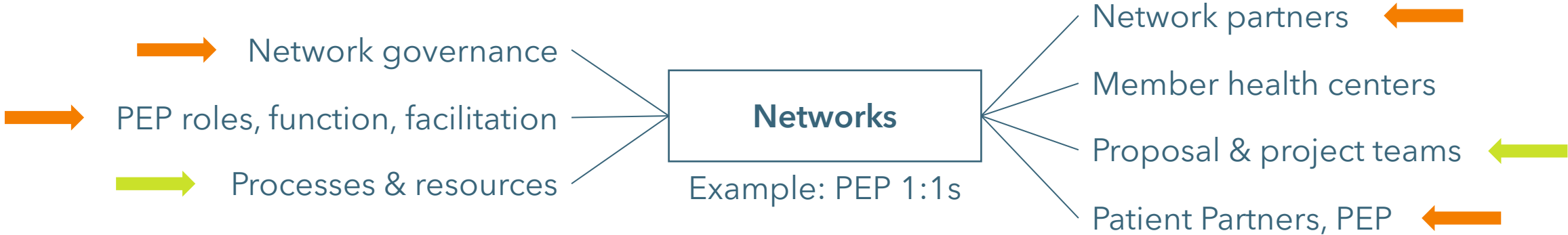
Values identified by the PEP and co-developed with OCHIN and ADVANCE to guide current practice, evaluation, and future planning



Informed PCORnet engagement principles and policy

- **Integrate** patient and caregiver experience and expertise
- **Elevate** patient and caregiver experience and expertise
- **Implement** changes according to patient and caregiver feedback
- **Report** impact and changes to patient and caregiver collaborators
- **Collaborate** on research proposal development
- **Collaborate** on research engagement and recruitment approaches
- **Engage** patient and caregiver collaborators with relevant lived experience
- **Measure** engagement together

Measuring & demonstrating engagement value – processes, outcomes, impacts



What tools and metrics? How standardized versus adaptive? Which outcomes and processes?



OCHIN-ADVANCE engagement functions and metrics

Functions	Engage	Educate	Facilitate	Integrate	Participate	Translate	Disseminate
Activity example	Research development	Research trainings	Study team support for PEP consultations	Facilitation practices	Contribute to study team consultation	Present proposals to PEP members (request letter of support)	Communication or dissemination consultations
Metric example	Number of proposals and engagement roles Advisor or collaborator roles	Number of trainings - Participants - Format - Topic area	Number of consultations PEP participation and feedback - Format - Topic areas	Thematic review of semi-structured annual PEP member check-ins	Number of contributions (e.g., Letters of Support, study activities, study materials, co-author)	Number of signees Process review at PEP meeting	Number and type of consultations
Areas for growth	<ul style="list-style-type: none"> - Consistent documentation and tracking of feedback and input - Consistent reporting of impacts back to PEP members 						

Reflections and open discussion

What is your experience with network engagement?

What does engagement look like in your networks?

What's worked well for you or what have you learned you'd like to share here?

OCHIN-ADVANCE PEP and engagement resources

OCHIN-ADVANCE Patient Engagement Panel Handbook – example of member agreement or charter. Updated and signed yearly by all PEP members:

<https://www.pcori.org/sites/default/files/OCHIN-ADVANCE-Patient-Engagement-Panel-Handbook.pdf>

OCHIN-ADVANCE Engagement Values, Functions, and Metrics – example of co-developed guiding principles, best practices, and evaluation measures. Updated yearly (mostly!) with all PEP members:

<https://www.pcori.org/sites/default/files/OCHIN-ADVANCE-Engagement-Core-Values-Functions-and-Metrics.pdf>

OCHIN-ADVANCE Patient Engagement Panel Guide and Request Form – example of PEP consultation guide (what to expect) and request form (what to ask for and how to prepare). Updated as needed:

<https://www.pcori.org/engagement/engagement-resources/ochin-advance-patient-engagement-panel-guide-and-request-form>

Many others available through PCORnet Engagement Resources and PCORI Engagement Tool and Resource Repository:

<https://pcornet.org/resources/engagementdomain/>

<https://www.pcori.org/engagement/engagement-resources/Engagement-Tool-Resource-Repository>

Thank you for joining us today!

Susan Lowe & Anna Templeton

www.ochin.org

www.advancecollaborative.org

Any questions or more information:

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