



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

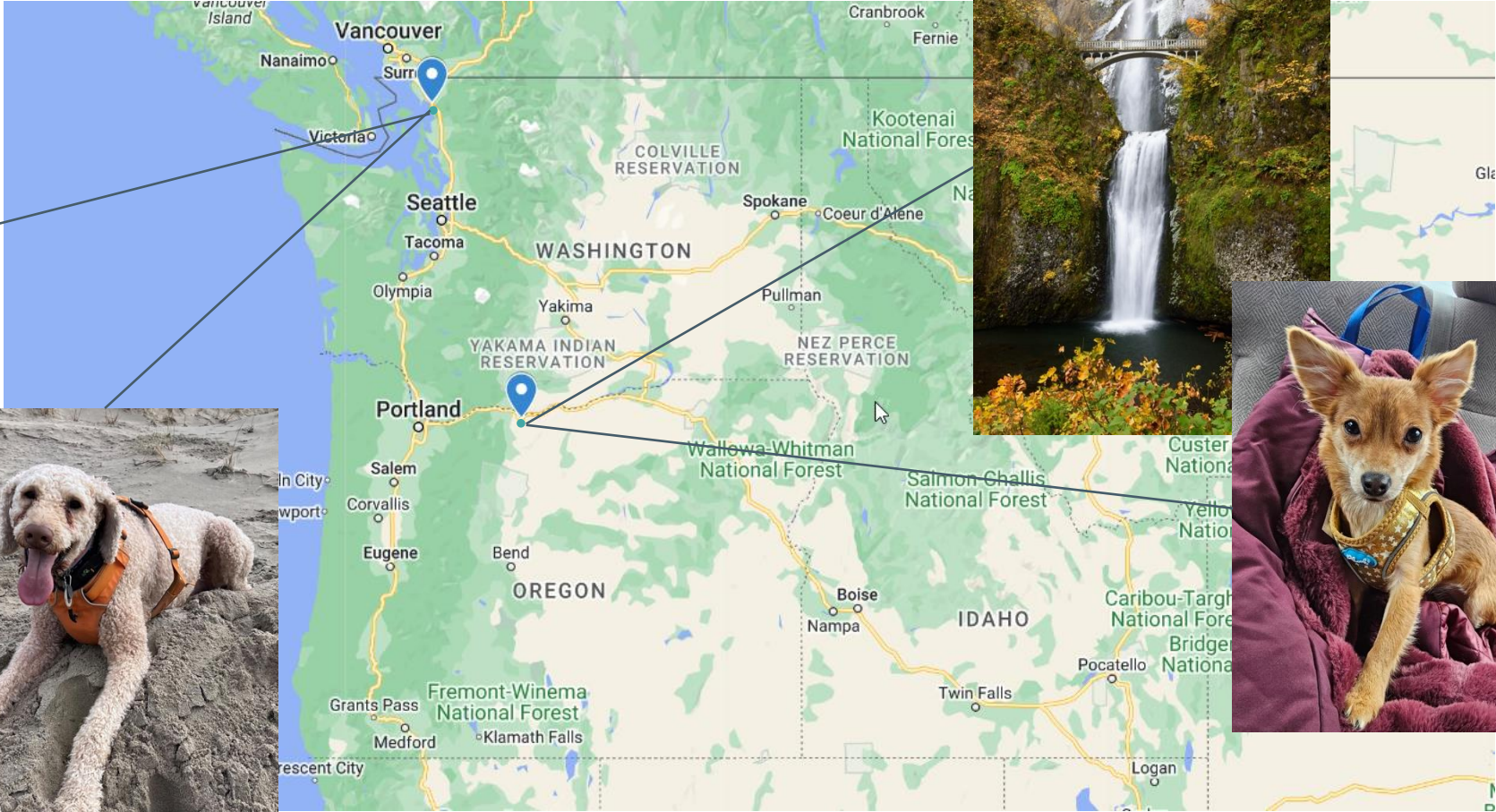
Susan Lowe & Anna Templeton  
PaCE TeaTime, 10 September 2024


**OCHIN**



This work was powered by PCORnet<sup>®</sup>. PCORnet has been developed with funding from the Patient-Centered Outcomes Research Institute<sup>®</sup> (PCORI<sup>®</sup>) and conducted with the Accelerating Data Value Across a National Community Health Center Network (ADVANCE) Clinical Research Network (CRN). ADVANCE is a Clinical Research Network in PCORnet<sup>®</sup> led by OCHIN in partnership with Health Choice Network, Fenway Health, University of Washington, and Oregon Health & Science University. ADVANCE's participation in PCORnet<sup>®</sup> is funded through the PCORI Award RI-OCHIN-01-MC.

# 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.

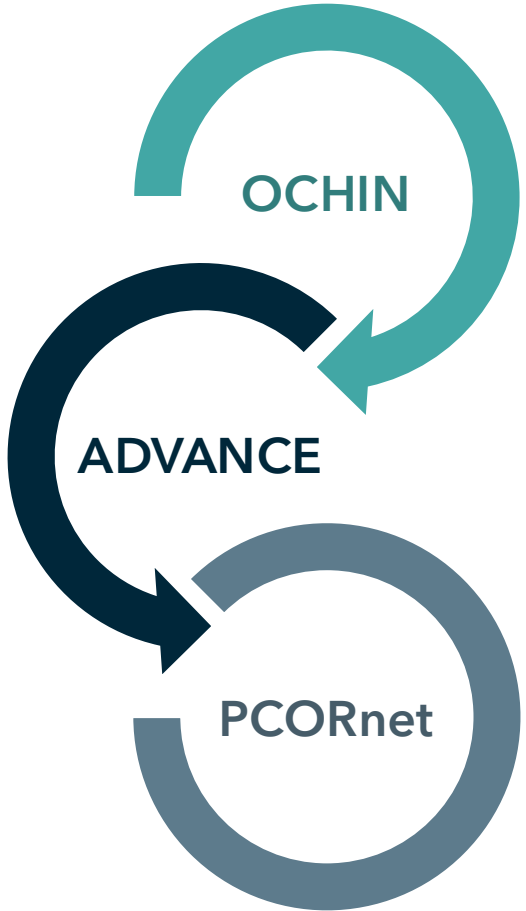


PCORI-funded, health center-focused network led by OCHIN in partnership with Fenway Health, Health Choice Network, Oregon Health & Science University, and the University of Washington.



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

<b>PCORI</b>	<ul style="list-style-type: none"><li>Equitable partners</li><li>Involved throughout research process</li><li>Produce more patient centered, relevant, useful results</li><li>Improve uptake and use of results</li></ul>
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<b>OCHIN &amp; ADVANCE</b>	<ul style="list-style-type: none"><li>Community health center settings</li><li>Communities, populations, care settings underrepresented in research</li><li>Practice-based, pragmatic research</li></ul>
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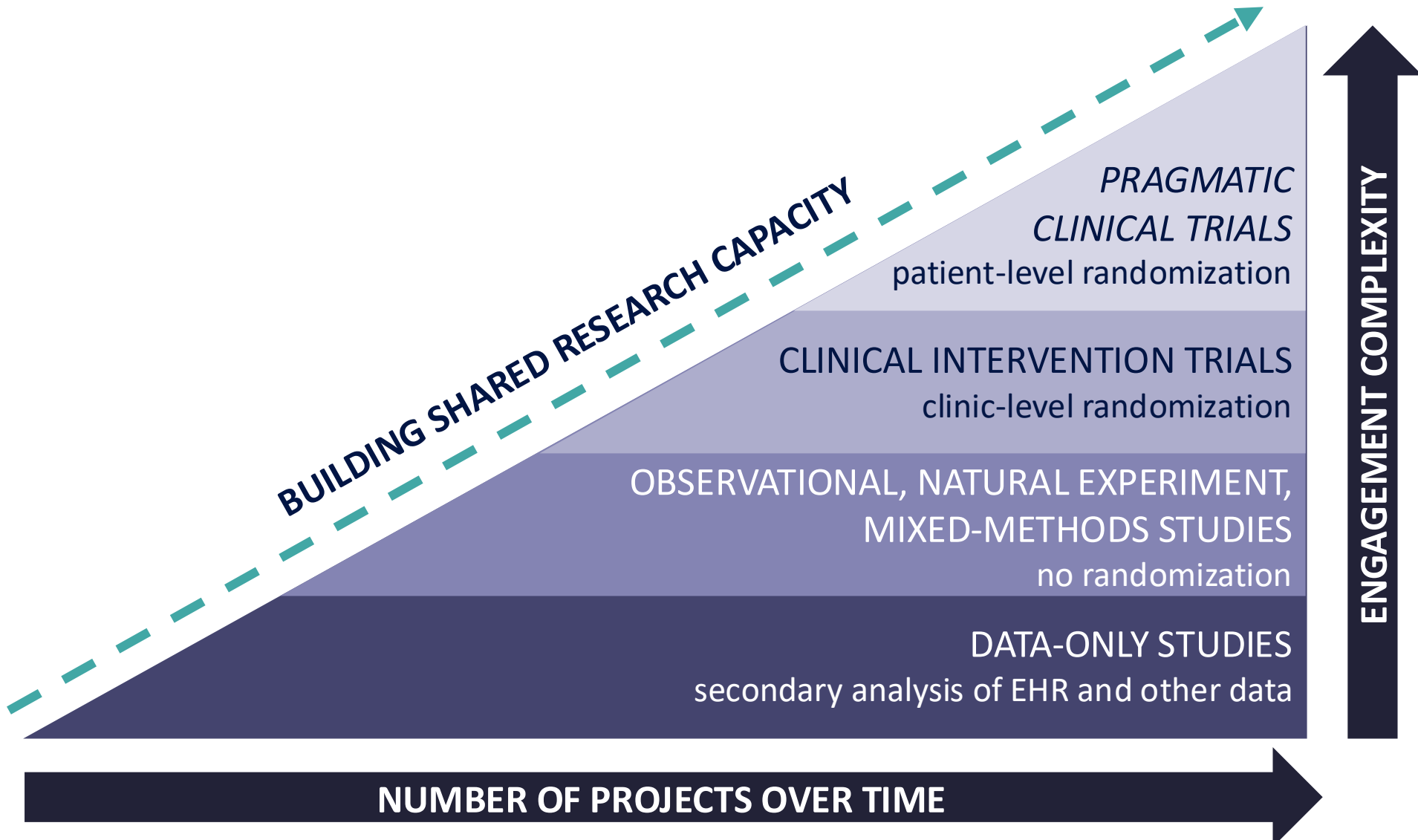
**Develop equitable, sustainable, adaptive systems** for patient, provider, and health systems engagement

**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

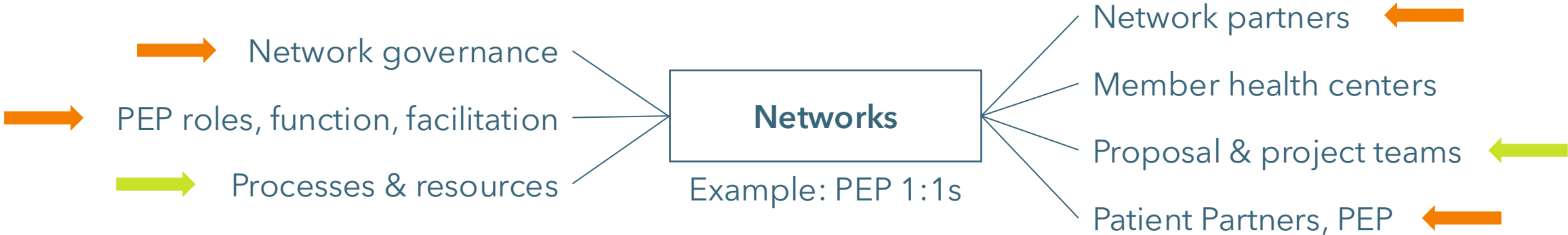
Values identified by the PEP and co-developed with OCHIN and ADVANCE to guide current practice, evaluation, and future planning



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"> <li>- Consistent documentation and tracking of feedback and input</li> <li>- Consistent reporting of impacts back to PEP members</li> </ul>						

# 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](http://www.ochin.org)

[www.advancecollaborative.org](http://www.advancecollaborative.org)

Any questions or more information:

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