Welcome to the 10th Anniversary of the NW PCI Network Annual Meeting!

April 13-14, 2023

Institute of Translational Health Sciences

Providence Inland Northwest Health

Welcome!

Robert H. Coker
Research Professor, Deputy Director
Montana Center for Work Physiology and Exercise Metabolism
University of Montana

Chair, NW PCI Network Steering Committee
Institute of Translational Health Sciences

Welcome to the UW / Gonzaga Health Sciences and Innovation Building!

Darryl Potyk
Associate Dean for Eastern Washington
Clinical Professor of Medicine

University of Washington School of Medicine

Goals for the meeting

Allison Lambert
Pulmonary and Critical Care Physician
Providence Inland Northwest Health

Assistant Professor of Medicine
University of Washington, Division of Pulmonary and Critical Care Medicine

Co-Director
NW PCI Network

Research as a driver of evidence-based practice

- **Learn** more about this year's theme with Margaret Rosenfeld from Seattle Children's
- **Meet** new friends and connect with peers from NW PCI Network sites
- **Highlight** interesting regional research and available resources
- **Focus** on integrating research at the point of care with NW PCI research leaders
- **Share** strategies for facilitating participation in research
- **Develop** quality improvement pilot project ideas
- **Acknowledge** the important contributions and stellar career of Bonnie Ramsey

Introducing the Bonnie Ramsey Northwest Participant & Clinical Interactions Network Keynote Lectureship

Introduced by:

Katherine Tuttle,

Executive Director for Research, Providence Health Care

Professor of Medicine, University of Washington

Co-Principal Investigator, Institute of Translational Health Sciences

Thank you, Bonnie!

Meeting begins at 9 am in the Providence Auditorium

Please stay for conversation and refreshments!

10th Anniversary NW PCI Network Annual Meeting

Institute of Translational Health Sciences

Providence Inland Northwest Health

WELCOME!

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

Meeting materials- use QR code:

Need help? Contact Aurora at auroraf@uw.edu or via private chat.

Welcome and Introductions!

Katherine R. Tuttle
Executive Director for Research
Providence Health Care

Professor of Medicine
University of Washington

Co-Principal Investigator
Institute of Translational Health Sciences

We acknowledge the peoples – past, present and future…

Apsaalooké
Cheyenne
Chumash
Coast Salish
Dena’ina Ełnena
Dënéndeh
Duwamish
Kizh
Ktunaxa ʔamakʔis
Muckleshoot
Niitsítpiis-stahkoii
Očhéthi Šakówiŋ
Palouse
Salish Kootenai
Shoshone-Bannock
Spokane
Schitsu’umsh
Stillaguamish
Suquamish
Tanana
Tongva

… and other Indigenous peoples on whose lands and waters we live and work.

https://native-land.ca/

Foundational Principles

- PARTNERSHIP
- RESPECT
- TRUST
- INCLUSIVENESS

During today's meeting, we will value:

Inclusion

Questions, comments, feedback and suggestions are welcome from all meeting attendees during all sessions.

Diversity of experiences and opinions

All experiences and opinions are real and valuable and are important contributions to improving clinical and translational research.

Honest communication

*Feedback can be difficult to share and to hear, "but the discomfort creates an impetus for improved care practices and research."**

Shared purpose

Our goal is to teach and learn from each other to be more inclusive and better equipped to improve equity, diversity and inclusion in research across our region.

*https://necsociety.org/2019/07/12/nec-societys-10-step-guide-for-an-all-in-meeting/

Today's Agenda

Welcome and Introductions, NW PCI Network Updates

Regional Research Highlight and Trial Innovation Network Resources

Bonnie Ramsey Northwest Participant & Clinical Interactions Network Keynote Lecture by Margaret Rosenfeld

Panel: Integrating Research at the Point of Care

Working Sessions

Making it Easy to Integrate Patients in Research

Opportunities for Network-wide Quality Improvement

Impressions from the Day

Meeting Packet and Website Contents

- NW PCI Annual Meeting Agenda *(green)*
- NW PCI 10th Anniversary Executive Summary
- Speaker, panelist and facilitator biographies
- Manuscripts *(website only)*
- Meeting Evaluation Form *(pink)*
- Steering Committee Information Flyer
- Photo release *(yellow)*
- Project Update *(website only)*
- Session slides *(posted after the meeting)*

Disclosure: Conflicts of Interest

Neither I, nor any immediate family member has any financial relationship with, or interest in, any commercial enterprise connected with today's presentations or activities.

The NW PCI Coordinating Center

- *Katherine Tuttle*
- *Robert Coker*
- *Allison Lambert*
- *Laurie Hassell*
- *James Probus*
- *Jennifer Acosta*

The Institute of Translational Health Sciences

is dedicated to speeding science to the clinic for the benefit of patients and communities throughout Washington, Wyoming, Alaska, Montana and Idaho.

ITHS promotes this translation of scientific discovery to practice by fostering innovative research, cultivating multi-disciplinary research partnerships, and ensuring a pipeline of next generation researchers through robust educational and career development programs.

ITHS | Institute of Translational Health Sciences

ACCELERATING RESEARCH. IMPROVING HEALTH.

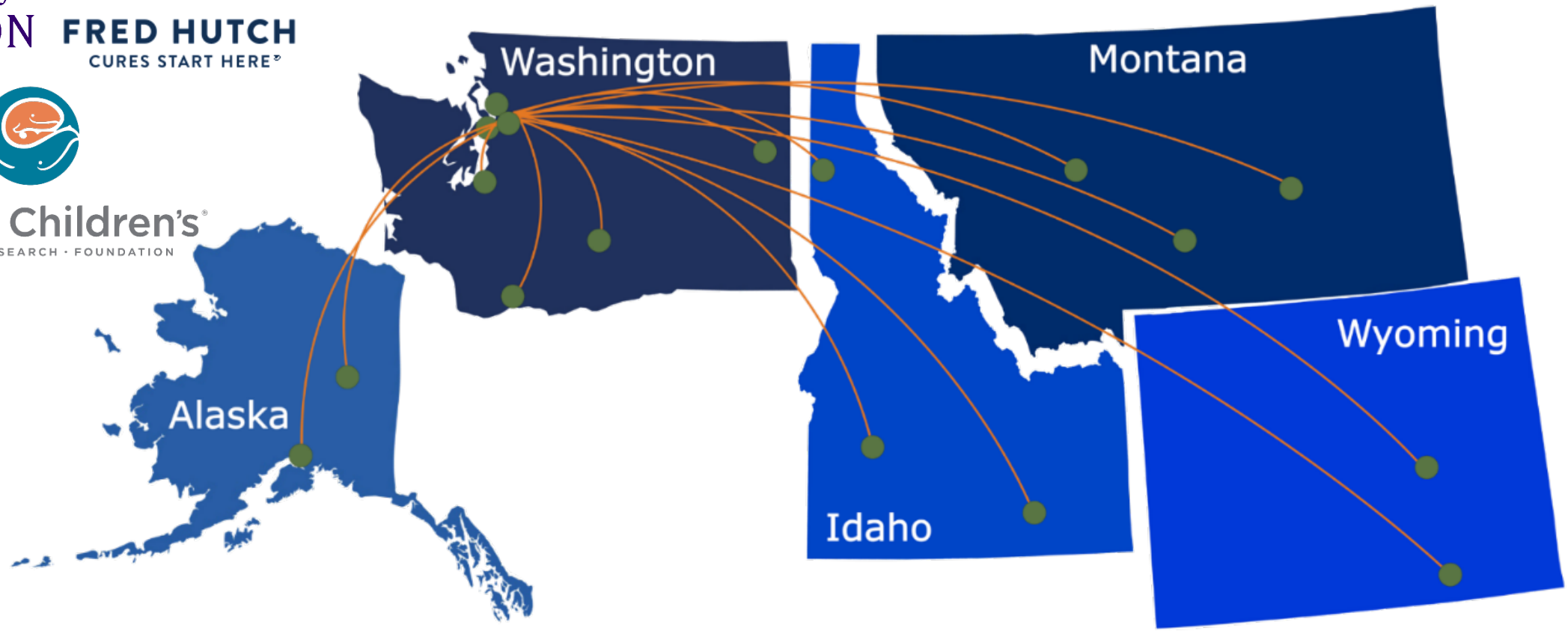
Our Partner Institutions

UNIVERSITY of WASHINGTON

FRED HUTCH
CURES START HERE®

Seattle Children's®
HOSPITAL · RESEARCH · FOUNDATION

More than 100 Collaborating Organizations across WWAMI Region



ITHS
Institute of Translational Health Sciences

Northwest Participant & Clinical Interactions (NW PCI) Network

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

Vision and Mission

Individuals have local access to high-quality clinical research studies offering cutting-edge innovation in diagnostics and treatments

Build Collaborations

Build successful research collaborations between NW PCI sites, investigators, and organizations in the WWAMI region

---

Expand Research Capacity

Expand engagement of investigators with research and training programs across collaborating institutions

---

Ensure Highest Quality Research

Ensure availability of best practices and standard operating procedures, as well as training in core competencies for conducting clinical research within the NW PCI

Welcome Research Volunteers Marilyn and Robert!

Many people supported this meeting, and we thank you!

ITHS Executive Leadership: John Amory, Nora Disis, Stephanie Lee, Paul Martin (Emeritus), Bonnie Ramsey (Emeritus), Shelly Sakiyama-Elbert, Elizabeth Shanahan, Jodi Smith, Tong Sun, Katherine Tuttle

UW School of Medicine / Gonzaga University Partnership: Brendon Algeier, Emily Drake, Deborah Greene, Darryl Potyk

Providence Inland Northwest Health: Joy Durham, Susan Erickson, Brian Hoots, Ed Kelly, Allison Lambert, Katherine Tuttle

ITHS and NW PCI Faculty and Staff: Jennifer Acosta, Amanda Amundsen, Liesje Bertoldi, Stepheny Bonner, Aurora Fonseca-Lloyd, Mihila Gomes, Laurie Hassell, Kiet Pham, Frank Pichinini, James Probus, Lisa Stromme-Warren

Let’s get to know each other!

Please introduce yourself and tell us about a time when a research volunteer, colleague or collaborator made you smile.

NW PCI Network Update

Robert H. Coker
Research Professor, Deputy Director
Montana Center for Work Physiology and Exercise Metabolism
University of Montana

Chair, NW PCI Network Steering Committee
Institute of Translational Health Sciences

Steering Committee Representatives

Amanda Amundson, Research Navigator, Seattle Children's

Laura Baker, Director, Pediatric Clinical Research Center, Research Nursing Services, Seattle Children's

Jamie Besel, Research Scientists, Billings Clinic

Elizabeth Brewer, Director, Research and Care Transformation, Kootenai Health

Jonathan Griffin, Chief Medical Innovation Officer, St. Peter's Health

Cindi Laukes, Director and Chief Operating Officer, Neural Injury Center; Research Affiliate Faculty, School of Integrative Physiology, The University of Montana; Research Navigator, ITHS

Annie Reedy, Chief Research and Education Officer, MultiCare Institute for Research & Innovation

Jodi Smith, Medical Director, Kidney Transplant, Seattle Children's

NW PCI Network Leadership and Coordinating Center Representatives

Katherine R. Tuttle, Executive Director for Research, Providence Health Care; Regional Co-Principal Investigator; Director, NW PCI Network, ITHS

Robert H. Coker, Deputy Director/Research Professor, Montana Center for Work Physiology and Exercise Metabolism, University of Montana; Chair, NW PCI Network Steering Committee, ITHS

Allison Lambert, Pulmonary and Critical Care Physician, Providence Health Care, Co-Director, NW PCI Network, ITHS

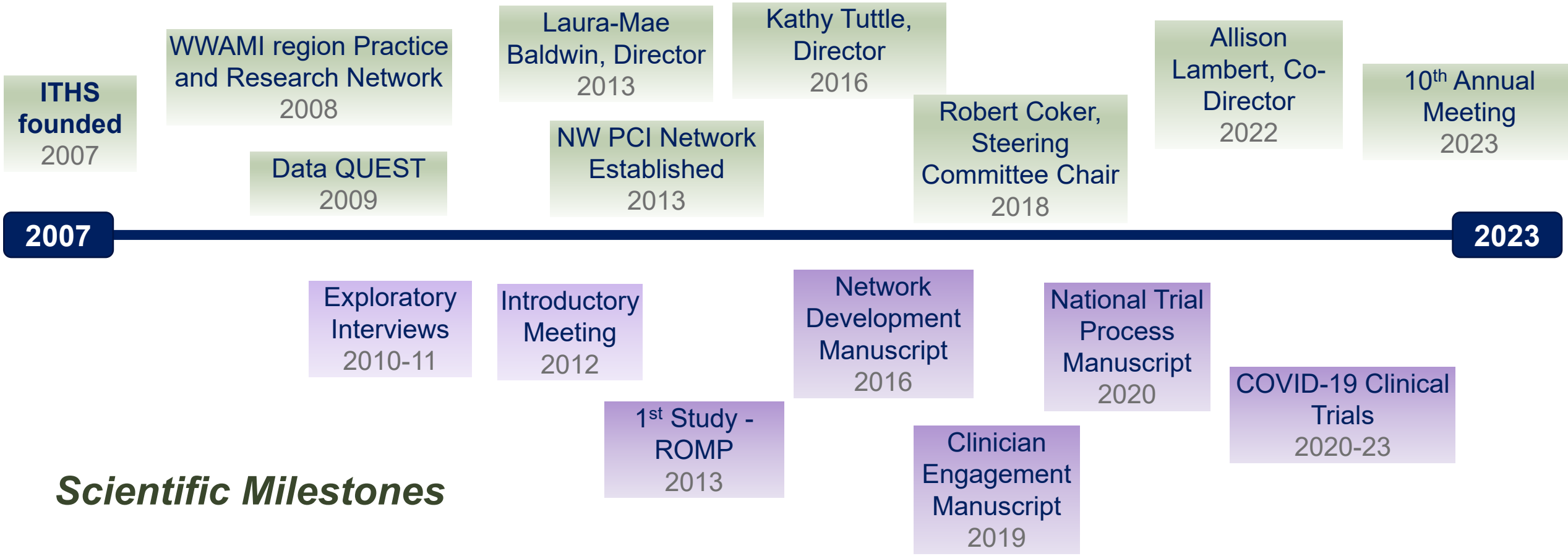
Laurie Hassell, Director of Community Engagement; Coordinator, NW PCI Network, ITHS

James Probus, Project Coordinator, NW PCI Network, ITHS

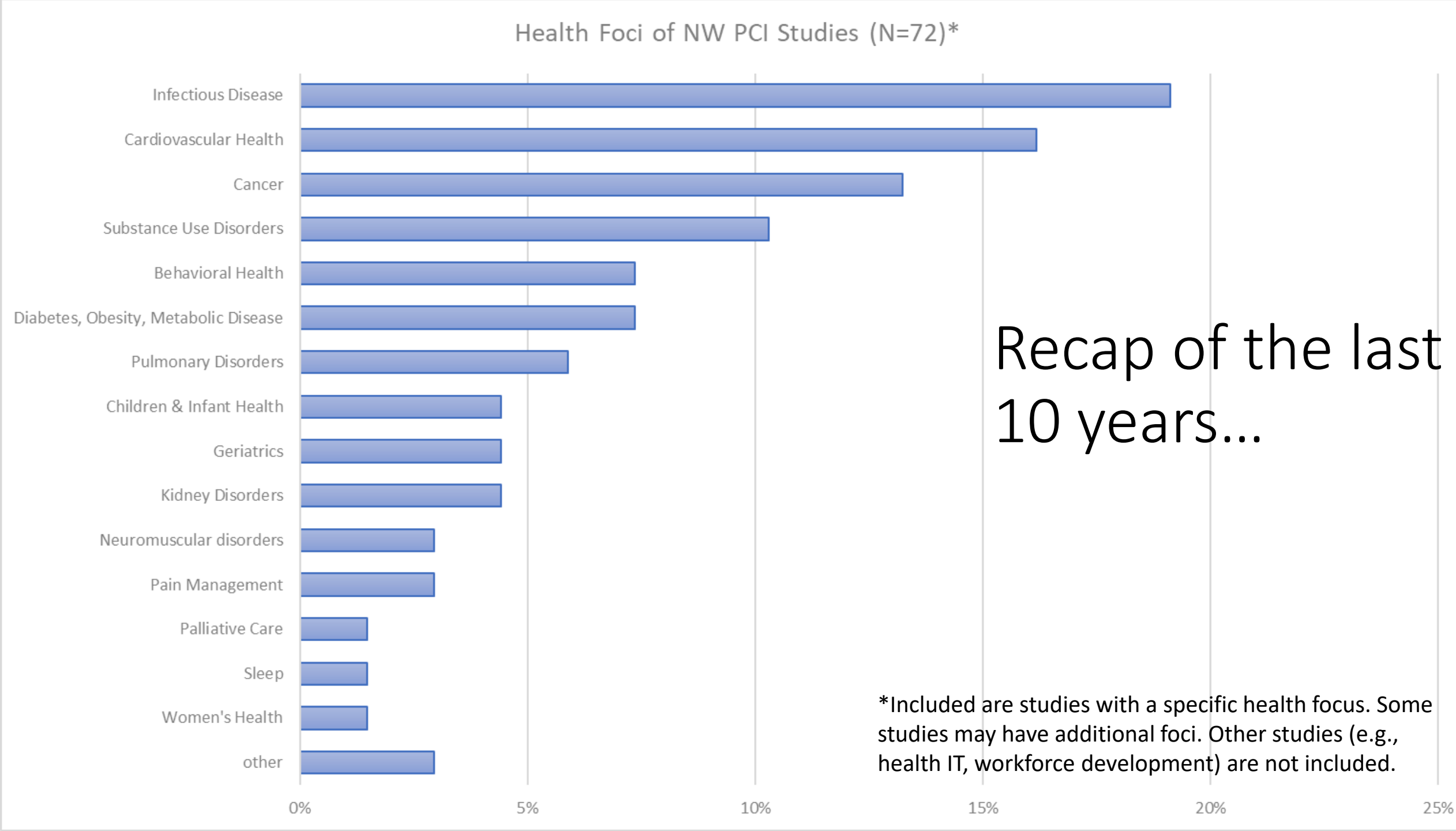
Jennifer Acosta, Data Analyst, Seattle Children's, ITHS

NW PCI History

Operational Milestones

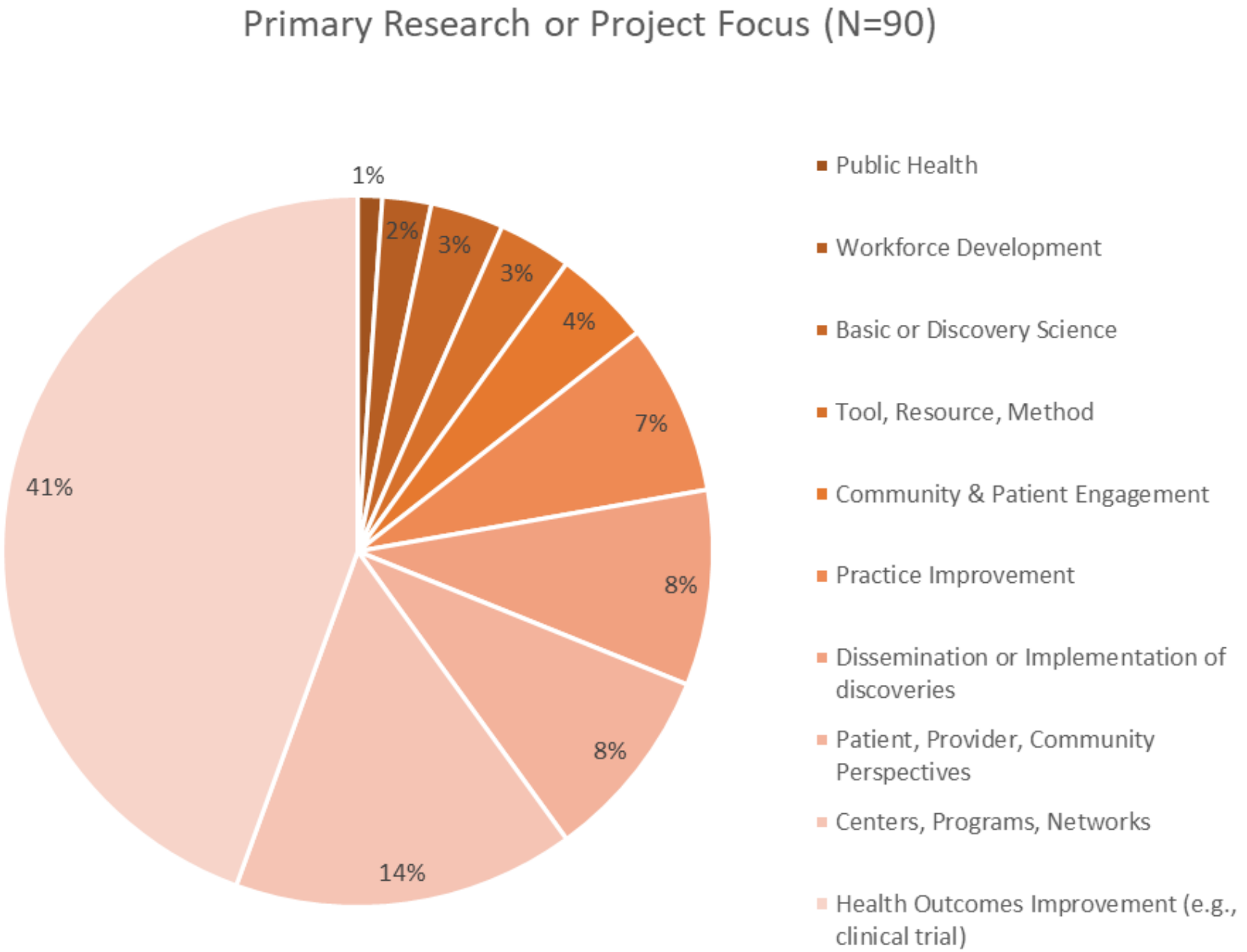


Scientific Milestones



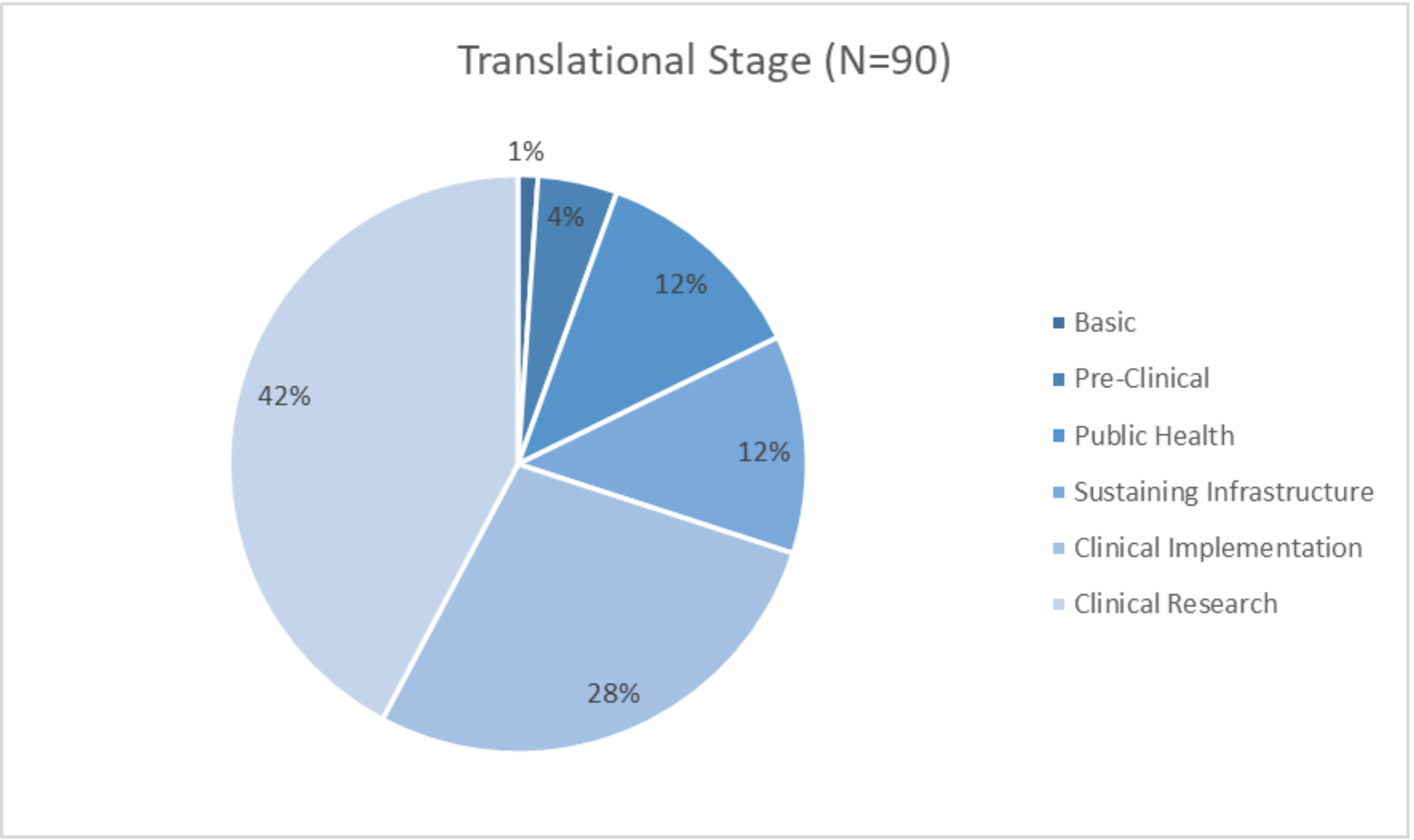
Recap of the last 10 years…

*Included are studies with a specific health focus. Some studies may have additional foci. Other studies (e.g., health IT, workforce development) are not included.



ITHS
Institute of Translational Health Sciences

Recap of the last 10 years…



ITHS
Institute of Translational Health Sciences

Recap of the last 10 years…

NW PCI Across the Board…

ITHS
Institute of Translational Health Sciences

Facilitated 165 matches with NW PCI sites

47% with rural serving sites

12 NW PCI sites were matched with 8 national COVID platform trials

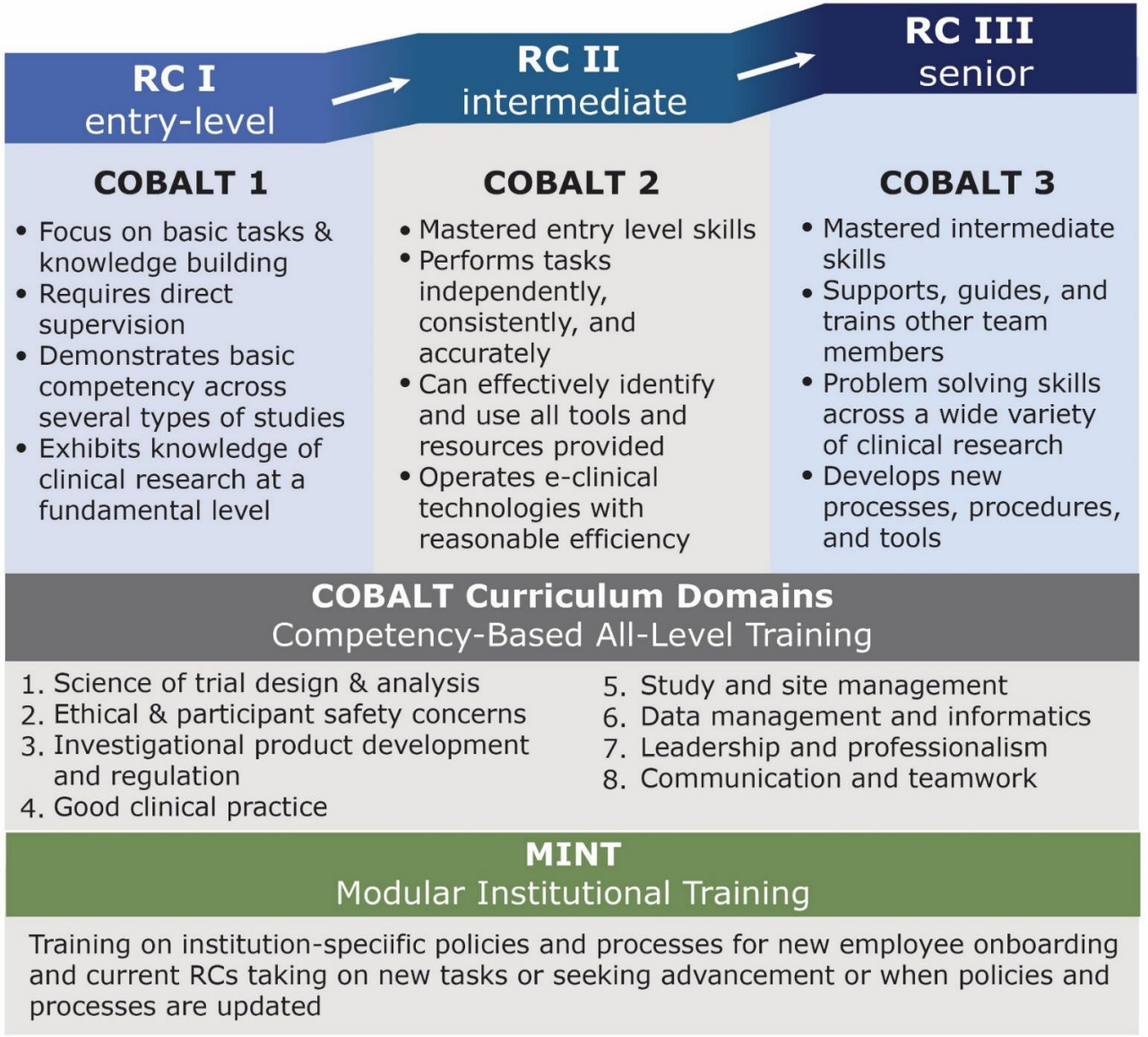
Supported submission of 62 grant applications

28 grants awarded from 21 funding organizations

$96M total

Collaborated with principal investigators at 27 institutions

COBALT UPDATE



MULTI-REGIONAL CLINICAL TRIALS
THE MRCT CENTER of BRIGHAM AND WOMEN'S HOSPITAL and HARVARD

Competency Domains

We'd like to know more about:

- How RCs find information about training?
- What are the critical training needs at your site?
- Will training modules meet your needs?

Laurie will send more information in the coming weeks.

Network Updates

Center for American Indian and Rural Health Equity (CAIRHE) Montana State University

Concluded a COVID-19 Testing Study

Led by Director Alexandra Adams, CAIRHE concluded their "Protecting Our Community: A Pragmatic Randomized Trial of Home-Based COVID-19 Testing with Native American and Latino Communities" study, which has moved into a publication and dissemination phase.

Promoting Indigenous Research Leadership Workshop (QR)

CAIRHE presented its third annual Promoting Indigenous Research Leadership workshop, a three-day event for Indigenous and other early-career faculty working with Indigenous communities in the US. This year's workshop is scheduled for November 13-15 in Tempe, Arizona.

Network Updates

Providence Medical Research Center

Center for Kidney Research, Education, and Hope (CURE-CKD) Work Highlighted in *Nature* (QR)

World Kidney Day 2023 articles reported on the enormous public health problem of Chronic Kidney Disease, and detailed CURE-CKD's work to reduce disparities in access to critical medications.

Providence leads Northwest regional consortium for the Cystic Fibrosis Foundation Therapeutic Development Network

The Providence Medical Group Cystic Fibrosis Care Center joined the Therapeutic Development Network in 2019 and now leads the Northwest Consortium, including sites from Seattle, Boise, Portland and Anchorage.

Network Updates

Kootenai Health

Opened Three New Clinical Trials

Specialties include neurology, infectious disease and pulmonology, which are all in new research foci for Kootenai Health.

Joined a Genomic Tumor Board Study

The study will bolster the site's oncology practice by providing an additional level of review and recommendation for patient treatment based on genomic testing results.

Clinical Trials Highlighted in Kootenai Health's Quarterly Publication (QR)

Read more about their work by following the QR code.

Network Updates

Montana Center for Work Physiology and Exercise Metabolism
University of Montana

Published Diversity, Equity, Inclusion and Accessibility Recommendations for the National Institutes of Health Clinical and Translational Science Award Program (QR)

Defined recommendations across institutional, programmatic, community-centered and social, cultural, and environmental focus areas.

Awarded Two Significant Grants

Received awards from the Air Force Research Laboratory and the Medical Technology Enterprise Consortium to study sex-specific differences in energy metabolism and muscle protein dynamics, respectively.

Published Works

"Physiology of Wildland Firefighting: Managing Extreme Energy Demands in Hostile, Smoky, Mountainous Environments" was published in the journal Comprehensive Biology.

Network Updates

Billings Clinic

NBC Montana's News Coverage of Billings Clinic Improving Access to Clinical Trials (QR)

Follow the QR code to watch the report.

Book Chapter Published in "The Oxford Handbook of Self—Determination Theory "

Besel, J.M., Williams, G. (23 February 2023). The Ethics and Practice of Autonomy-Supportive Medicine. In R. Ryan (Editor), The Oxford Handbook of Self-Determination Theory. Oxford University Press.

Billings Clinic

We care where you are.

Opportunities and Barriers to Genetic Testing Among Rural and Urban Populations

Jamie M. Besel, Ph.D., RN

Research Nurse Scientist, Billings Clinic – Billings, MT

Conflict of Interest

- Nothing to disclose

Research Partners:

- Co-Principal investigators:
  - Deborah Bowen, PhD (UW)
  - Elizabeth Swisher, MD (UW)
- Co-Investigators:
  - Jeannine Brant, PhD (Billings Clinic)
  - Catharine Wang, PhD, MSc (Boston University)
  - Michael Raff, MD (MultiCare Health System)
  - Allison Cole, MD (UW)
  - Barbara Norquist, MD (UW)
  - Sarah Knerr, PhD (UW)
  - Beth Devine, PharmD, PhD (UW)

Funding: National Cancer Institute; U01 CA232795-01A1

EDGE
Early Detection of GEnetic risk

Billings Clinic Team:
Laurie Riemann, RN, BSN
Jamie M. Besel, PhD, MN, RN
Yvonne Mullowney, BS

University of Washington Team:
Heather Harris
DaLaina Cameron
EJ Dusic, MPH
Tesla Theoryn, MEd
Faith Beers

UW Medicine

DEPARTMENT OF
BIOETHICS & HUMANITIES

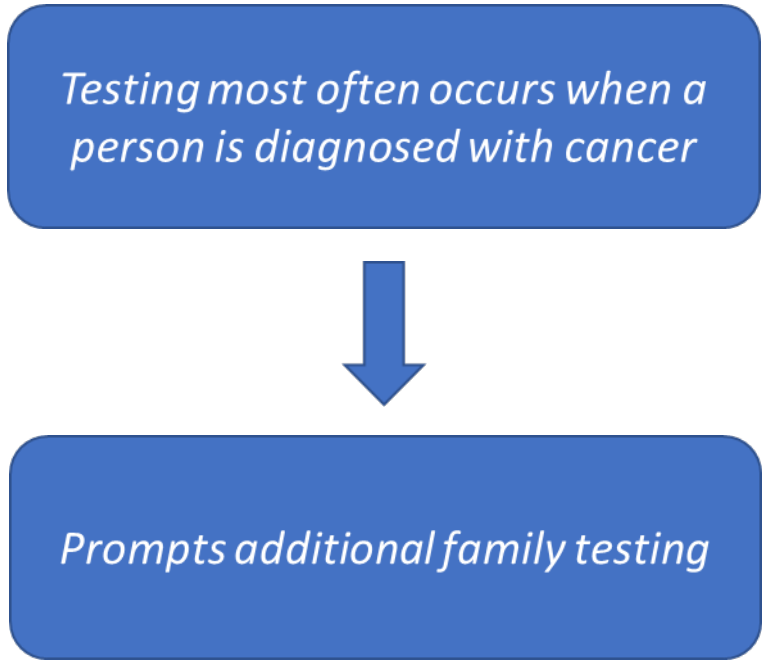
Health through Social Justice

In Memoriam

Deb Bowen, PhD
Professor

Background & Significance

- Genetic testing for cancer risk has been recommended > 10 years
- No best practices are identified for healthcare systems to increase uptake
- Uptake of testing is still quite low at 20%
- Studies to date have been conducted in high resourced facilities, under optimal conditions
- Few studies have examined underserved populations' knowledge, attitudes, reasons towards genetic testing



Rural Nursing Theory

- Definition of health from perspective of rural person (Long & Weinert, 1989; Winters & Lee, 2018)
  - Ability to work and do usual tasks, be productive
- Rural dwellers are self-reliant
  - Concepts: Outsider, insider, old-timer, newcomer
- Posited that rural persons prefer to seek healthcare from persons they are familiar with, termed “insiders.”
- Health care-seeking behaviors
  - Great distances from a health care facility
  - Do not feel isolated
- Rely on family, relatives, and close friends for help and support before seeking care from a healthcare provider

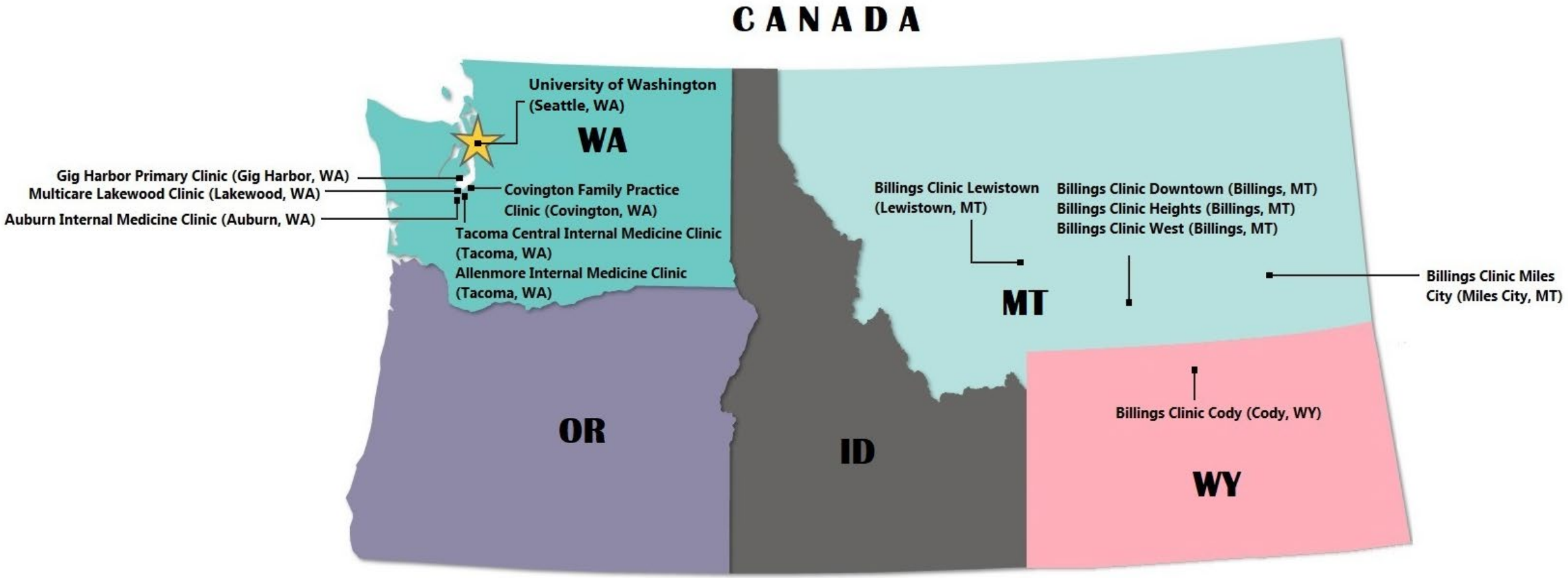
Study Design -Overall

- Randomized controlled trial of two methods of engaging patients in the genetic testing process
  - Arm 1: Approach at a primary care visit (point of care)
  - Arm 2: Contact outside of an office visit via mailed letter (direct patient engagement)
- Outcomes:
  - Proportion of patients who complete risk assessment screening
  - Proportion of patients who complete genetic testing
- Secondary outcomes include:
  - Patient, provider and healthcare leader genetic literacy and attitudes about genetic testing
  - Cost-effectiveness and budget impact of each screening strategy

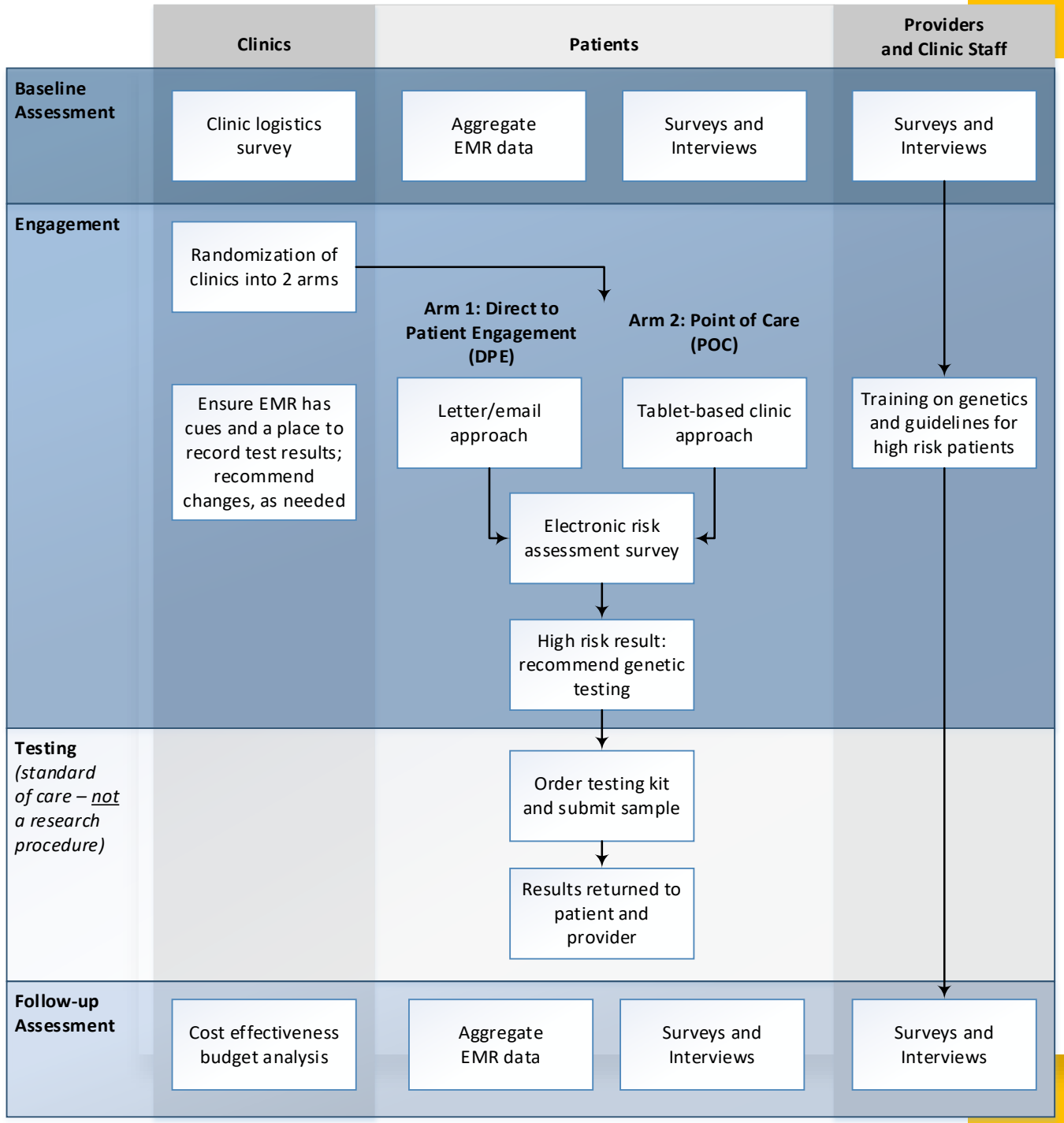
Study Purpose

- The purpose of this study was to examine the attitudes and potential barriers to getting genetic testing among patients attending rural and urban primary care clinics using baseline data from the Early Detection of Genetic Risk (EDGE) study.

Map of EDGE Clinics - Settings

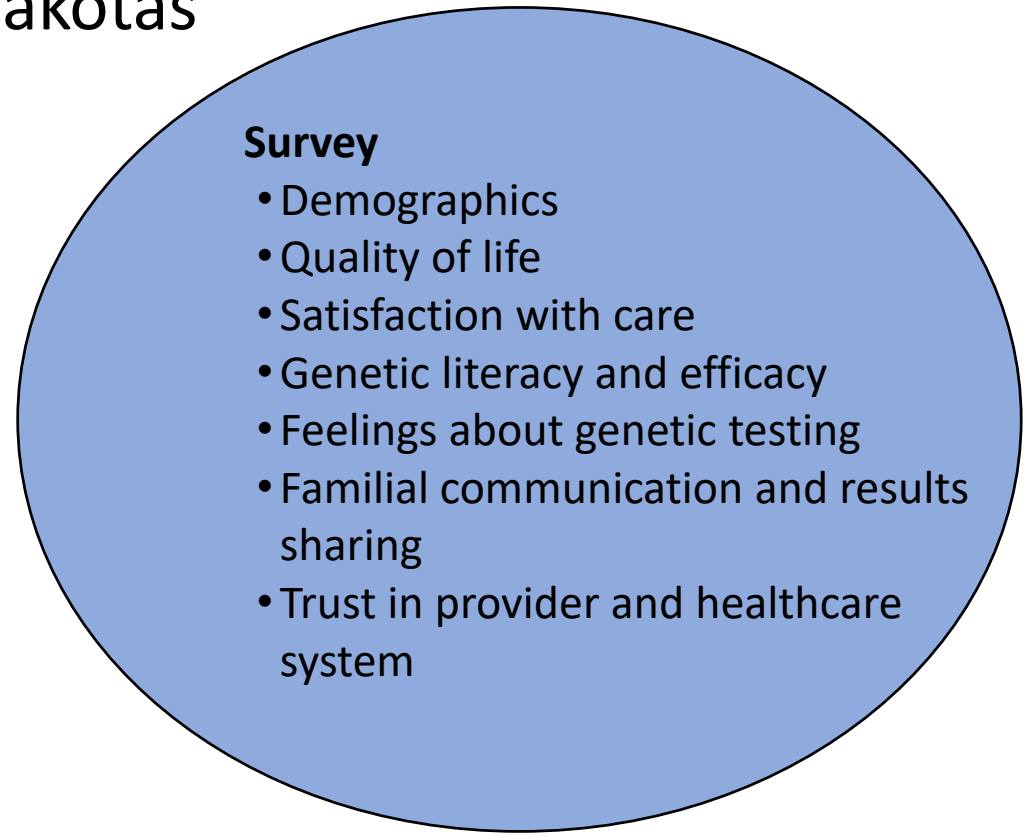


Procedures


Clinics
Patients
Providers and Clinic Staff
Baseline Assessment
Clinic logistics survey
Aggregate EMR data
Surveys and Interviews
Surveys and Interviews
Engagement
Randomization of clinics into 2 arms
Arm 1: Direct to Patient Engagement (DPE)
Arm 2: Point of Care (POC)
Ensure EMR has cues and a place to record test results; recommend changes, as needed
Letter/email approach
Tablet-based clinic approach
Training on genetics and guidelines for high risk patients
Electronic risk assessment survey
High risk result: recommend genetic testing
Testing (standard of care – not a research procedure)
Order testing kit and submit sample
Results returned to patient and provider
Follow-up Assessment
Cost effectiveness budget analysis
Aggregate EMR data
Surveys and Interviews
Surveys and Interviews

Methods

- 3 rural and 3 urban primary care clinics
- Healthcare network serving MT, WY, Dakotas
- Age 25 years or older
- Self-administered baseline survey
- Analysis
  - Rural versus Urban
  - Univariate, descriptive
  - Independent t-tests



Participants

Characteristics (n=1285)	Rural (n=622)		Urban (n=663)	
	No. of Participants	%	No. of Participants	%
Age, years Mean (SD)	61.7 (15.1)		60.9 (15.9)	
Gender (Female)	359	58%	412	63%
Race* (white)	591	95%	620	94%
Ethnicity (Not Hispanic or Latino)	544	88%	594	90%
Education				
Lower than Associate's Degree	259	42%	253	38%
Associate's Degree or Higher	354	57%	408	62%
Insurance*				
Only No Insurance or Non-commercial Insurance	418	40%	426	37%
Commercial insurance	372	60%	415	63%
Household size**				
>2	146	24%	171	27%
≤2	448	72%	463	73%
Household Income				
<$75,000	306	50%	311	48%
≥$75,000	304	49%	340	52%

* Participants had the option to select more than one response. Participants who selected more than response were counted for each box they checked.
** Participants were given the selection one through ten on the survey, but responses have been grouped for analytic purposes

Results

- 6.1% of patients attending rural clinics have had genetic testing vs. 5.4% of patients attending urban clinics
- ~25% of patients at either urban or rural clinics had a personal history of cancer
- Patients attending rural clinics are less certain about discussing family health history with members of their family compared to patients attending urban clinics (60.1% vs. 57.8%)

Results – Interest and Motivation

Variables	Rural	Urban	t-test	95% CI
	M (SD)	M (SD)		
If your family and personal history suggested you were high risk for cancer, how interested would you be in genetic testing?	3.35 (1.18)	3.49 (1.24)	-2.09*	[-0.273,-0.009]
I would get genetic testing to determine if my family members should have genetic testing.	3.7 (1.06)	3.8 (1.07)	-1.59 (ns)	[0.06, -0.21]
I would get genetic testing if my doctor recommended it.	3.89 (0.93)	3.94 (0.99)	-0.99 (ns)	[-0.158, 0.052]
I would get genetic testing if the test was free/low cost.	4.13 (0.93)	4.19 (0.96)	-1.04 (ns)	[-0.159,-0.049]

* Statistically significant, where $p < 0.05$
** Statistically significant, where $p < 0.01$

Results - Trust

Variables	Rural	Urban	t-test	95% CI
	M (SD)	M (SD)		
How sure are you that you could discuss family health history with members of your family?	2.91 (1.15)	2.99 (1.11)	-1.34 (ns)	[ ]
How much would you trust information about health or medical topics from… ➢ A doctor	1.31 (0.55)	1.26 (0.5)	1.96*	[0.00,0.115)
➢ Government health agency	2.58 (0.93)	2.37 (0.95)	3.95**	[-0.105, -.0312]
➢ Religious organizations & leaders	3.12 (0.84)	3.29 (0.82)	-3.64**	[-0.261,-0.78]

* Statistically significant, where $p < 0.05$
** Statistically significant, where $p < 0.01$

Results – PSQ-18

Variables	Rural	Urban	t-test	95% CI
	M (SD)	M (SD)		
Those who provide my medical care sometimes hurry too much when they treat me.	2.42 (0.96)	2.59 (1.07)	-3.11**	[0.057,-0.289]
Doctors sometimes ignore what I tell them.	2.39 (0.94)	2.54 (1.05)	-2.71**	[0.046,-0.261)
I find it hard to get an appointment for medical care right away	2.60 (1.1)	3.05 (1.2)	-7.11**	[0.064,-0.58]

* Statistically significant, where $p < 0.05$
** Statistically significant, where $p < 0.01$

Discussion

- Rural clinic patients
  - Trust - healthcare providers (HCPs), government officials
  - Felt HCPs were more prepared to provide care
  - Did not feel as comfortable discussing family health history with family members
- Urban clinic patients
  - Trust – religious organizations and leaders
  - Difficulty with accessing healthcare needs, including medical specialists
  - HCPs rush care, less opportunity to discuss
- Study adds to limited knowledge about patients seeking care at rural vs. urban primary care clinics and genetic testing

Limitations

- Baseline survey
- Generalization of findings limited
- Limited analysis – only an overview
- Next steps –
  - Analysis of all clinics from EDGE study
  - Zip codes of participants vs. clinic

Take home messages

- Opportunities exits to mitigate sociocultural and structural barriers for genetic testing and surveillance – rural and urban
- Important to understand relationship between knowledge and attitudes towards genetic testing
- Future research – explore how to best reach underserved, rural populations
- Nurses and healthcare providers play crucial role:
  - Building trust
  - Identifying who may benefit from genetic testing
  - Providing support and education

Thank you!

Trial Innovation Network:

Resources for NW PCI Network Members

Charlie Gregor
Manager
Hub Liaison Team
Institute of Translational Health Sciences

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

ITHS Hub Liaison Team

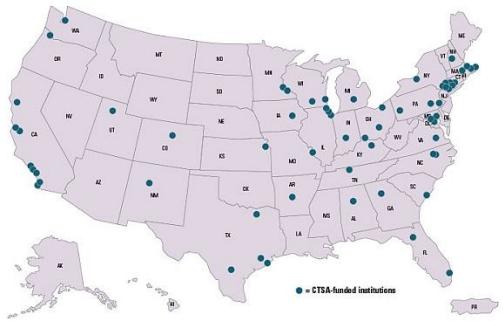
- Advance the use of remote technologies in research
- Multi-site clinical trial management
- Engage in national informatics endeavors

- Liaison with the Trial Innovation Network
- Endorse interventions to speed and ease the implementation of multi-site clinical studies

The Trial Innovation Network (TIN)

64 CTSA Program Sites

CTSA Clinical & Translational Science Awards Program



ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

TRIAL INNOVATION NETWORK

Mission

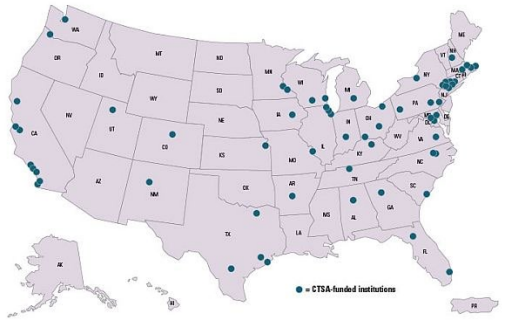
- To leverage the talent, expertise, and resources of the **CTSA program**
- To act as a national laboratory to study, understand, and improve **multi-site trials**
- To inform healthcare by supporting successful **multi-site trials** that answer important clinical questions

CTSA Clinical & Translational Science Awards Program

The Trial Innovation Network (TIN)

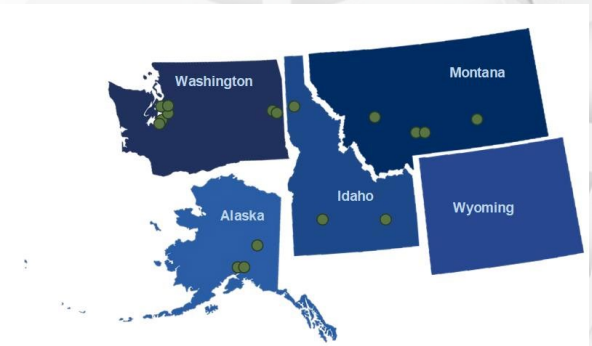
64 CTSA Program Sites

CTSA Clinical & Translational Science Awards Program



TIN Innovation Centers

ITHS Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.



TRIAL INNOVATION NETWORK

CTSA Clinical & Translational Science Awards Program

Finding Partners

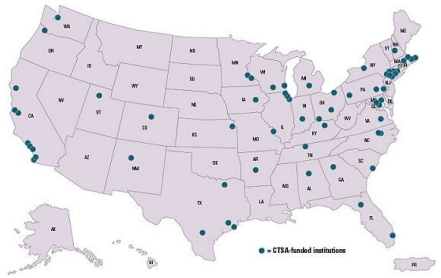
connecting researchers through the CTSA networks

Research site seek partners

(connects with TIN)

TIN enhances study design and recruitment strategies

TIN co-develops partnership criteria, site selection criteria, regulatory process and information packets



TIN Innovation Centers

TIN Innovation Centers

TRIAL INNOVATION NETWORK

CTSA Clinical & Translational Science Awards Program

Finding Partners

connecting researchers through the CTSA networks

CTSA Hub Liaison Teams are engaged

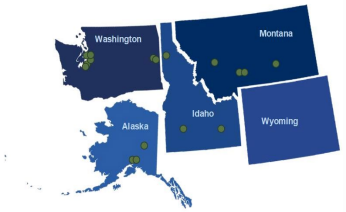
HLT pre-screening for Network fit

Modified site selection process (feasible and time-efficient)

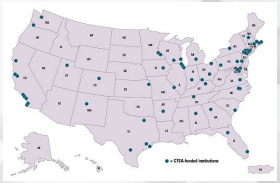
Co-submit start-up materials

Ongoing advocacy for Network sites

TIN Innovation Centers



ITHS Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.



TIN Innovation Centers

ITHS Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

TRIAL INNOVATION NETWORK

CTSA Clinical & Translational Science Awards Program

Connecting The Network with Multi-Site Trials (N=10)

Cardiovascular

- REACT-AF
- CINEMA
- PRECEDE

Influenza

- COMBO AC

Alzheimer's

- MAP

COVID-19

- ACTIV-1
- ACTIV-2
- ACTIV-6
- PassItOn
- DeCODe

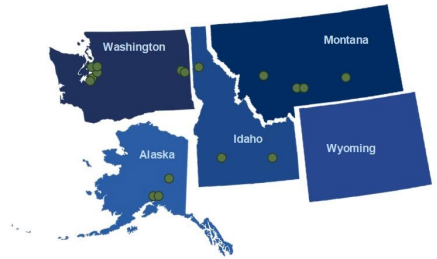
TRIAL INNOVATION NETWORK

CTSA Clinical & Translational Science Awards Program

Connecting The Network with Multi-Site Trials

PASS IT ON
PASSIVE IMMUNITY TRIAL FOR OUR NATION

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.



SEATTLE
WASHINGTON

THE GREAT SEAL OF THE STATE OF MICHIGAN
E PLURIBUS UNUM
TUEBOR
CIRCUMSPICE
A.D. MDCCCXXXV.

SEAL OF THE STATE OF ILLINOIS
AUG. 26TH 1818
1868
1818

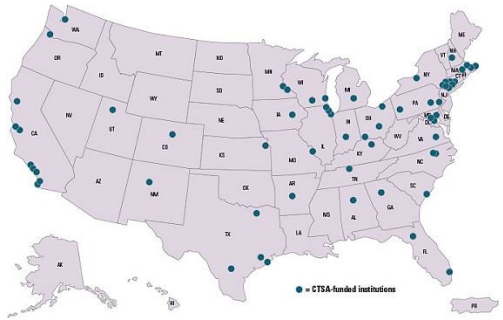
TRIAL INNOVATION NETWORK

CTSA Clinical & Translational Science Awards Program

The Trial Innovation Network - bidirectional

64 CTSA Program Sites

CTSA Clinical & Translational Science Awards Program



TIN Innovation Centers

TRIAL INNOVATION NETWORK

ITHS Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

CTSA Clinical & Translational Science Awards Program

The Trial Innovation Network Services

- Protocol development
- Study Design
- Study Budget
- Single IRB (cost per study budget)
- Recruitment Feasibility Assessment
- Site identification
- Recruitment
- Community Engagement Studio
- EHR-Based Cohort Assessment
- Innovations in Clinical Effectiveness Trial Design

TRIAL INNOVATION NETWORK

CTSA Clinical & Translational Science Awards Program

Charlie Gregor

Trial Innovation Network, ITHS Point of Contact

cgregor2@uw.edu

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

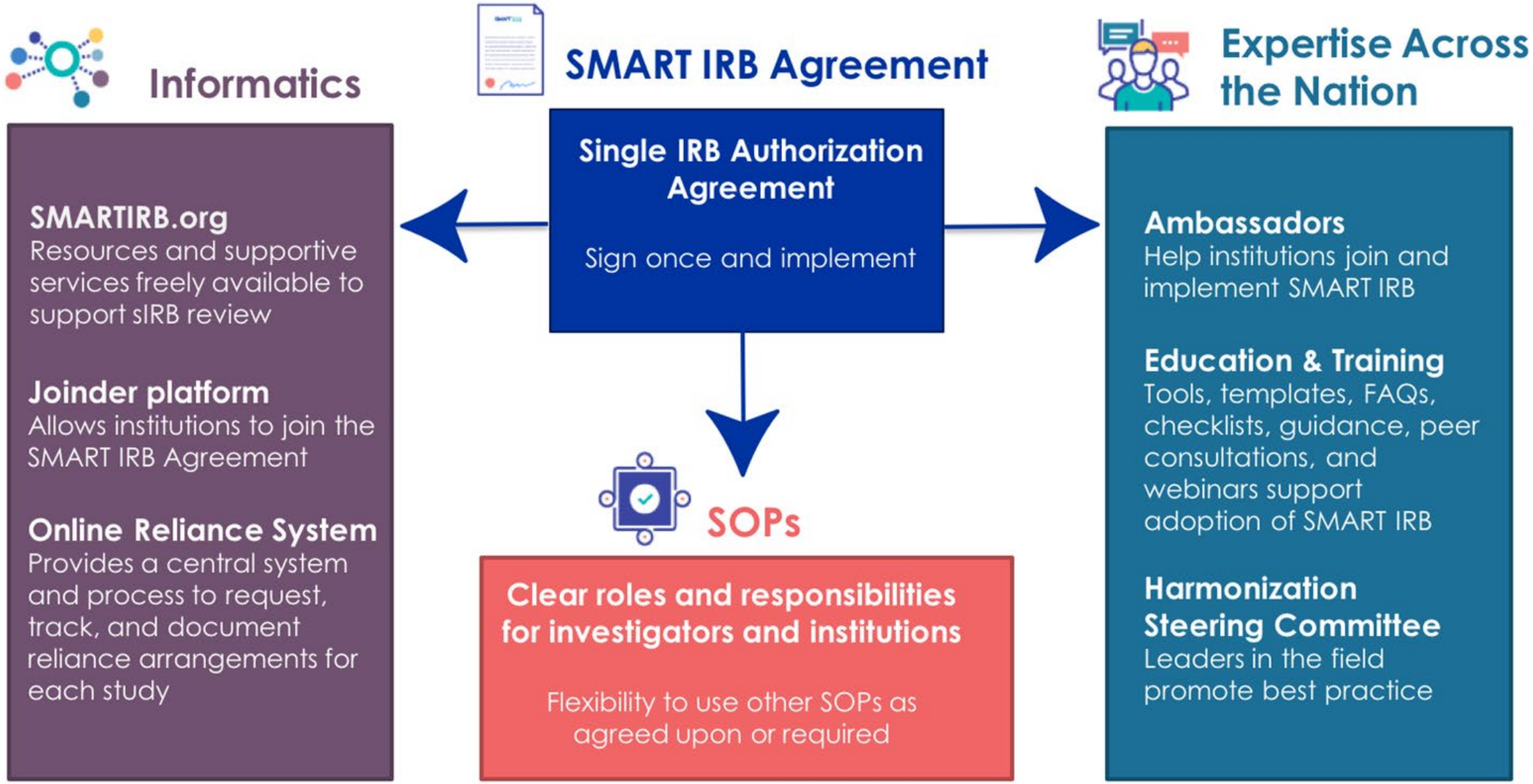
- UW, Director of Reliance
- HLT regulatory & sIRB subject matter expert
- Transitioned UW through the single IRB mandates
- Opened UW to providing SIRB for UW investigators
- Former SMART IRB Ambassador

The SMART IRB Agreement and Resources

Adrienne Meyer
Institute of Translational Health Sciences & UW Human Subjects Division
Assistant Director of Reliances

ITHS | Institute of Translational Health Sciences

ACCELERATING RESEARCH. IMPROVING HEALTH.



ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

Why join SMART now?

- Reduces need to negotiate IRB reliance terms on a study-specific basis.
- Pre-negotiated terms help institutions to align institutional policies and practices to support reliance on a single IRB.
- **Institutions may be required to use SMART to rely on a single IRB for TIN studies or other NIH funded research. Becoming a SMART participating institution now will prepare the institution for rapid onboarding for future research.**

Steps to becoming a SMART Participating Institution

1. Confirm that your institution has an active Federalwide Assurance (FWA)
2. Review the terms of the agreement at https://smartirb.org/agreement/
   - May require review by your legal or other departments
3. Sign and submit your joinder agreement in the SMART online joinder platform
4. Wait for activation
5. Review the SMART resources at https://smartirb.org/resources/
6. Join in discussions at monthly SMART Talks https://smartirb.org/irb-admin/#smartTalk

SMART IRB Ambassadors can help you with the joinder process. Find and contact your ambassador at smartirb.org/ambassadors

UW TIN IRB Liaison available to consult on how to plan for implementing SMART at your institution, including how UW uses SMART with relying institutions. Contact Adrienne Meyer at gevjon@uw.edu.

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

SMART Start-up Package For Relying Institutions

- Responsibilities Associated with the Review of Study Personnel
- Relying Institution PI Checklist
- FAQs for Research Teams - Relying on an External IRB
- Customizable Training Presentations
- Video: Responsibilities of Relying Institutions
- Video: Implementing the SMART IRB Agreement

Guidance on how to use SMART in this resource and more at https://smartirb.org/resources/

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

- Oversees contracts and agreements at UW
- HLT contracts & agreements subject matter expert
- Liaison with the Accelerated Research Agreements initiative
- Available to discuss standard agreement templates

Standard Agreements and Templates

Jennifer Lopez
Institute of Translational Health Sciences & UW Office of Sponsored Programs
Assistant Director, Research Partnerships and Contracts Management

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

Why are standard agreements useful?

Launching studies in multiple institutions is a complex process that can take many months.

One of the main reasons for the time delays associated with launching studies is the review and negotiation process for various agreements associated with research activities.

For each new study, several agreements may need to be reviewed, including confidential disclosure, clinical trial, data use, and material transfer agreements.

What are the CTSA standard agreements?

CTSA-DTUA

Data Transfer and Use Agreement

facilitates a more streamlined process for transfer and use of data between sites.

FDP-CTSA

Fixed Price Clinical Trial Subaward Agreement

a sub-award template for federally funded clinical trials negating the need for tedious negotiations. Approved for use by the CTSA stakeholders, the NIH, and the FDP.

Other useful non-CTSA agreements

ACDA

Accelerated Confidential Disclosure Agreement

protocols can be obtained by participating sites without confidentiality agreement negotiation

ACTA

Accelerated Clinical Trial Agreement

sponsor-initiated multi-site trials. This streamlined process reduces delays in contract negotiations

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

Accelerated Research Agreements Initiative

- To help expedite the study initiation process, the Accelerated Research Agreements Initiative provides participating institutions and organizations with pre-approved agreements that are acceptable to all parties involved.
- By using these pre-approved agreements, researchers and sponsors can avoid lengthy negotiation periods and accelerate the start of their studies, ultimately saving time and resources.
- For more information on the use of standard and accelerated research agreements and to download templates for use, please visit:

https://ara4us.org/

Questions about the:
Trial Innovation Network,
SMART IRB Agreement,
contract and agreement templates

cgregor2@uw.edu

ITHS | Institute of Translational Health Sciences
ACCELERATING RESEARCH. IMPROVING HEALTH.

Research as a driver of evidence-based practice… An equity and inclusion lens

Margaret Rosenfeld, MD, MPH

Seattle Children's Research Institute

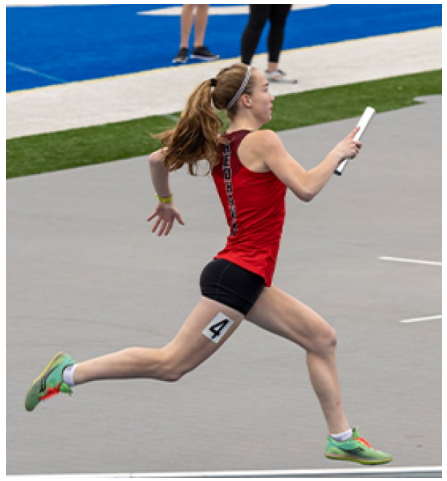
Department of Pediatrics, University of Washington

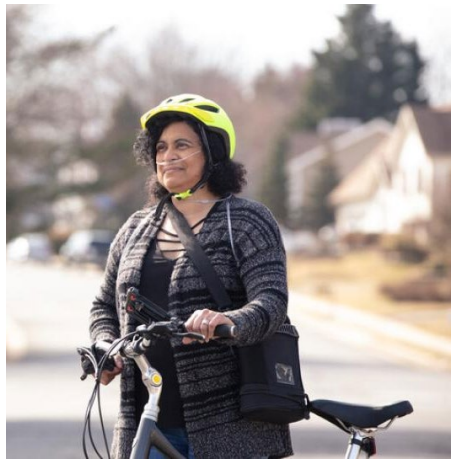
The Bonnie Ramsey Keynote Lectureship

Disclosures

- Grant funding from NIH, Cystic Fibrosis Foundation

The Faces of Cystic Fibrosis





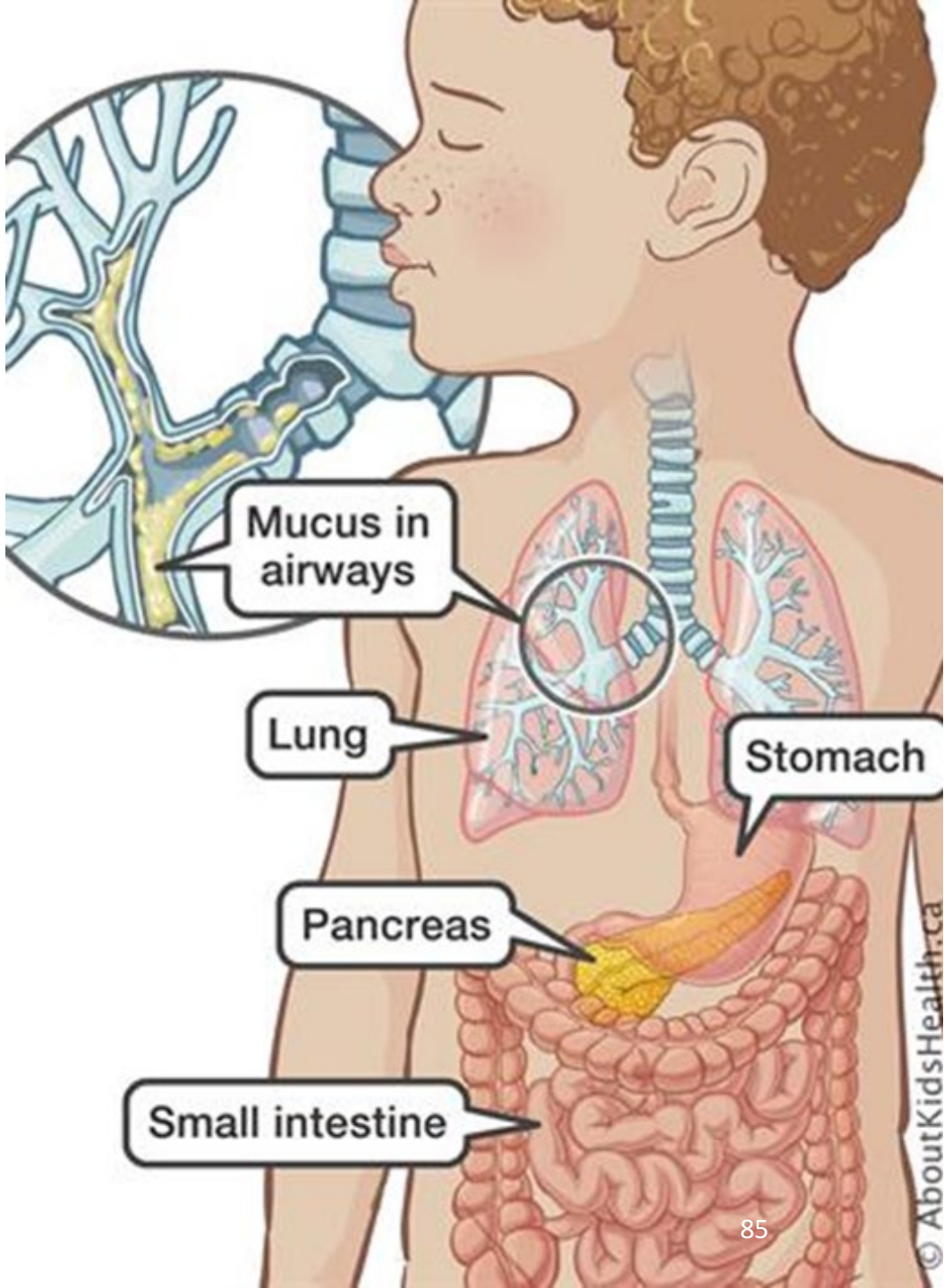
What is Cystic Fibrosis (CF)?

Genetic condition affecting all races/ethnicities

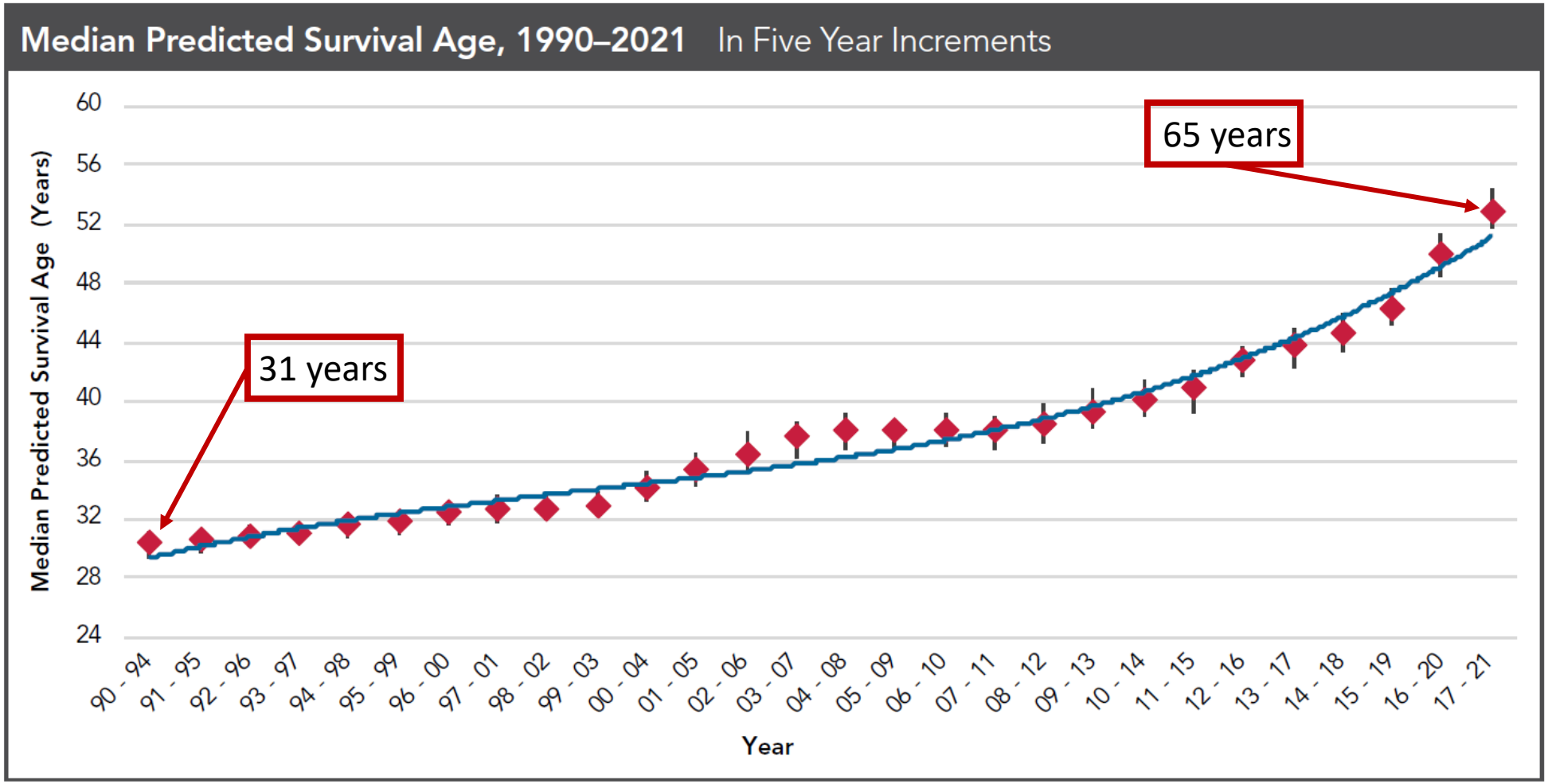
Affects multiple organ systems

Burdensome treatments and recurrent hospitalizations

Despite significant advances, remains a life-shortening disease



Dramatic Improvements in CF Survival



As researchers, we aim to drive change in clinical practice – What is required?

- Clinical trials that
  - Address an important question
  - Representative study population
  - Rigorous study design
  - Meaningful outcomes
- Who are our stakeholders?
  - Patients who stand to benefit from new therapies/approaches
  - Providers prescribing these therapies

Improving diverse engagement in research leads to better evidence

Research participants need to be representative of the study population

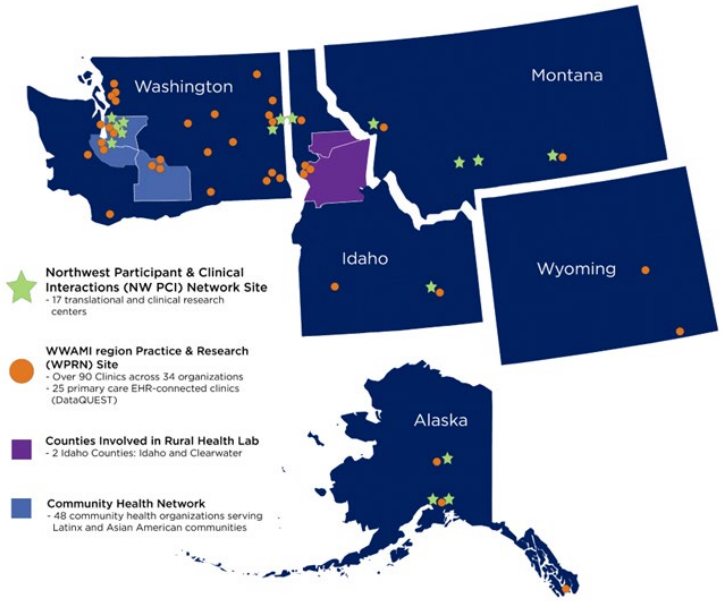
Study design and procedures need to feel reasonable to potential participants

Results need to be meaningful to our patient and community stakeholders

Bonnie Ramsey built multicenter clinical trial networks to promote innovation and discovery

CYSTIC FIBROSIS FOUNDATION
THERAPEUTICS
DEVELOPMENT NETWORK

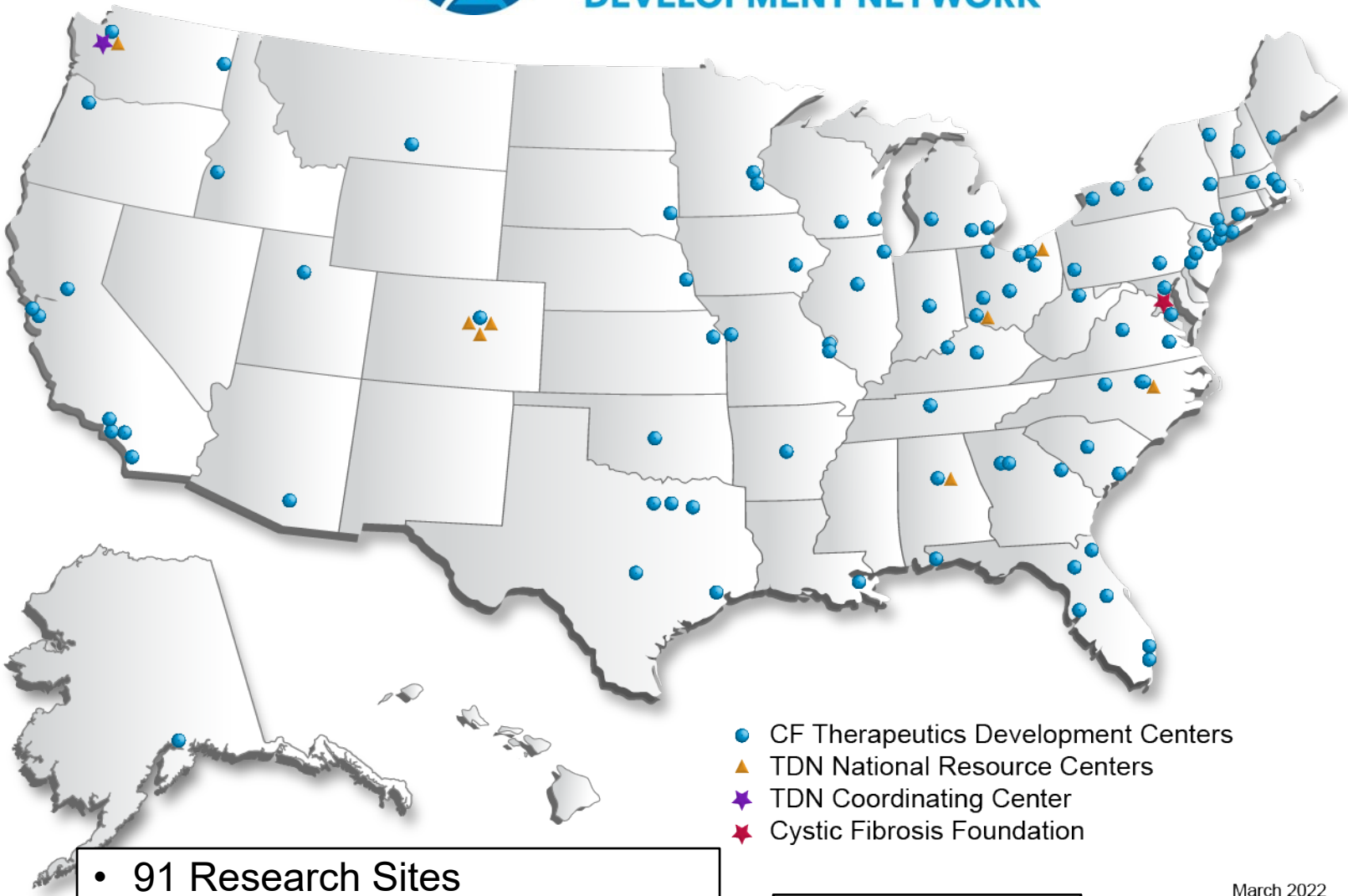
- National
- Disease-specific
- Patients are seen in specialty clinics



- Regional
- Rural
- Community-based

CYSTIC FIBROSIS FOUNDATION

THERAPEUTICS DEVELOPMENT NETWORK



- 91 Research Sites
- >150 Investigators
- >330 Research Coordinators

23,750 patients

March 2022

Three themes for today from my work in CF, prioritizing equity and centering the participant voice

Remote endpoints for clinical trials	Could decrease participant burden and increase access to clinical trials for under-represented groups
Co-production	Engaging patients or community members as partners in study design
Ensuring equitable diagnosis of CF	CF newborn screening

Remote Clinical Trial Endpoints

- COVID pandemic accelerated teleresearch and remote endpoint ascertainment
- Opportunity for paradigm shift in clinical trial design
  - “Bring the trial to the patient”
- Has potential to improve participant experience, reduce burden and improve access to clinical trial participation

Remote Clinical Trial Endpoints – We Must Get it Right!

CF Remote Endpoints

Home spirometry	Digital cough monitors	Home respiratory sample collection	Capillary blood self-collection
Continuous glucose monitors	Digital scales	Wearables (actigraphy, RR, oxygen saturation)	Electronic patient reported outcomes

CFF Remote Endpoint Taskforce

- Systematic evaluation of remote endpoints relative to CF clinical trials
- Members are content experts and people with CF

The example of home spirometry

- Key clinical trial endpoint
- Requires training to perform correctly
- During pandemic, pivot to remote spirometry for clinical care
- Accuracy and feasibility in research setting unknown

Ongoing prospective, longitudinal, multi-center observational study comparing home to office spirometry in children and adults with CF

Aims to address key unanswered questions for replacing or supplementing office with home spirometry in CF clinical trials of the future

- Is home spirometry accurate?
- How variable are home measures?
- Does virtual coaching improve measurement quality?
- What is the adherence to weekly home measurements?
- What is the feasibility and acceptability of home measurements from the perspective of participants and of the research team?

Three themes for today from my work in CF

Remote endpoints for clinical trials	Could decrease participant burden and increase access to clinical trials for under-represented groups
Co-production	Engaging patients or community members as partners in study design
CF Newborn Screening	Ensuring equitable detection of CF

Focus Groups - Qualitative Needs Assessment

Perspectives of PwCF

- Most found home spirometry convenient
- Many experienced technical barriers, reported a “learning curve” to home measurement, and expressed uncertainty about the quality and reliability of home measurements

Perspectives of research coordinators

Major barriers identified by RCs

- Tailoring participant training to individual needs
- Scheduling remote coaching
- Performing effective coaching remotely

Qualitative Needs Assessment: Summary

Important recommendations provided by PwCF and RCs during focus groups

Incorporating these recommendations made the protocol stronger and better able to meet the needs of our key stakeholders

Co-production in OUTREACH

Given barriers and facilitators identified through focus groups, we convened a *co-production study group* to develop OUTREACH materials with goal of *optimizing the experience of study participants and research coordinators*

Participant-facing materials

Research coordinator-facing materials

What is Co-production?

"The interdependent work of users and professionals who are creating, designing, producing, delivering, assessing, and evaluating the relationships and actions that contribute to the health of individuals and population"[1]

Principles

- Collaboration between professionals & "end users"
- Co-creation of value
- Enhance convenience, efficiency & cost-effectiveness

Who participated?

People with CF, including a caregiver/parent for a child with CF

Research coordinators, including a respiratory therapist

Members of the research team

How did we engage in co-production?

- Biweekly meetings over 5 months via zoom
- Each meeting had a specific focus
  - Pre-meeting input (“Pre work”)
  - Synthesis of input for targeted discussion
  - Post meeting feedback survey

Meeting	Focus
1	Consent from
2	Set up and maintenance
3	How to do virtual coaching
4	Mock virtual coaching
5	How to do a PFT at home
6	Video resources
7	Revisiting remote coaching
8	Supporting kids and caregivers

What did we co-produce?

- Consent form
- User guides
  - Research participant
  - Research coordinator
- Video guides
  - (link to video)
- All materials in English and Spanish

Three themes for today from my work in CF

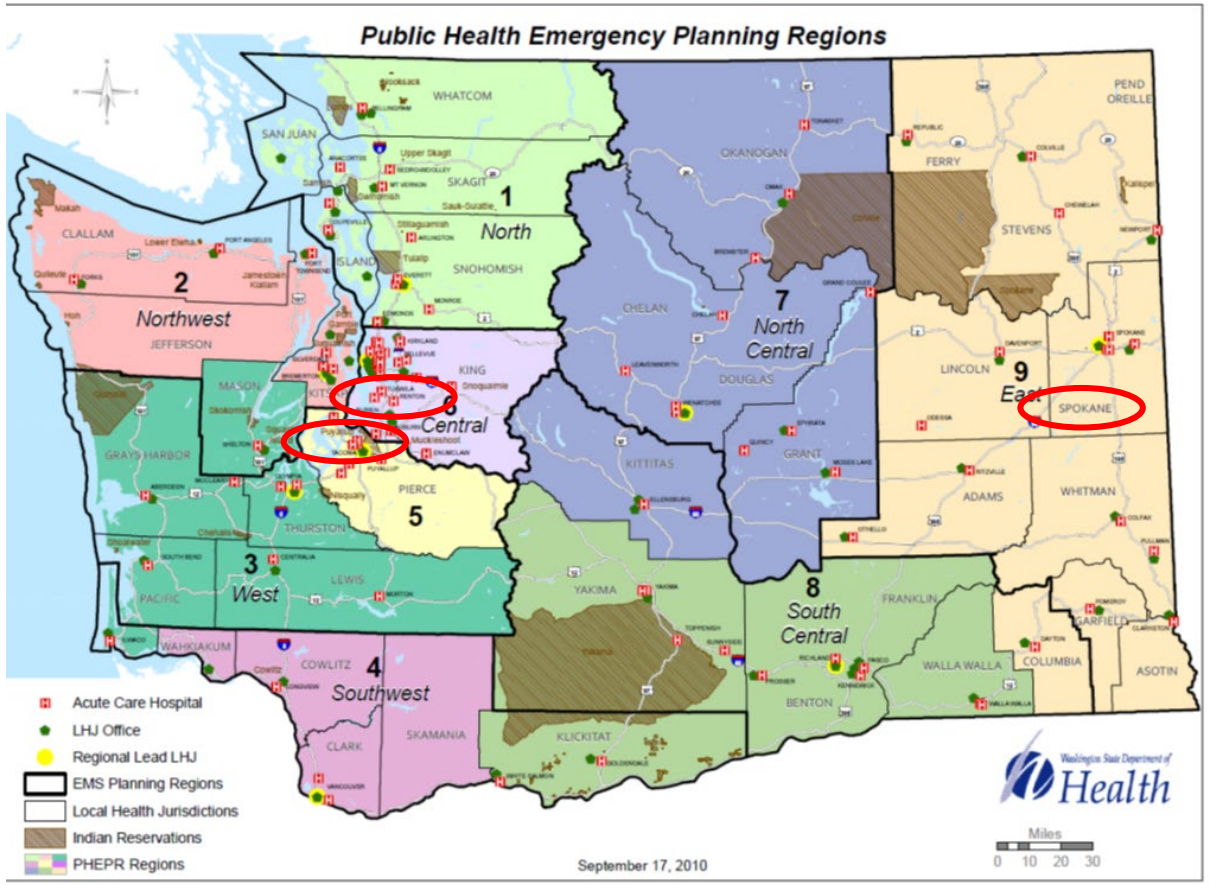
Remote endpoints for clinical trials	Could decrease participant burden and increase access to clinical trials for under-represented groups
Co-production	Engaging patients or community members as partners in study design
CF Newborn Screening	Ensuring equitable detection of CF

CF Newborn Screening – Promoting Equity through QI and Advocacy

- All babies in WA State (and U.S.) screened for CF
- Inequalities in timeliness of diagnosis
  - Rural vs. urban
  - White vs. Black and Hispanic
- Projects to address these disparities

Sweat Testing QI Project

- Sweat testing is gold standard for diagnosing CF
- Rapid and reliable sweat testing critical to timely diagnosis
- Only 3 accredited sweat test facilities in WA State
- Infants from central WA at greatest risk of delayed diagnosis
- Successful QI project – partnership with Yakima Valley Memorial Hospital to collect sweat locally and ship to Seattle Children's for analysis



Advocacy Project with our Parent Partners

- Partnered with 3 parents of children with CF
- Lobbied state legislature to support fee increase to streamline newborn screening algorithm in WA State
  - Created our pitch
  - Contacted multiple state representatives
  - Met in person or remotely with five state representatives
  - One agreed to be our champion – submitted budget request
  - Approved by House Appropriations Committee; under review in Senate
  - Fingers crossed!!

Streamlining CF NBS in WA State

WA State CF NBS takes **3 steps** ("IRT-IRT-DNA"):

- High IRT on blood spot 1 collected at <24 hours
- High IRT on blood spot 2 collected 7-14 days
- DNA testing

We propose to move to a 2-step (IRT-DNA) process

- Removing the testing of IRT on the second blood spot will save at least 1-2 weeks

Why Make This Change?

To improve *timeliness of diagnosis* for all babies with CF in WA State

To *reduce disparities* in age at diagnosis by enabling earlier identification of babies with 1 mutation so they can have specialized testing more quickly

To bring WA State in line with national recommendations

Early Diagnosis is Critical

In newborn screened infants, earlier age at diagnosis results in

- Improved height and weight
- Decreased hospitalizations

Minoritized infants with CF are diagnosed later

- Median age at diagnosis in the U.S.
  - 13 days for non-Hispanic whites
  - 21 days for Black and Hispanic babies

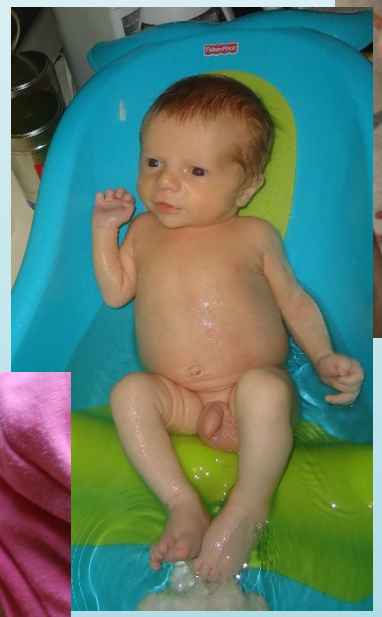
Later diagnosis in Hispanic and Black babies results in poorer outcomes

- More respiratory symptoms at diagnosis
- More failure to thrive
- Worse nutrition in first two years of life

Martiniano, et al, Pediatric Pulmonology 2021:56:3758
McColley SA, et al. https://doi.org/10.1016/j.jcf.2
McColley SA, et al. https://doi.org/10.1016/j.jcf.2022.07.0022.07.

Sharing our experiences

"My child did not pass the newborn screening. What they found, they blamed on my breastfeeding. If the nurse or doctor is telling me don't worry about it, I'm not going to worry about it. A month later, your child is dehydrated, showing all the symptoms…**I don't know how to rewire that.**"



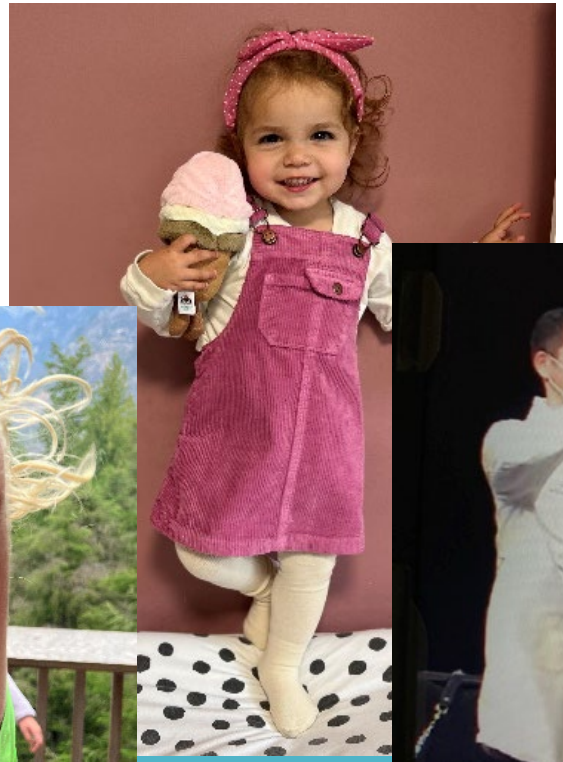
"We have to be at **the brink of death** before being diagnosed because of the persistent stereotype of it being a Caucasian disease."

"I was diagnosed in 1995, I was two-and-a-half years old, and **I almost was dead before I was diagnosed**. The reason was because of my father's side and they said Hispanics can't have CF."

Source: Communities of Color Report:

https://www.cff.org/sites/default/files/2022-05/CF-Foundation-Communities-of-Color-Report.pdf

Please support the DOH request for a newborn screening fee increase to enable more timely and equitable CF newborn screening FOR ALL BABIES



ITHS | Institute of Translational Health Sciences

ACCELERATING RESEARCH. IMPROVING HEALTH.

Initiatives to promote equitable remote clinical trials and remote monitoring tools

Developing best practices for teleresearch equity

Integrating Special Populations

Known digital divides

- High-speed internet access vs. reliance on mobile phones
- Usability of devices
- Disparities in telemedicine use

ITHS goal

Engage children & older adults from diverse communities in virtual/remote research

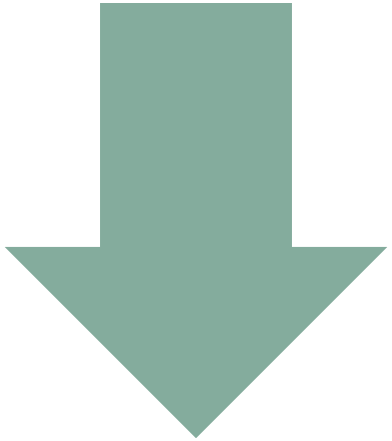
Impact of remote tech on participant diversity

Higher enrollment

Latino & rural families

Women

Geographic reach

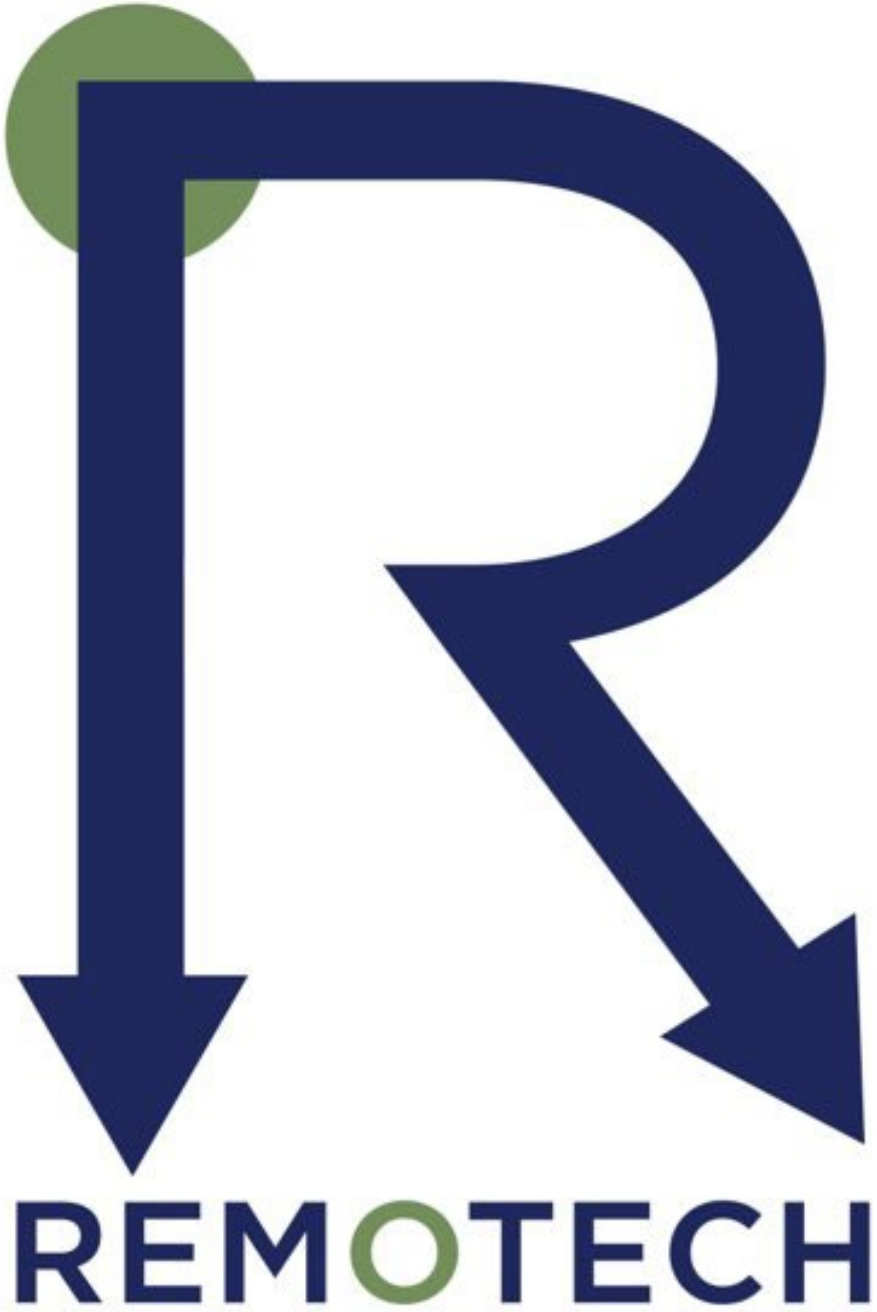


Lower enrollment/completion

Older adults, especially from underrepresented racial or ethnic groups

Languages other than English

Lower education or SES levels



Remote Technologies for Research Center (REMOTECH)

Ease the use of remote technologies in research

REMOTECH's Objectives

Identify opportunities to use remote technologies, bringing the trial to the participant

Define issues limiting adoption of remote tech in WWAMI studies

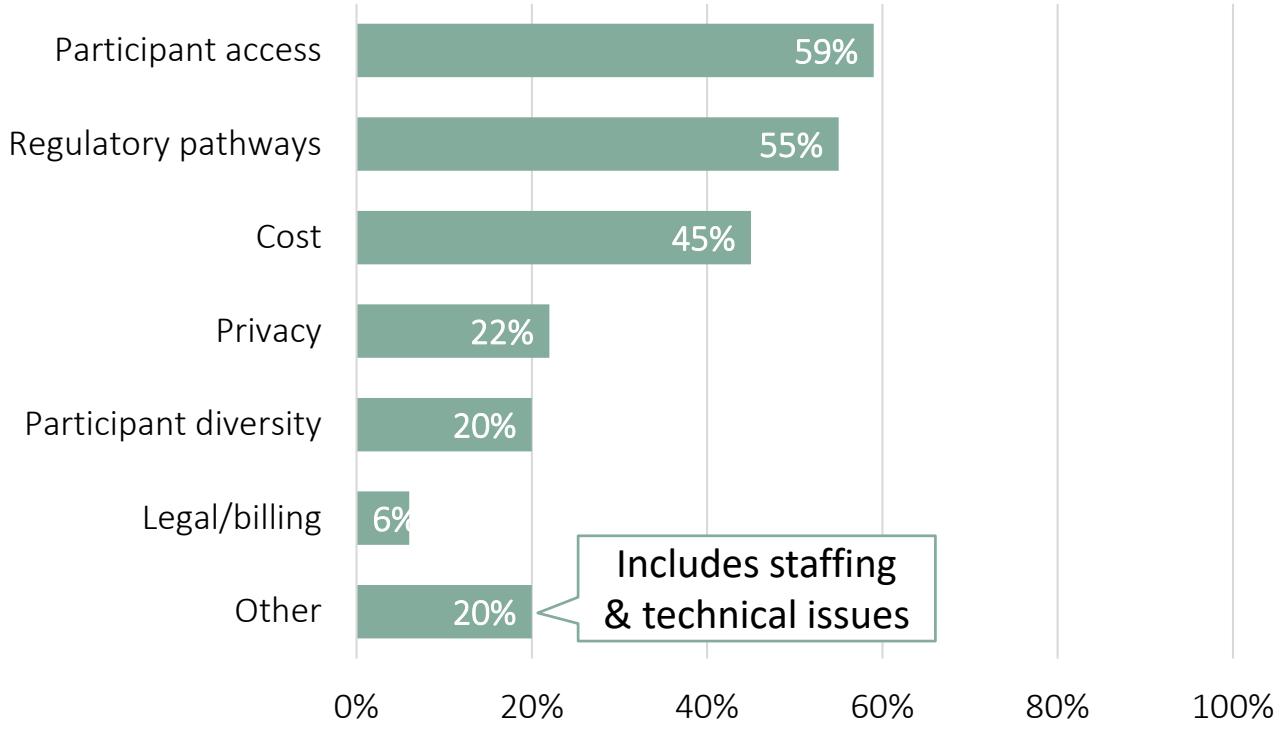
Develop a knowledge repository to help research teams select & use technologies effectively, ethically & equitably

Assessing regional context & gaps in remote research

105 respondents from NW PCI Network and Seattle

- 70% using remote tech in studies
  - Remote consenting most common (81%)
  - 43% for patient assessments
  - 42% using remote intervention – mostly behavioral

More than 2/3 encounter barriers when implementing remote methods, related to…



Developing Community-Responsive mHealth:

Understanding Perspectives of Hispanic Community Members in Washington State

RATIONALE

mHealth apps have potential to support a pro-active, preventive model of healthcare

Could reduce barriers to healthcare access due to cost, geography, language, or systemic racism

If developed without incorporating community values, mHealth tools risk exacerbating rather than alleviating health disparities

THE PROJECT

Focus groups to understand perspectives of Hispanic community members in WA about the potential benefits and burdens of mHealth

Deliverable: resource to guide mHealth and AI/ML researchers in development of community-responsive technologies

Collaboration between bioethicists, community-based participatory researchers, community members, computer science faculty, clinical trialists

Conclusions

- Research can only drive evidence-based practice for all patients if it is equitable and inclusive
- Rapid innovations in remote endpoints for clinical trials
  - Hold promise of increasing equity and inclusion by improving access to and decreasing burden of participation in research
  - But can actually worsen disparities if we don't get it right
- Co-production centers the patient voice and ensures trials are designed to meet community priorities
- Advocacy and QI projects can also focus on decreasing inequities

Acknowledgements

Dr. Bonnie Ramsey!!!

Patients and families

Participating sites

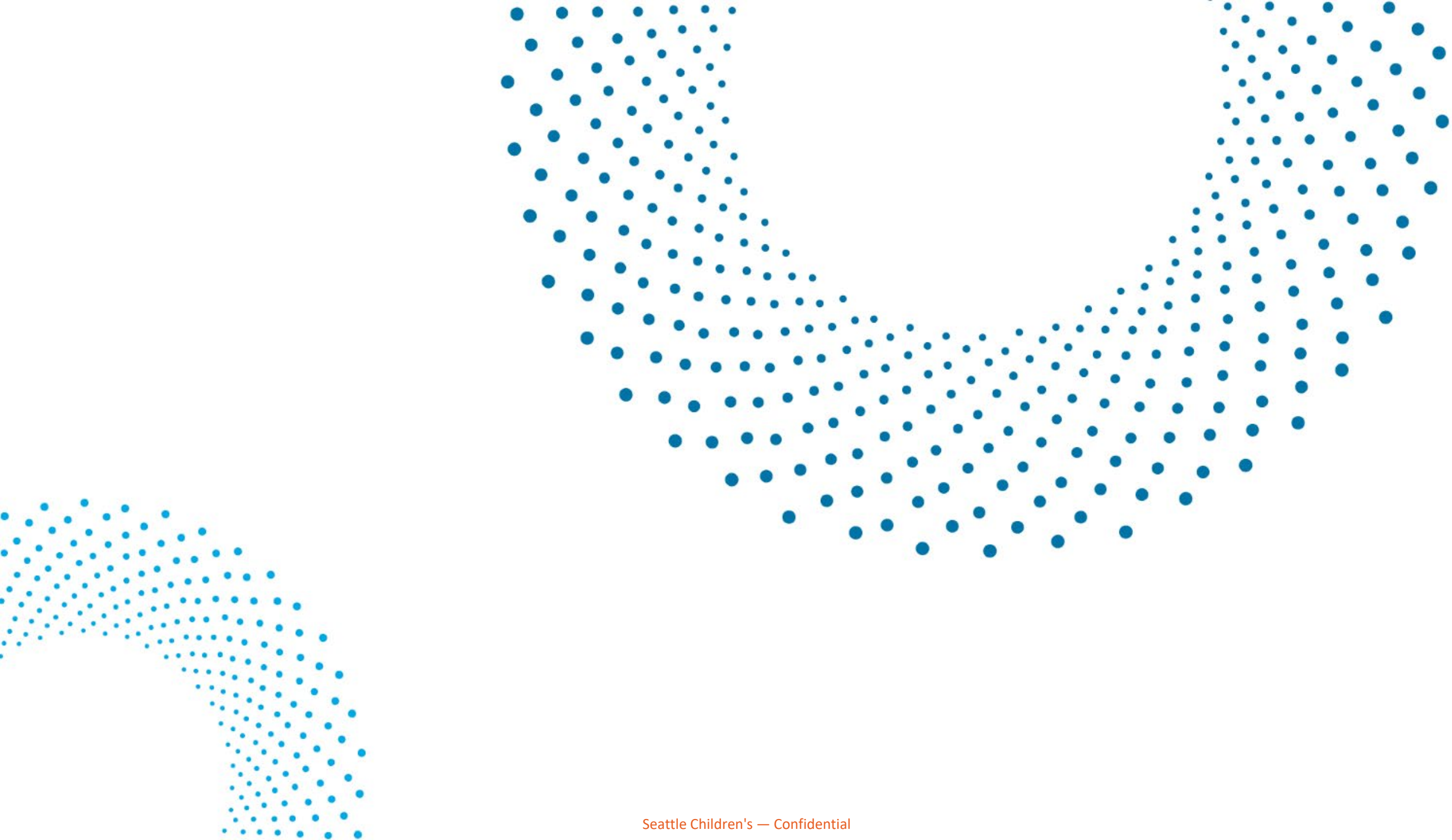
TDN Coordinating Center

ITHS

WA State Department of Health

CF Foundation

NIH



Let’s take a break!

See you back here at 11:30 am…

Panel: Integrating Research in Clinical Care

Moderator:

Annie Reedy
Chief Research and Education Officer
MultiCare Institute for Research and Innovation
MultiCare Health System

Panelists:

Kara Cooper
Manager for Training and Curriculum Development
Seattle Children's

Joan Milton
Senior Clinical Research Coordinator
Providence Medical Research Center

Cherese Pullum
Director, Clinical Research
MultiCare Institute for Research and Innovation
MultiCare Health System

Laurie Riemann
Manager, Business and Grants
Collaborative Science and Innovation
Billings Clinic

Integrating Research into Clinical Care

MultiCare

Objectives for Session

- Describe what it looks like when research is fully integrated into a clinical practice
- Discuss common challenges and barriers
- Identify best practices and facilitators

Meet your Panelists

Annie Reedy, MBA, CRA

Chief Research & Education Officer

MultiCare Institute for Research & Innovation

11 Hospitals*

2,099 Beds*

8,989 Births

19,669 Employees

1,568 Employed Providers

458,921 ER Visits

240+ Clinics Primary, Specialty & Urgent Care

166 Research Investigators

7,141 Patient Visits for Research Studies

76,043 Hospital Admissions

$3.8 Billion Revenue

Bond ratings: Aa3 (Moody's), AA- (Standard & Poor's) and AA- (FitchRatings).

As of 12/31/2021 unless specifically indicated.

*Wellfound Behavioral Health Hospital, our joint venture with Virginia Mason Franciscan Health, as well as its 120 licensed beds, are included in these counts.

MultiCare

Cherese Pullum, MS, RN, CCRC

Director, Clinical Research, MultiCare Institute for Research & Innovation

75 **Dedicated research staff members throughout MultiCare**

141 **Investigators actively involved in research**

2,598 **New Participants Enrolled in 2022**

515 **Awards managed**
491 clinical trials
24 research grants

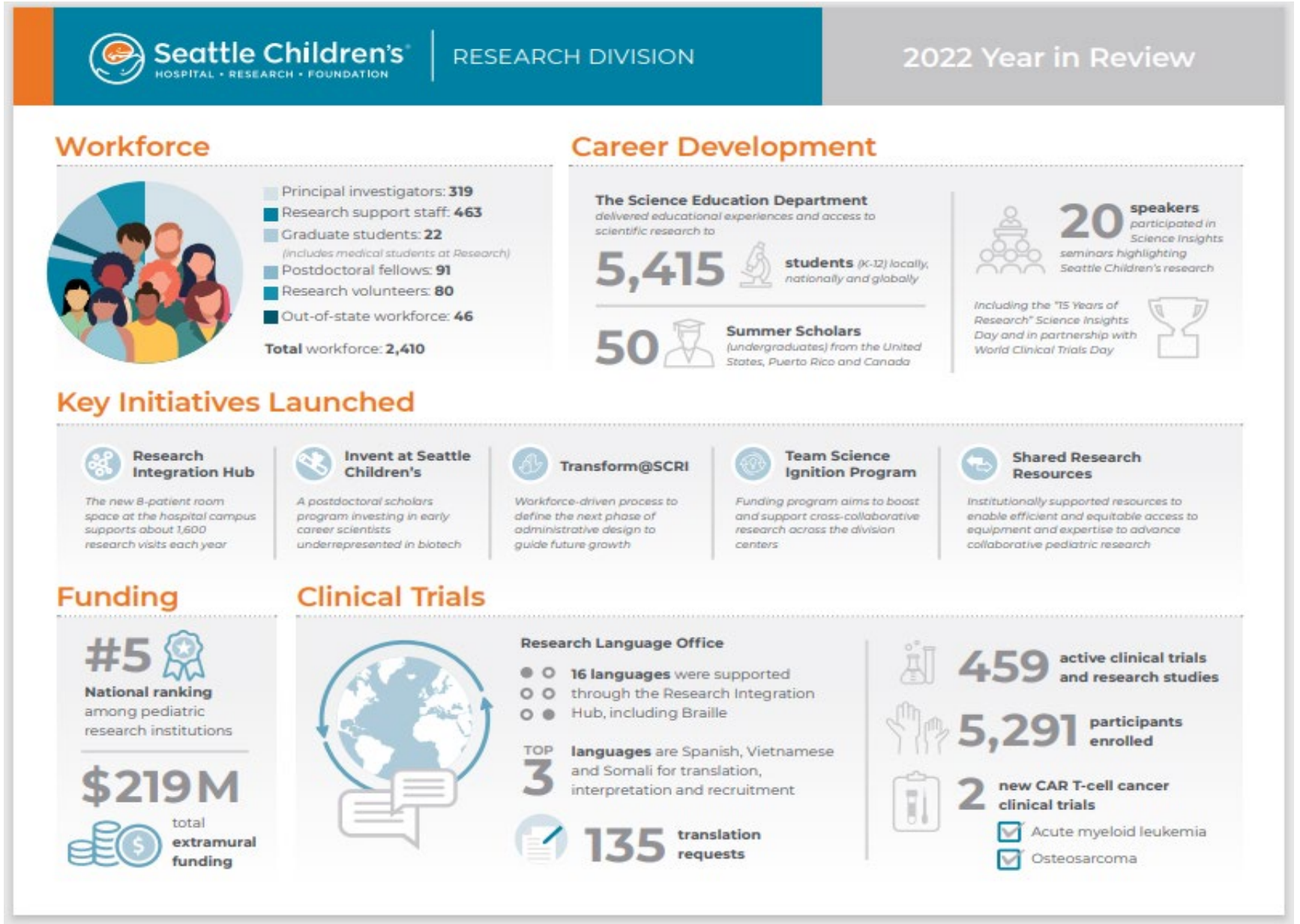
Therapeutic Areas of Study:

Addiction Medicine, Adult Oncology, Bariatric, Behavioral Health, Cardiology, COVID-19, Dermatology, Endocrinology, Family Practice, Infectious Disease, Internal Medicine, Nephrology, Neurology, Pediatric Neurology, Pediatric Oncology, Pediatrics, Pulmonology, Rare Diseases and Women's Health

MultiCare

Kara Cooper, CCRC

Manager, Training & Curriculum Development, Research Integration Hub



MultiCare

Providence

Joan Milton, MS, RDN, CCRC

Cystic Fibrosis Therapeutics Development Center Primary CRC

Providence Medical Research Center, Spokane, WA

Providence Medical Research Center (PMRC) is the research hub for the Spokane and Stevens County areas of Providence Health & Services.

Primary areas of research include adult cardiology, pediatric oncology, nephrology, pulmonology, cystic fibrosis, and neuroscience.

Laurie Riemann, BSN, RN

Manager, Collaborative Science & Innovation

Billings Clinic

Collaborative Science & Innovation Studies:

- Genentech Grant
- Magnet Nursing Research
- Trauma Research
- Randomized Controlled Trials
- Investigator Led Research

Other Research at Billings Clinic:

- Diabetes Clinical Trials
- Oncology Clinical Trials
- Collaboration with Montana Cancer Consortium
- Specialty Pediatric Studies

Collaborative Science & Innovation offers expertise in a broad spectrum of health services research.

Our purpose: Partner with scientists, physicians, nurses, clinicians, and other health care professionals across our organization to investigate and integrate novel strategies and innovative models to improve patient outcomes.

The Collaborative Science & Innovation Team collaborates with interdisciplinary professionals to conduct research studies throughout Billings Clinic, and with regional, national, and international researchers.

Group Activity!

How does it look and feel when research is fully integrated into a clinical practice?

- To our patient participants?
- To us as research professionals?
- To our researchers?

Group Activity!

What are some barriers that need to be considered to achieve ideal research integration?

Considerations

View of research by clinical team members (ancillary to or not needed)

- Various service areas (CT, MRI, Pharmacy, members of team at clinic location, IS&T, Translation Services, etc.)

Space

- Clinical Rooms
- Storage (IP and other study needs)

Equipment needed and availability

- Calibration
- Utilization
- Space needed to store

Considerations

Multiple clinics in multiple locations

- Availability of resources needed
- Variety of clinical team members and approaches

Distance from clinic to research participants home

- Transportation mode
- Parking availability and cost

Ability to utilize virtual visits (in-person vs remote)

- Consent Process

Key Takeaways

Questions & Answers

Please join us for lunch!

See you back here at 1:15 pm…

Learning Laboratory:
Making it Easy to Integrate Patients as Partners in Research

Facilitator:

Jamie Besel
Research Nurse Scientist
Collaborative Science and Innovation
Billings Clinic

Research Volunteers:

Marilyn Hanley

Robert Zador

Learning Laboratory:
Opportunities for Network-wide Quality Improvement

Facilitators:

Jennifer Acosta
Data Analyst
Seattle Children's

Allison Lambert
Pulmonary and Critical Care Physician
Providence Inland Northwest Health

Co-Director
NW PCI Network

Elizabeth Brewer will Chair the Data Governance Working Group

Welcome!

Elizabeth Brewer
Director, Research and Care Transformation
Kootenai Health

Chair, Data Governance Working Group
NW PCI Network

NW PCI Research Study Metrics Dashboard

Regional Database and Dashboard | Rationale

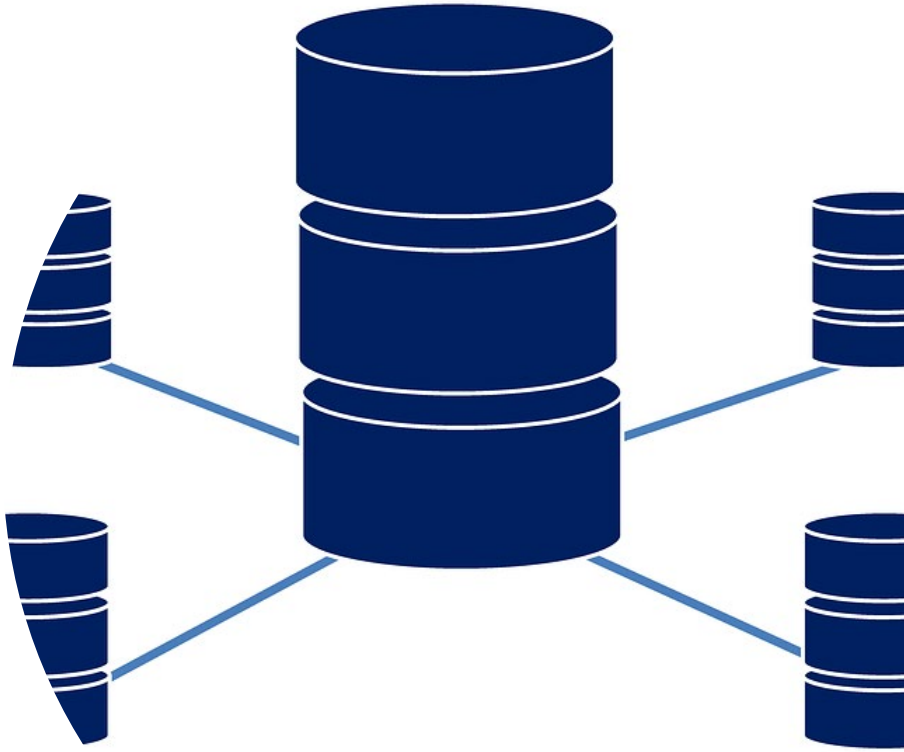
Allison Lambert, MD MHS; Co-Director NW-PCI

Overarching ITHS NW PCI Goals

- Foster collaboration among NW PCI members
- Enable dissemination of best practices for research operations across member sites
- Promote shared decision-making

Database aims to answer: How can the ITHS best support the NW PCI research institutions

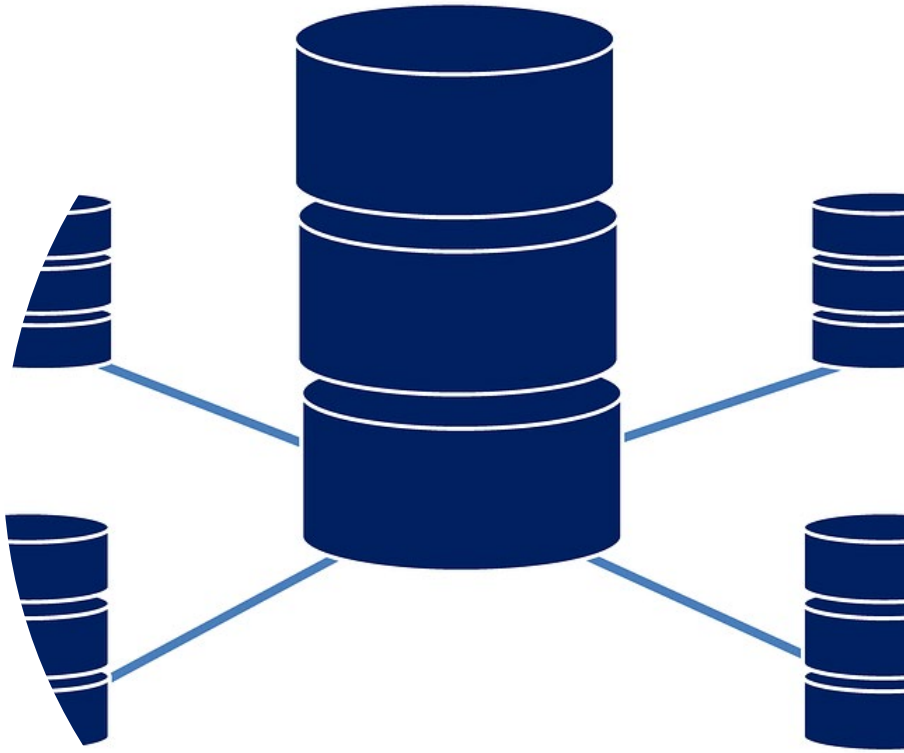
- What are the gaps in training that can be centrally generated and circulated?
- What common research operation metrics can easily be measured and shared in order to support individual institutional research operation goals?



NW PCI Research Study Metrics Dashboard

Regional Database and Dashboard | Rationale

Allison Lambert, MD MHS; Co-Director NW-PCI



Specific Aim 1

Advance research quality and efficiency by standardized metric monitoring, collaborative continuous process improvement, and shared professional training

Measurable Outcomes

- Common study metric definitions, frequent and transparent assessment of study metrics
- Earlier identification of study challenges to enable quality improvement
- Improved clinical trial efficiency: maintain compliance, fully enroll, and reach study endpoints on schedule

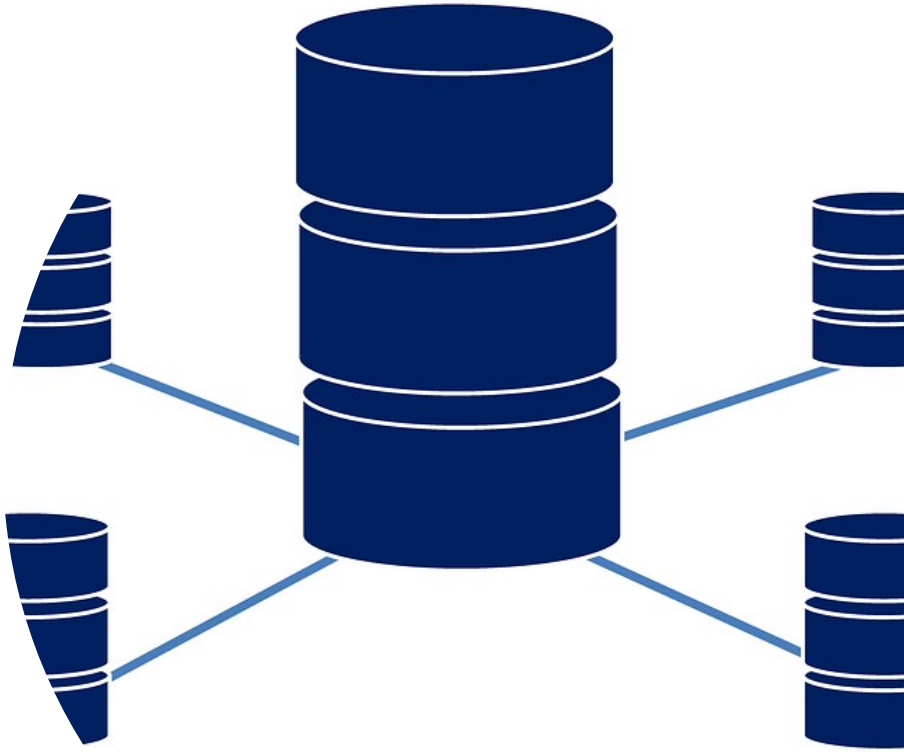
NW PCI Research Study Metrics Dashboard

Regional Database and Dashboard | Rationale

Allison Lambert, MD MHS; Co-Director NW-PCI

Examples of Potential Metrics

- Study startup time
- Percent Recruitment
- Registration and reporting in ClinicalTrials.gov
- Compliance with training, regulations, and approved protocols
- Timely review of safety events; and data access and quality



Dashboard Features

RSM Dashboard | Showcase

Jen Acosta, Data Analyst Seattle Children's

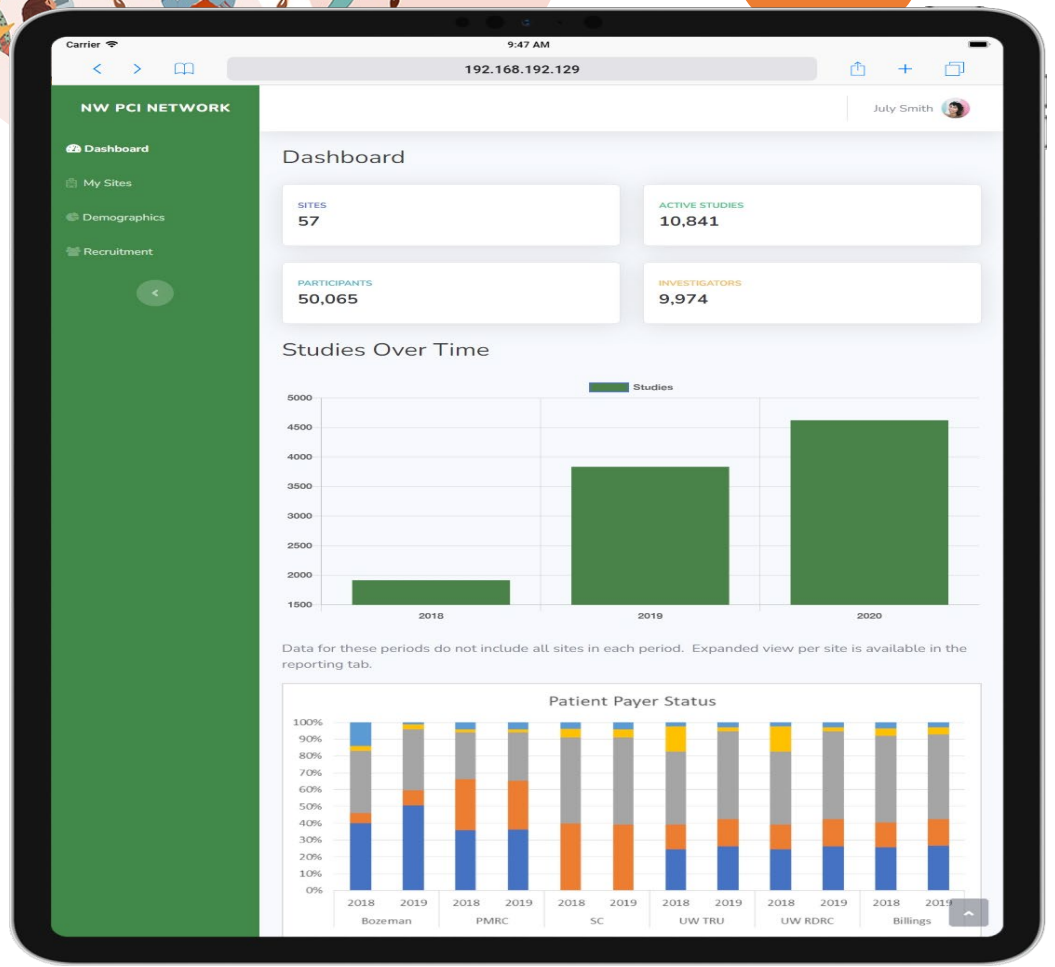
- Showcase Data
  - Aggregate Data
  - Site Specific Data (Only Visible to Site Owner)

Metrics are informed by interviews and focus groups

An opportunity to objectively highlight areas of opportunity

Give a solid foundation to beginning quality improvement evaluations & track progress

Multi-site QI projects can increase the robustness of QI findings

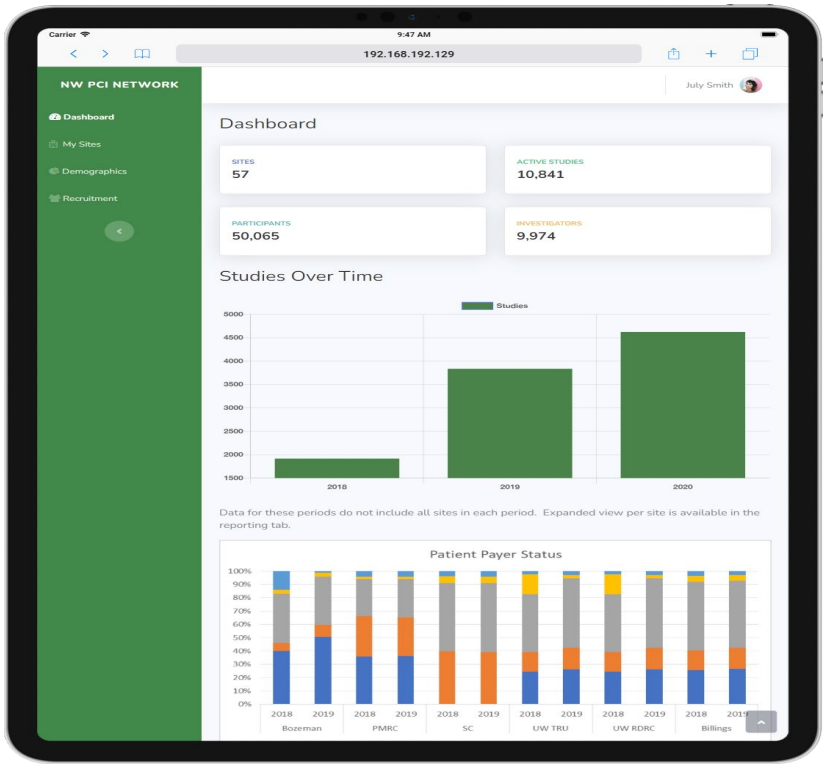


Dashboard Features

RSM Dashboard | Showcase

Jen Acosta, Data Analyst Seattle Children's

- Download Data
  - Based on data governance principles & permissions
- Dashboard Support
  - Standard technical support
  - Feedback system
  - Automated Notifications

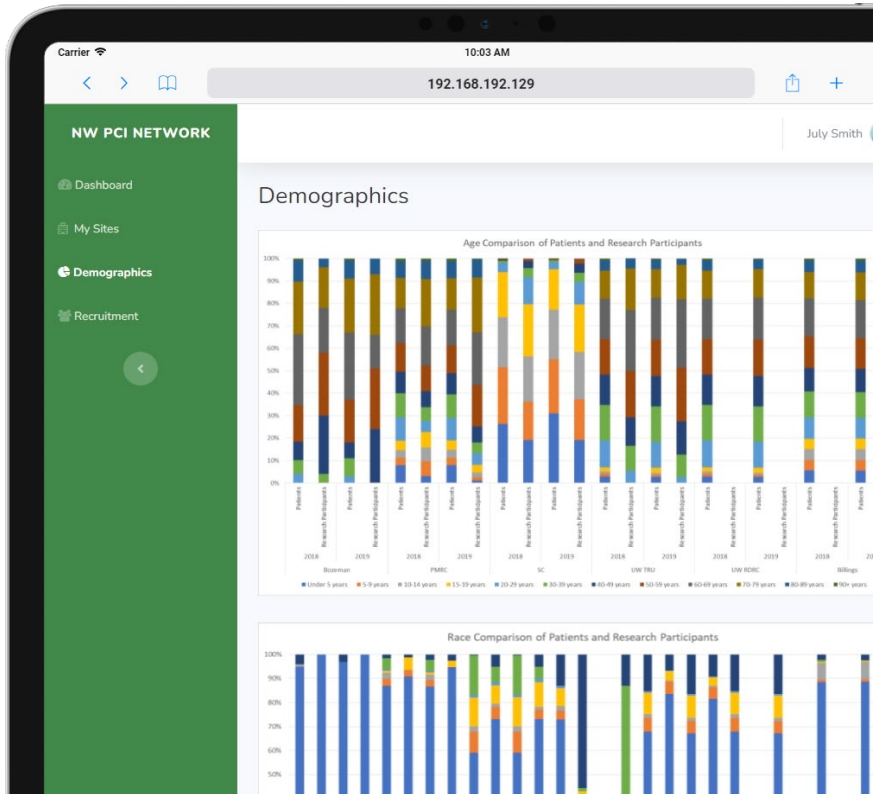


Future Additions

RSM Dashboard | Showcase

Jen Acosta, Data Analyst Seattle Children's

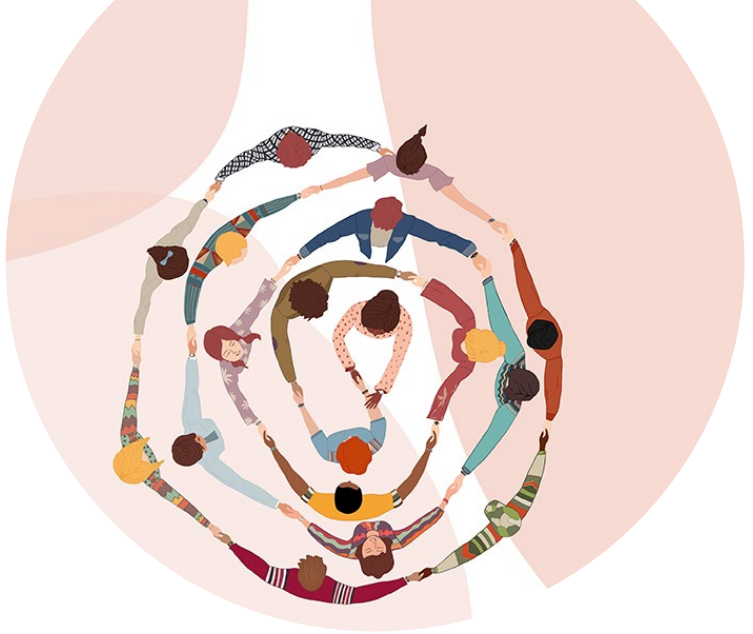
- Continued modifications to enhance user experience
- Continued modifications to metrics being tracked
- Evaluate automation of data transfer where feasible
- Dynamic Counter for current QI projects
- Library of published Quality Improvement Articles

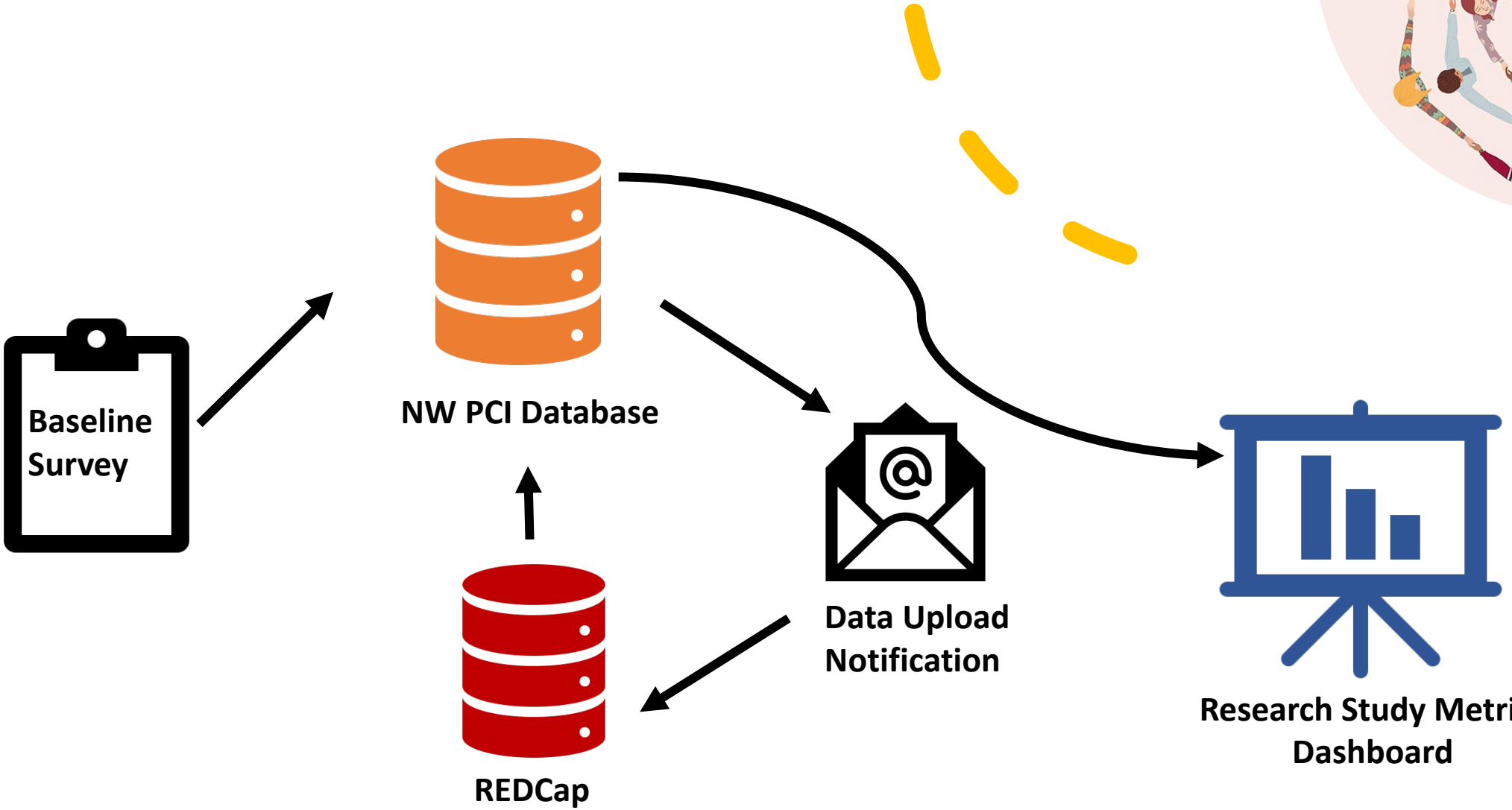


How does this work?

RSM Dashboard | Showcase

Jen Acosta, Data Analyst Seattle Children's



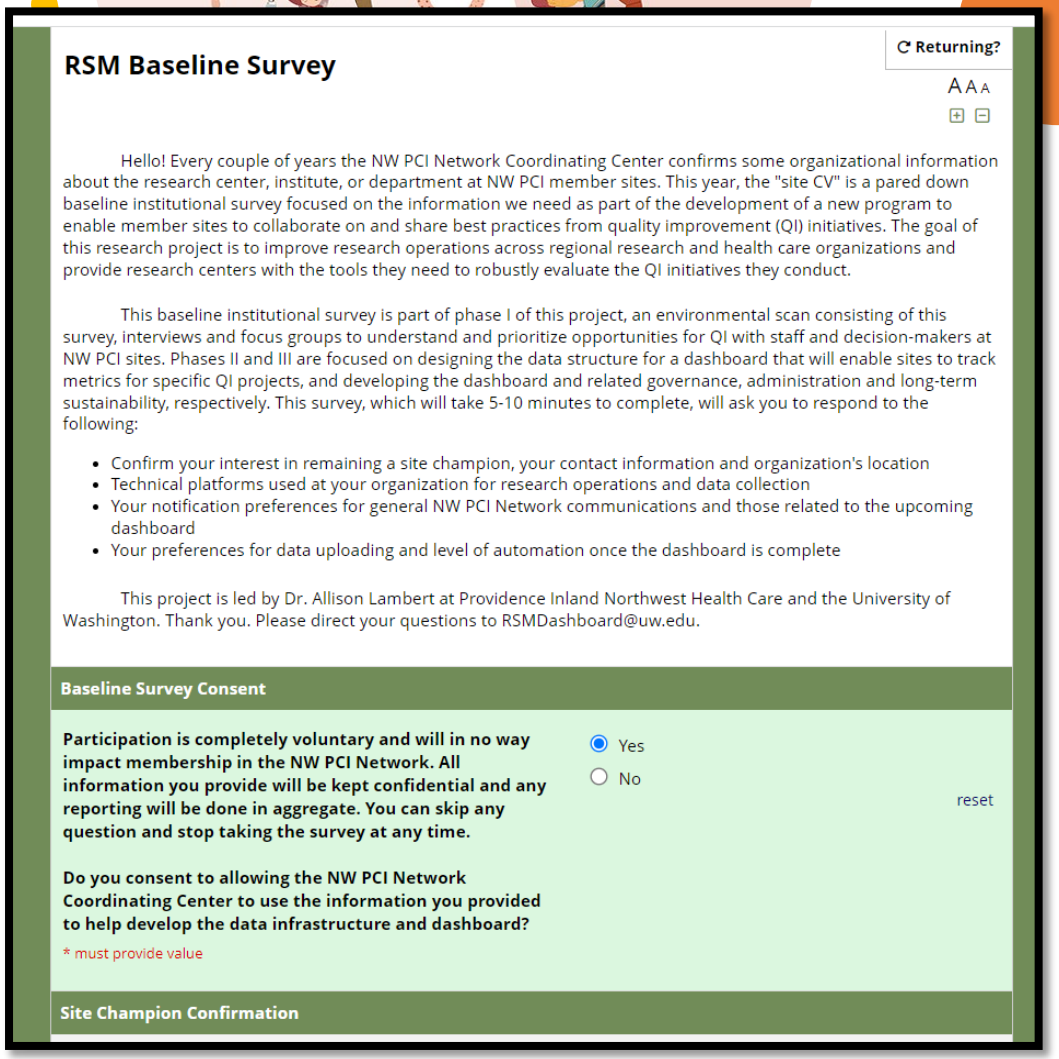


NW PCI Research Study Metrics Dashboard

Jen Acosta, Data Analyst Seattle Children's

For Site Champions Only : Baseline Survey

- https://redcap.link/RSMBaseline



RSM Baseline Survey

Returning?

AAA

Hello! Every couple of years the NW PCI Network Coordinating Center confirms some organizational information about the research center, institute, or department at NW PCI member sites. This year, the "site CV" is a pared down baseline institutional survey focused on the information we need as part of the development of a new program to enable member sites to collaborate on and share best practices from quality improvement (QI) initiatives. The goal of this research project is to improve research operations across regional research and health care organizations and provide research centers with the tools they need to robustly evaluate the QI initiatives they conduct.

This baseline institutional survey is part of phase I of this project, an environmental scan consisting of this survey, interviews and focus groups to understand and prioritize opportunities for QI with staff and decision-makers at NW PCI sites. Phases II and III are focused on designing the data structure for a dashboard that will enable sites to track metrics for specific QI projects, and developing the dashboard and related governance, administration and long-term sustainability, respectively. This survey, which will take 5-10 minutes to complete, will ask you to respond to the following:

- Confirm your interest in remaining a site champion, your contact information and organization's location
- Technical platforms used at your organization for research operations and data collection
- Your notification preferences for general NW PCI Network communications and those related to the upcoming dashboard
- Your preferences for data uploading and level of automation once the dashboard is complete

This project is led by Dr. Allison Lambert at Providence Inland Northwest Health Care and the University of Washington. Thank you. Please direct your questions to RSMDashboard@uw.edu.

Baseline Survey Consent

Participation is completely voluntary and will in no way impact membership in the NW PCI Network. All information you provide will be kept confidential and any reporting will be done in aggregate. You can skip any question and stop taking the survey at any time.

(•) Yes
( ) No

reset

Do you consent to allowing the NW PCI Network Coordinating Center to use the information you provided to help develop the data infrastructure and dashboard?

* must provide value

Site Champion Confirmation

Let’s hear some impressions from research volunteers

Allison, Marilyn and Robert

Where should we hold the NW PCI Annual Meeting next year?

If you would like us to bring the meeting to your city, please contact James and Laurie.

Please take a moment to:

Complete the Meeting Evaluation Form (pink)

Complete the OPTICC Cancer Center Survey (yellow), if you received one

Trade contact information with a new friend

Take a moment to consider what you learned today that you want to bring back to your team

Thank you for joining us today!

We are so grateful you were able to join us! Safe travels on your way home.