



AGENCY FOR HEALTHCARE RESEARCH AND QUALITY

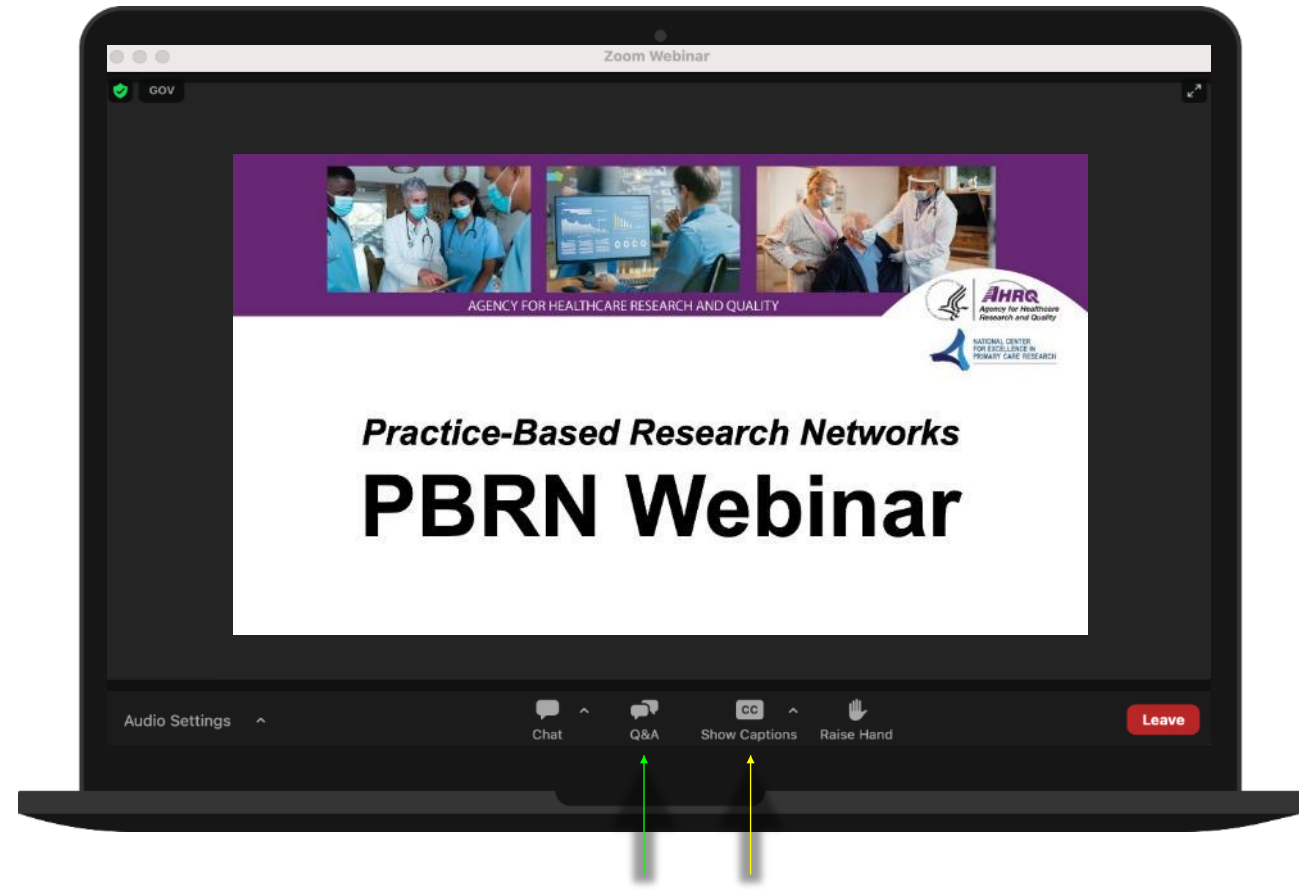


Highlighting and Promoting the Value of Practice-Based Research Networks (PBRNs)

July 11, 2024
4 p.m. – 5 p.m. ET

Housekeeping and Logistics

- **Closed Captioning** is available through Zoom.
- If you have questions, submit them in the **Q&A** tool in Zoom.
- This webinar is being recorded and will be posted on AHRQ's website.



Aimee R. Eden, Ph.D., M.P.H.



Aimee Eden is Acting Director of AHRQ's National Center for Excellence in Primary Care Research. She is a medical anthropologist and qualitative researcher with a background in public health and international development. Prior to joining AHRQ in 2022, Dr. Eden was a Senior Research Scientist conducting mixed-methods primary care research at the American Board of Family Medicine.



Presentation Topics



- Benefits of practice-based research for primary care practices and health systems.
- Engagement with practices and clinicians.
- Collaboration and interdisciplinary approaches.
- Data systems to track trends in network patients and populations.

Neil Korsen, MD, MS



Name: Neil Korsen, MD, MS

PBRN: Northern New England CO-OP Practice and Community Based Research Network

Location: I work for MaineHealth Institute for Research in Portland and live about an hour away in coastal Maine.

PBRN experience: I spent the first 20 years of my career as a rural family doctor and the last 25 as a researcher. I was a CO-OP member as a clinician and have been able to return as a research director in the past few years.

Research interests: Behavioral health integration, shared decision making, lung cancer screening, community-engaged research.

Practice-Based Research: What is it and Why is it Important?

Neil Korsen, MD, MS

MaineHealth Institute for Research

July 11, 2024

What is a Practice-Based Research Network?

- Agency for Healthcare Research and Quality defines a **primary care practice-based research network**, or PBRN, as:
 - ▶ A group of ambulatory practices *devoted principally to the primary care of patients*, and
 - ▶ Affiliated in their mission to investigate *questions related to community-based practice* and to improve the quality of primary care.



Dartmouth/Northern New England CO-OP PBRN

- Oldest PBRN in existence, started in the 1970's
- Members involved in decisions about research questions and project design
- Designed to fit into busy practice settings

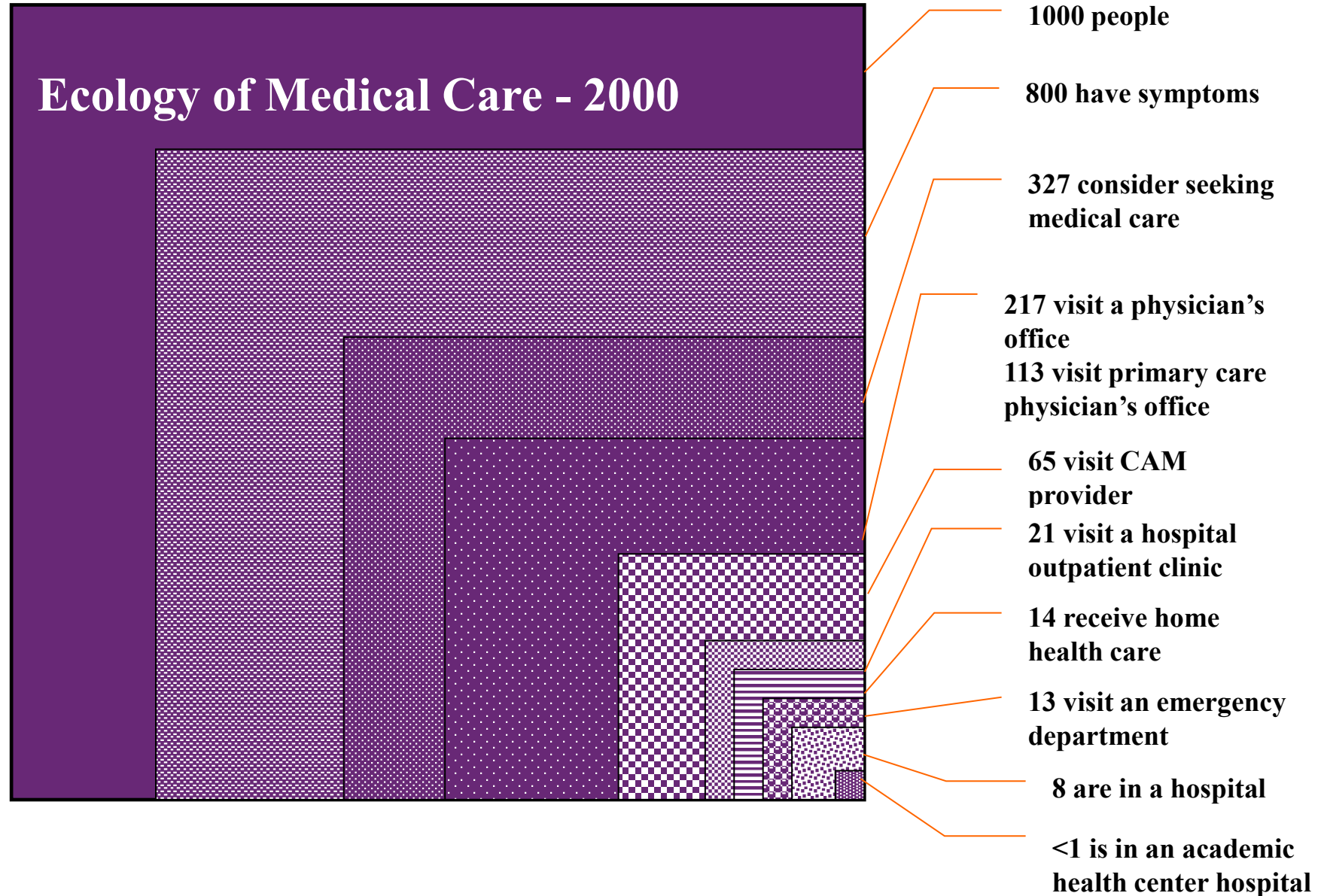


Why Practice-Based Research?

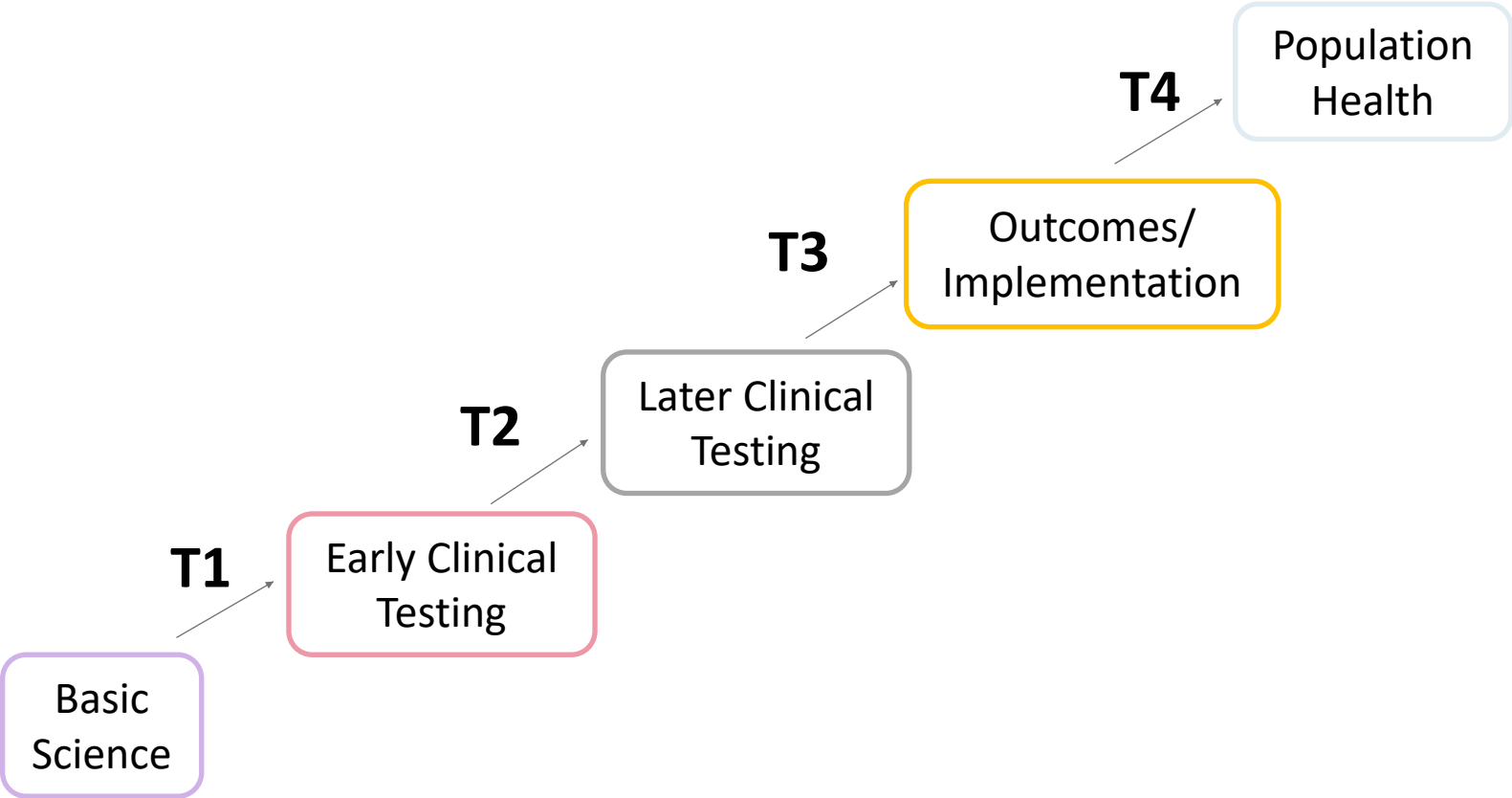
“If we want more evidence-based practice, we need more practice-based evidence.”

L.W. Green, MPH, Dr.PH,
University of California, San Francisco

In an average month: KW Boxes 2000



Translational Research Continuum



Reasons to Do Practice-Based Research



- **Reasons a Clinician Might Do Practice-Based Research**
 - ▶ Personal satisfaction
 - ▶ Improving care in one's own practice/organization
 - ▶ Contributing to knowledge about primary care and improving primary care generally
 - Fagnan et al, JABFM, 2010
- **Reasons an Organization Might Benefit from Participating in a PBRN**
 - ▶ There is evidence that clinicians who participate in a PBRN are more professionally satisfied and are more likely to stay in their practices.
 - Sinclair-Lian N et al, J Am Board Fam Med 2008

SPECIAL COMMUNICATION

Practice-based Research is Community Engagement

John M. Westfall, MD, MPH, Lyle J. Fagnan, MD, Margaret Handley, PhD, MPH, Jon Salsberg, MA, Paul McGinnis, MPA, Linda K. Zittleman, MSPH, and Ann C. Macaulay, CM, MD

Community engagement has become a major contributor to medical research during the past 10 years and is an essential component of the current National Institutes of Health (NIH) Roadmap and the Clinical and Translational Science Awards program.^{1,2} But, what is a community? And what community gets to be engaged?

Kerr White described one of the major problems with clinical research in the United States as using the tertiary academic medical center as the main location of research ideas and subject recruit-

that mixes scientific inquiry and community engagement. However, practice-based research has faced growing confusion surrounding the terms community and engagement.

Location and Orientation

What is the community? Is a community a single geographic location or region or neighborhood? Is community a single racial, ethnic, or religious group; a collection of patients with the same disease; or a population defined by multiple charac-

Principles of Community Engagement



- Co-equal
- Co-created
- Trust
- Bi-directional
- Inclusive
- Culturally centered
- Equitable finances
- Multi-knowledge
- Shared governance
- Ongoing

A Community-based Randomized Trial Encouraging Sun Protection for Children

Allen J. Dietrich, MD*; Ardis L. Olson, MD*‡; Carol Hill Sox, Engr*; Marguerite Stevens, PhD*;
Tor D. Tosteson, ScD*; Tim Ahles, PhD§; Charlotte Woodruff Winchell*; Jennifer Grant-Petersson, MS*;
Daniel W. Collison, MD||; and Rob Sanson-Fisher, PhD¶

ABSTRACT. *Objective.* We evaluated the impact of an intervention promoting sun protection behavior among children 2 to 11 years of age through schools and day care centers, primary care practices, and recreation areas.

Methods. Ten towns in New Hampshire were paired, then assigned randomly to intervention or control status. The multicomponent SunSafe intervention was provided to children and caregivers through primary care practices, day care centers, schools, and beach recreation areas. Training support and materials were provided by the SunSafe project, but project staff had no direct contact with children or parents in providing the intervention. All intervention components promoted the same message: avoid the sun between 11 AM and 3 PM, cover up

similar sets of curricular materials were used, one for grade schools and the other for preschools and day care centers. Both emphasized the importance of sun protection rather than the danger of skin cancer. Materials emphasized dynamic activities modeled after the "Slip, Slop, Slap" and "SunSmart" programs and included new material developed to suit regional needs. Both manuals offered structured plans but also provided a variety of activities from which teachers could choose. Teachers agreed to devote a minimum of two class periods to these materials.

For recreation areas, lifeguards in each of the intervention communities attended an in-service meeting, during which background about skin cancer prevention was presented by project staff. The project also provided dis-

Two Versions of the Same Story



Testing to Prevent Colon Cancer: Results From a Rural Community Intervention

John M. Westfall, MD, MPH¹

Linda Zittleman, MSPH¹

Christin Sutter, BS¹

Caroline B. Emsermann, MS¹

Elizabeth W. Staton, MS¹

Rebecca Van Vorst, MSPH²

L. Miriam Dickinson, PhD¹

for the Community Advisory Council³

¹Department of Family Medicine, University of Colorado Denver School of Medicine, Aurora, Colorado

²IPDO, Lake Success, New York

³High Plains Research Network, Aurora

ABSTRACT

PURPOSE Colon cancer is the second leading cause of cancer death in the United States. Despite tests that can detect and enable removal of precancerous polyps, effectively preventing this disease, screening for colon cancer lags behind other cancer screening. The purpose of this study was to develop and test a community-based participatory approach to increase colon cancer screening.

METHODS Using a community-based participatory research approach, the High Plains Research Network and their Community Advisory Council developed a multicomponent intervention—Testing to Prevent Colon Cancer—to increase colon cancer screening. A controlled trial compared 9 intervention counties in northeast Colorado with 7 control counties in southeast Colorado. We performed a baseline and postintervention random digit-dial telephone survey and conducted both intent-to-treat and on-treatment analyses.

RESULTS In all, 1,050 community members completed a preintervention questionnaire and 1,048 completed a postintervention questionnaire. During the

REFLECTION

Testing to Prevent Colon Cancer: How Rural Community Members Took on a Community-Based Intervention

Ned Norman¹

Shirley Cowart¹

Maret Felzien¹

Connie Haynes¹

Mike Hernandez¹

Mary Petra Rodriguez¹

Norah Sanchez¹

Sergio Sanchez¹

Kathy Winkelman¹

Steve Winkelman¹

Rebecca Van Vorst²

Linda Zittleman³

John M. Westfall³

ABSTRACT

Participatory research can elevate research relevance and effectiveness. The literature contains few first-hand descriptions of community members engaged in research. In 2003, the High Plains Research Network convened a Community Advisory Council (CAC) that quickly began providing input, feedback, innovation, and dissemination efforts. After receiving a participatory research grant from the Centers for Disease Control and Prevention aimed at increasing colorectal cancer screening, the CAC participated in an intensive training on colon cancer prevention and spent 6 months developing a locally relevant intervention—Testing to Prevent Colon Cancer. CAC members participated in all aspects of the research including intervention messaging, survey design, recruitment, implementation, analysis and interpretation of data, and dissemination of results including presentations at national venues and coauthoring manuscripts. Our experience attests to the power of participatory research in efforts to improve health outcomes.

Ann Fam Med 2013;568-570. doi:10.1370/afm.1586.

Sebastian Tong, MD, MPH



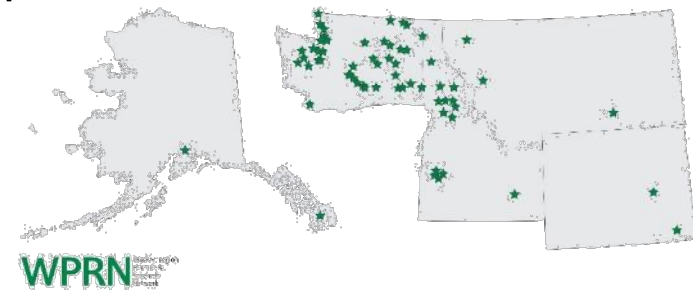
Name: Sebastian Tong, MD, MPH

PBRN: WWAMI region Practice and Research Network (WPRN)

Location: Seattle, WA

PBRN experience: Currently Associate Director of WPRN (2023–current); previously co-director of Virginia Ambulatory Care Outcomes Research Network (2015–2018)

Research interests: Behavioral health, substance use, chronic pain, practice, patient, community-engaged research



Highlighting And Promoting The Value Of PBRNs:
**Perspectives On Engagement
From The WPRN**

Sebastian Tong, MD, MPH

University of Washington

July 2024

Disclosures

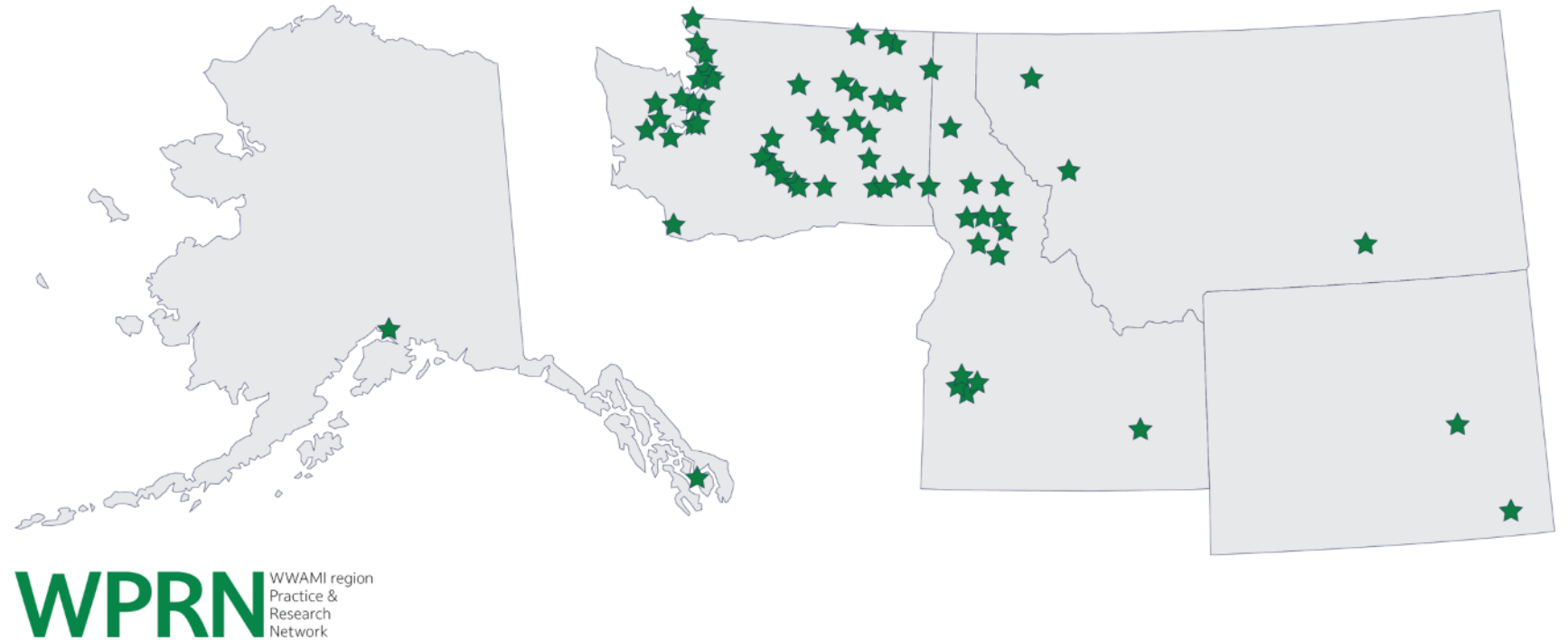
- None

Acknowledgments

- Infrastructural support for our PBRN from National Center for Advancing Translational Sciences (UL1TR002319).

Our network

- 140 practices across 40 organizations
- Variety of practice types including: FQHCs, health systems, tribal, rural health, independently-owned and naturopathic practices



Practice Engagement Modalities



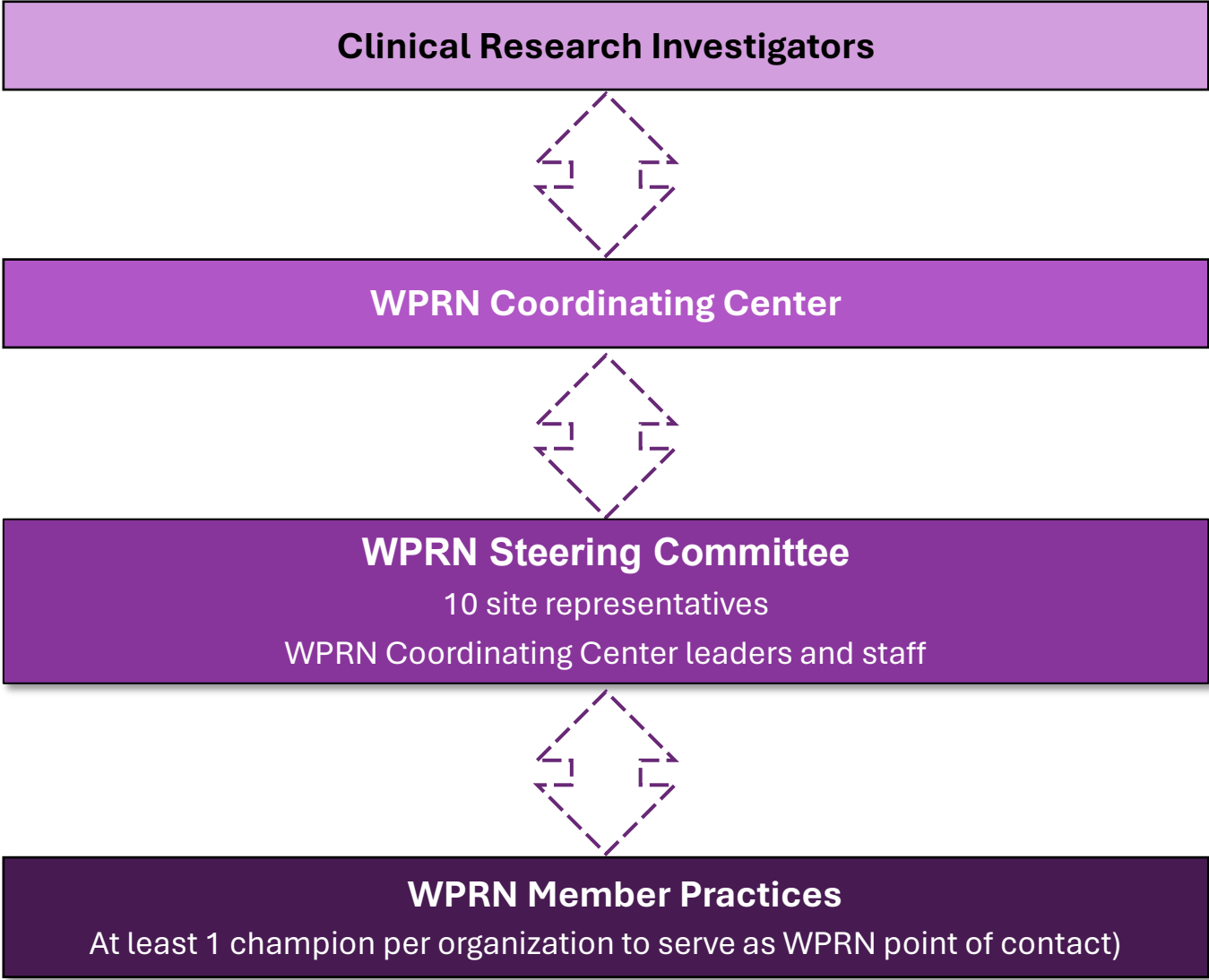
1. Steering Committee
2. Annual Conference
3. Provider Panel for Research
4. Community/Professional Events in Region

WPRN Steering Committee

- 1-hour monthly Zoom meetings
- Guide research priorities, approve/provide feedback on all WPRN studies
- Committee includes: BH providers, pharmacists, primary care clinicians, residency leadership, health system leadership



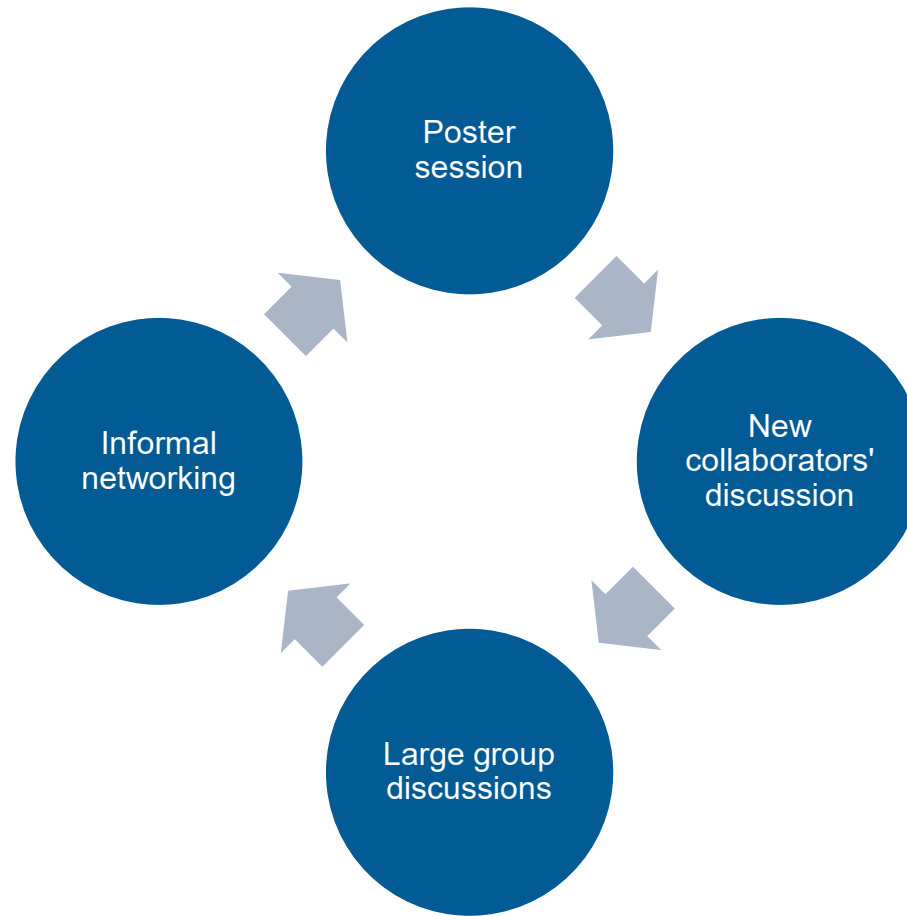
WPRN Project Workflow



Annual Meeting



Engagement opportunities at annual meeting



WPRN's Provider Panel for Research (PPR)



- A group of clinicians from WPRN practices who agree to receive up to 5 surveys and/or qualitative interview requests per year
- Designed to help investigators get perspectives of individuals working in primary care practices

How is survey research panel managed?

WPRN Coordinating Center Review

(Coordinating Center = Director, Associate Director, 2 research staff)

- Review proposals for criteria:
 - Short
 - Meet scope of panel
 - Compensation to clinicians for completing surveys

WPRN Steering Committee Review

(Steering Committee = 9 clinicians across 5 states)

- Reviews to ensure relevant to practices and aligned with WPRN strategic priorities

PPR studies from past 2 years



Year	Type	Topic	Resultant WPRN Collaboration?
2022	Survey	Pain Management Care in Older Adults	Part of R01
	Survey	Shared Decision Making for Firearm Safety	
	Survey	Firearm Survey for Policy Research	2 grants (1 funded)
2023	Survey	Team-based follow-up of abnormal cervical cancer screening tests	K award submitted
	Interview	Biased provider-patient interactions	
	Survey	Colorectal cancer screening through pharmacies	
	Interview	Complementary and Integrative Health for Chronic Pain and PTSD	Preliminary work for funded K99/R00
	Interview	Nonpharmacological treatments for chronic pain	Preliminary work leading to UG3/UH3
	Interview	Primary Care Provider Needs for Caring for Cancer Survivors	
2024	Interview	Lifespan approach for ADHD management	

Other engagement activities

- Exhibits/engagement at local professional meetings
- Site/community visits
- Local needs assessments



Top 5 Tips that lead to value for a PBRN



1. Identify a clear mission, vision and values.
2. Secure stable funding to support core infrastructure.
3. Engage members in bidirectional research.
4. Think creatively about the win-win.
5. Have fun!

Thank You!



Sebastian Tong, MD, MPH

Assistant Professor of Family Medicine

University of Washington

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Kim Fulda, DrPH



Name: Kim Fulda, DrPH

PBRN: NorTex

Location: University of North Texas Health Science Center, Fort Worth, TX

PBRN experience: 18 years of experience with NorTex between Assistant Director (2007–2013) and Director (2013–current) roles

Research interests: Health disparities, access to care for children with special healthcare needs, improving systems of care, improving care for adults with developmental disabilities

Conducting Interdisciplinary Research through PBRNs to Improve the Delivery of Primary Care

Advantages of PBRNs

- Ability to
 - ▶ Study problems unique to primary care or specialty of the PBRN
 - ▶ Recruit participants from multiple sites
 - ▶ Conduct research studies rapidly
 - ▶ Conduct research that is important to the community

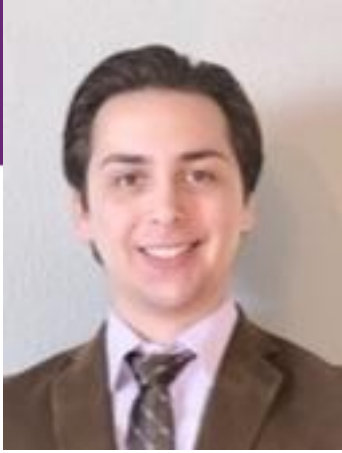
Why Multidisciplinary Research with PBRNs?



- The delivery of primary care is complex
 - Making a difference cannot be done by working in silos
 - Can include researchers outside of the clinical team
-
- PBRNs allow for the opportunity to bring together multidisciplinary teams to improve the delivery of care

NorTex

- Founded in 2005
- Primary care outpatient clinics
 - ▶ Academic medical center,
 - ▶ county hospital systems,
 - ▶ county public health clinics,
 - ▶ private practices,
 - ▶ federally qualified health centers,
 - ▶ rural clinics



PROMIS Lab



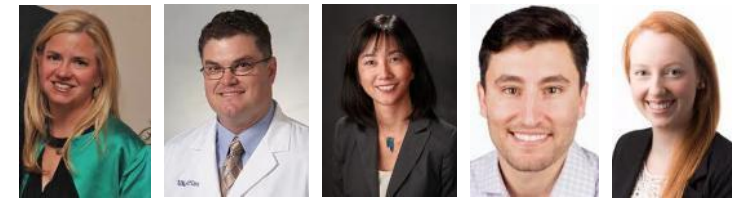
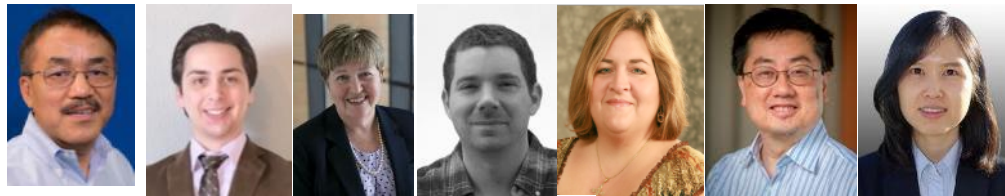
University of Texas at Arlington (PI: Yan **Xiao**, Manager: Noah **Hendrix**)

University of North Texas Health Science Center (PI: Kimberly **Fulda**)

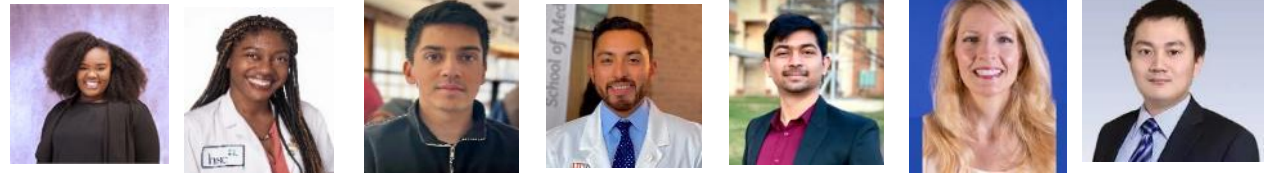
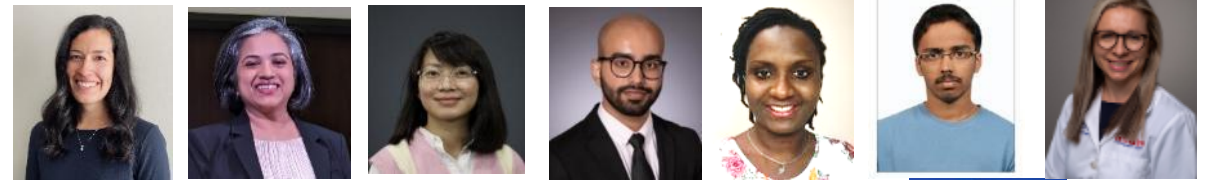
John Peter Smith Health Network (PI: Richard **Young**)

Johns Hopkins University (PI: Ayse **Gürses**)

Our core Team: UTA, JPS, JHU, UNTHSC (& advisors, students, clinicians, educators)



20 students (6 PhD, 13 Masters, 1 Undergraduate)



Partnership in Resilience for Medication Safety PROMIS PSL (2019 –)



Problem Analysis

60 interviews and focus groups

Gaps in expectations

Fear and reluctance in communication

Not knowing the basics of medications

Gaps in problem-solving skills

Design/Develop

6 focus groups 150 surveys

Patient Prep Guide

5 Educational Videos

Partnership Scripts

Implement/Evaluate

Stepped-wedge clinical trial

480 Encounters

3 clinics

Evaluation ongoing



8 Publications



40 presentations



30 Clinics represented
in data collection

Steven J. Atlas, MD, MPH



Massachusetts General Hospital Primary Care PBRN

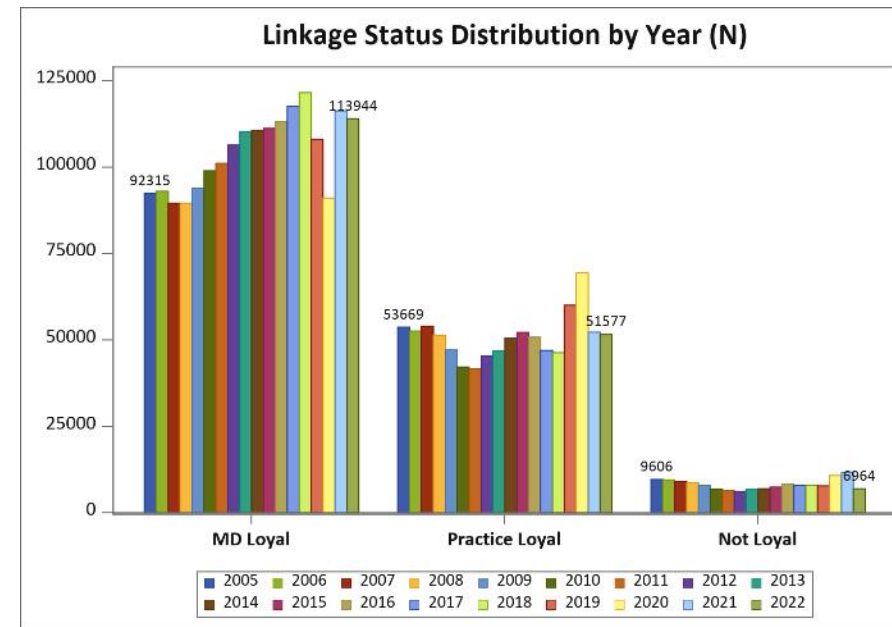
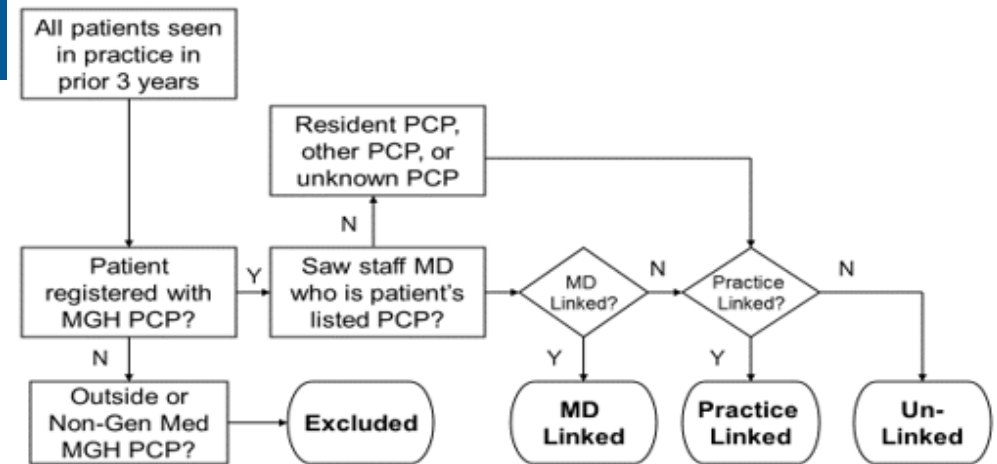
Director: Steven J. Atlas, MD, MPH

Location: Eastern Massachusetts (greater Boston area)

- **Overview**
 - Established in 2006
 - 18 practices, >300 clinicians, >165,000 patients
- **Attributing patients to PCPs and practices**
 - Denominators for retrospective studies
 - Prospective patient identification
- **Population-based research**
 - Implementation science
 - Quality, variation and equity of care
 - Integrating care of PCPs and specialists
 - Interventional trials

How to Link Patients with PCPs?

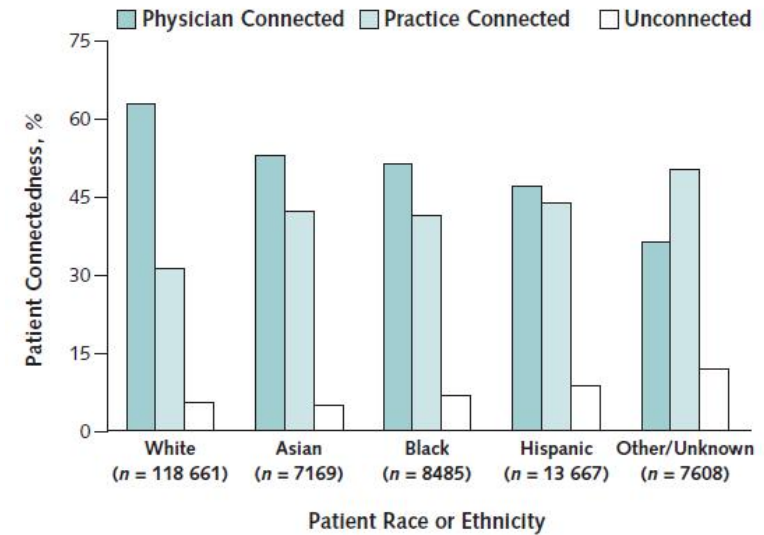
- **Visit-base point of care:**
 - In EHR, during patient registration
- **Health Insurer:**
 - Some require a listed PCP as part of coverage
- **Attributed or Inferred:**
 - Algorithm using billing claims or EHR data
 - MGH: retrospective data run yearly



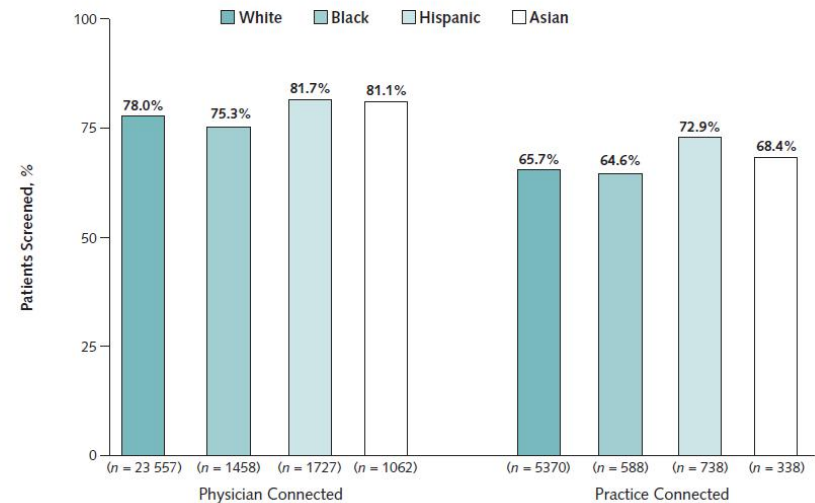
Year	Total Patients
2005	145984
2006	145515
2007	143372
2008	140786
2009	140947
2010	140995
2011	142659
2012	151786
2013	156887
2014	161028
2015	163279
2016	163998
2017	164458
2018	167747
2019	167994
2020	160335
2021	168390
2022	165521

Patient-PCP linkage and Quality of Care*

- 155,590 patients with 1 or more visits to an MGH practice
- Patients were variably linked (connected) to a specific physician
 - White patients more connected
- Less connected patients were less likely to receive guideline consistent care



Breast cancer screening rates, by patient connectedness and by race or ethnicity.

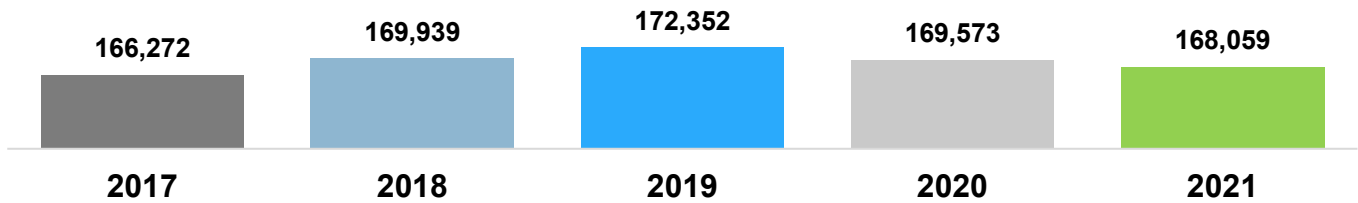


* Atlas SJ, Grant RW, Ferris TG, Chang Y, Barry MJ. Patient-Physician Connectedness and Quality of Primary Care: A Cohort Study. Ann Intern Med 2009

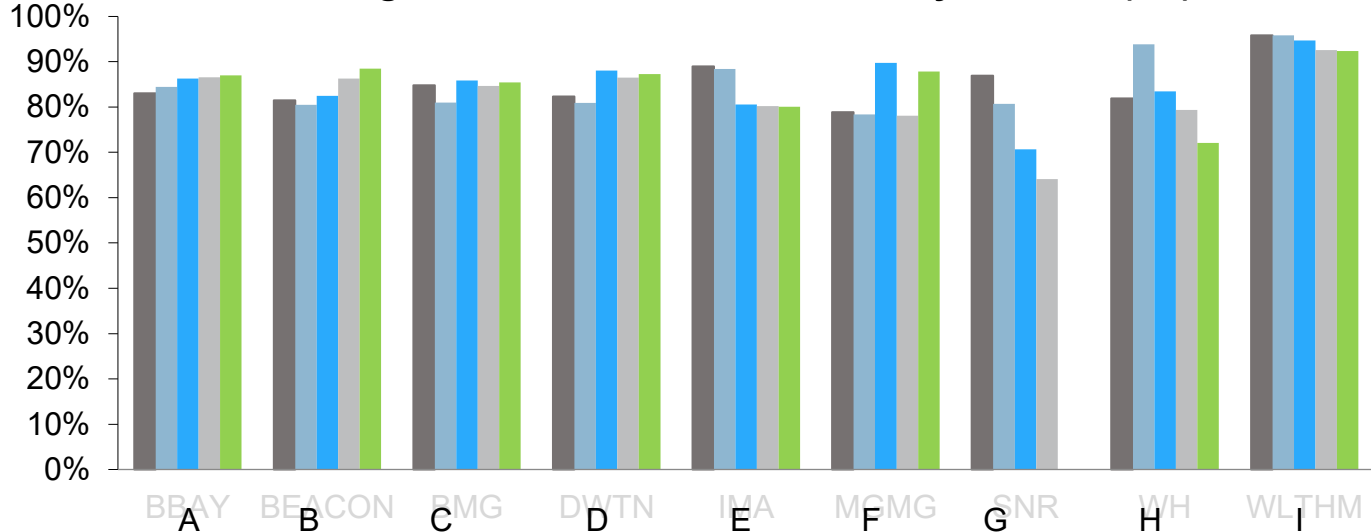
Prospectively Linking Patients and PCPs

- **Real-time Attribution of Patients to PCPs and practices**
 - Algorithm run weekly
 - More sensitive (less specific) than retrospective algorithm
- **Applications**
 - For quality reporting *
 - To identify patients for interventional studies

Prospective Linkage – Total Patients by Year (2017-2021)



Percentage of Patients linked to a PCP by Practice (A-I)

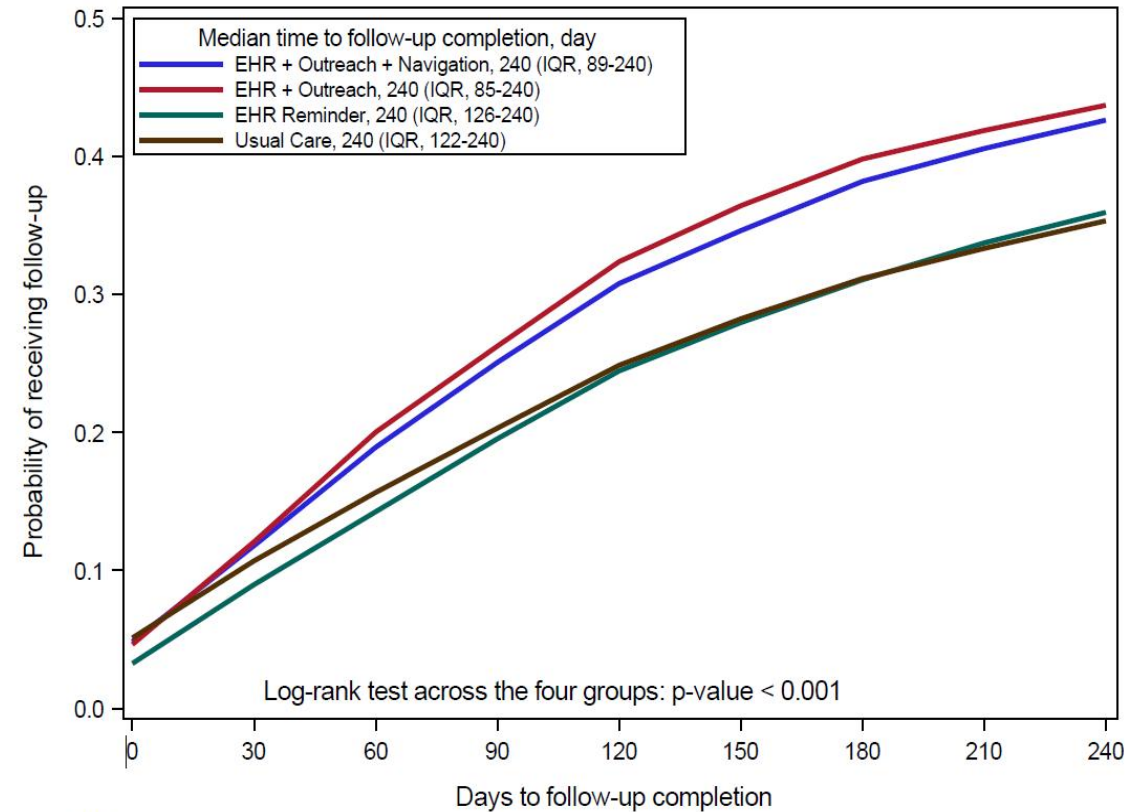


* Ward CE, Morella L, Ashburner JM, Atlas SJ. An Interactive, All-Payer, Multi-Domain Primary Care Performance Dashboard. J Ambulatory Care Manage. 2014



Improving Follow-up of Overdue, Abnormal Cancer Screening Tests

- Patients with abnormal breast, cervical, colorectal and lung cancer screening test results *
- Practices randomized to:
 - Usual care (-)
 - EHR reminders added (-)
 - EHR reminders plus patient outreach (-)
 - EHR reminders plus patient outreach plus navigation (-)



No. at risk (Intention to treat population)		Days to follow-up completion								
		0	30	60	90	120	150	180	210	240
EHR + Outreach + Navigation	3455	3050	2806	2588	2392	2258	2131	2051	1978	
EHR + Outreach	2569	2264	2062	1897	1739	1633	1546	1492	1448	
EHR Reminder	3254	2968	2794	2623	2463	2348	2245	2158	2086	
Usual Care	2702	2416	2282	2162	2033	1942	1861	1802	1747	

* Atlas SJ, et al. A multilevel primary care intervention to improve follow-up of overdue abnormal cancer screening test results: A cluster randomized clinical trial. JAMA 2023

AUDIENCE Q&A

PBRN Learning Series



Managing and Growing an Established PBRN



Panelists share tips and examples from their own experience on topics such as PBRN infrastructure and resources, governance, and developing and maintaining relationships with practices and partners.

View the recording: <https://www.ahrq.gov/ncepcr/communities/pbrn/learning-series/index.html>

E-Learning Course: Building a New PBRN



This course provides a variety of information and resources for anyone involved in setting up and growing a PBRN, such as recruiting and retaining practices, research considerations (including Institutional Review Boards), and business and funding tips.

To be published on the AHRQ website September 2024.