Recruitment, Engagement, and Retention in Practice-Based Research Networks (PBRNs)

LJ Fagnan, MD
Melinda M. Davis, PhD
Oregon Rural Practice-based Research Network (ORPRN)
27 October 2016

Objectives

- Provide a historical background on recruitment, engagement, and retention in PBRNs

- Identify strategies to engage clinicians, staff, and systems in research

- Explore the role of researchers and PBRN teams in the recruitment, engagement, and retention process

Presentation Overview

- Part 1 – Setting the Scene
  - Why did PBRNs emerge as a setting for research?
  - How is the PBRN landscape changing?
  - How has changing context impacted PBRN research?
  - So…what motivates clinicians, staff, health systems, and patients to engage in research?

- Part 2 - Case Example: How has ORPRN engaged stakeholders in research?
  - Network Overview
  - Facilitated Panel Discussion

- Part 3 - Discussion/Feedback Session with Fellows, Mentors, and Panel Members

Must Reads (and One Must Watch)

- Westfall JM, Mold J, Fagnan L. Practice-based research--"Blue Highways" on the NIH roadmap. *JAMA.* 2007 Jan 24;297(4):403-6.

- Carey TS et al. Practice-based Research Networks (PBRNs) in the Era of Integrated Delivery Systems. *J Am Board Fam Med* 2015; 28:658-662.

- Making Primary Care Better: Experiments in Front-Line Medicine (a 5 minute whiteboard by Dr. Mike Evans, see https://www.youtube.com/watch?v=kLuyXfdDz1A

Optional Readings

- Niebauer L, Nutting P. Practice-based research networks: the view from the office. *J Fam Pract.* 1994;38:409-414.

- Fagnan, L.J., et al., Voices from left of the dial: reflections of practice-based researchers. *J Am Board Fam Med*. 2010; **23**(4): 442-51.

- Practice-Based Research Network Business Opportunities with ACOs and Other Health Care Systems: Training and Technical Assistance. AHRQ Publication No. 15-0069-EF. Rockville (MD): Agency for Healthcare Research and Quality; 2015. https://www.pbrn.ahrq.gov/sites/default/files/docs/page/Primer-for-PBRN-Business-Opportunities.pdf

- Davis et al. Characteristics and lessons learned from practice-based research networks (PBRNs) in the United States. *J Healthcare Leadership* 2012; 4:107-116.

- Neale AV, et al. *PBRN Research Good Practices (PRGP)*. September 2014. Free download available at: http://www.napcrg.org/PBRNResearchGoodPractice [see also Dolor et al. Practice-based Research Network Research Good Practices (PRGPs): Summary of Recommendations. *Clin Trans Sci* 2015:1-9]

- To Recruit or To Be Recruited: Lessons Learned from the EvidenceNOW Large Scale Recruiting Experience. Blog post at: https://escalates.org/story/en-recruitment-lessons/

Why did PBRNs emerge as a setting for research?

(a brief review)

The Reach of Research

- It is estimated that it takes an average of 17 years to turn 14% of original research to reach practice and benefit the patients they care for.
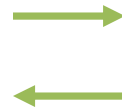 (Balas and Boren. *Yearbook of Medical Informatics* 2000:65-70)

- A 1998 review of published studies on the quality of care found that only 3 of 5 patients with chronic conditions receive recommended care.
  (Schuster M, McGlynn E, Brook R. How good is the quality of health care in the United States? *Milbank Quarterly* 1998;76:517-63)

Where Care Happens

113 : 1

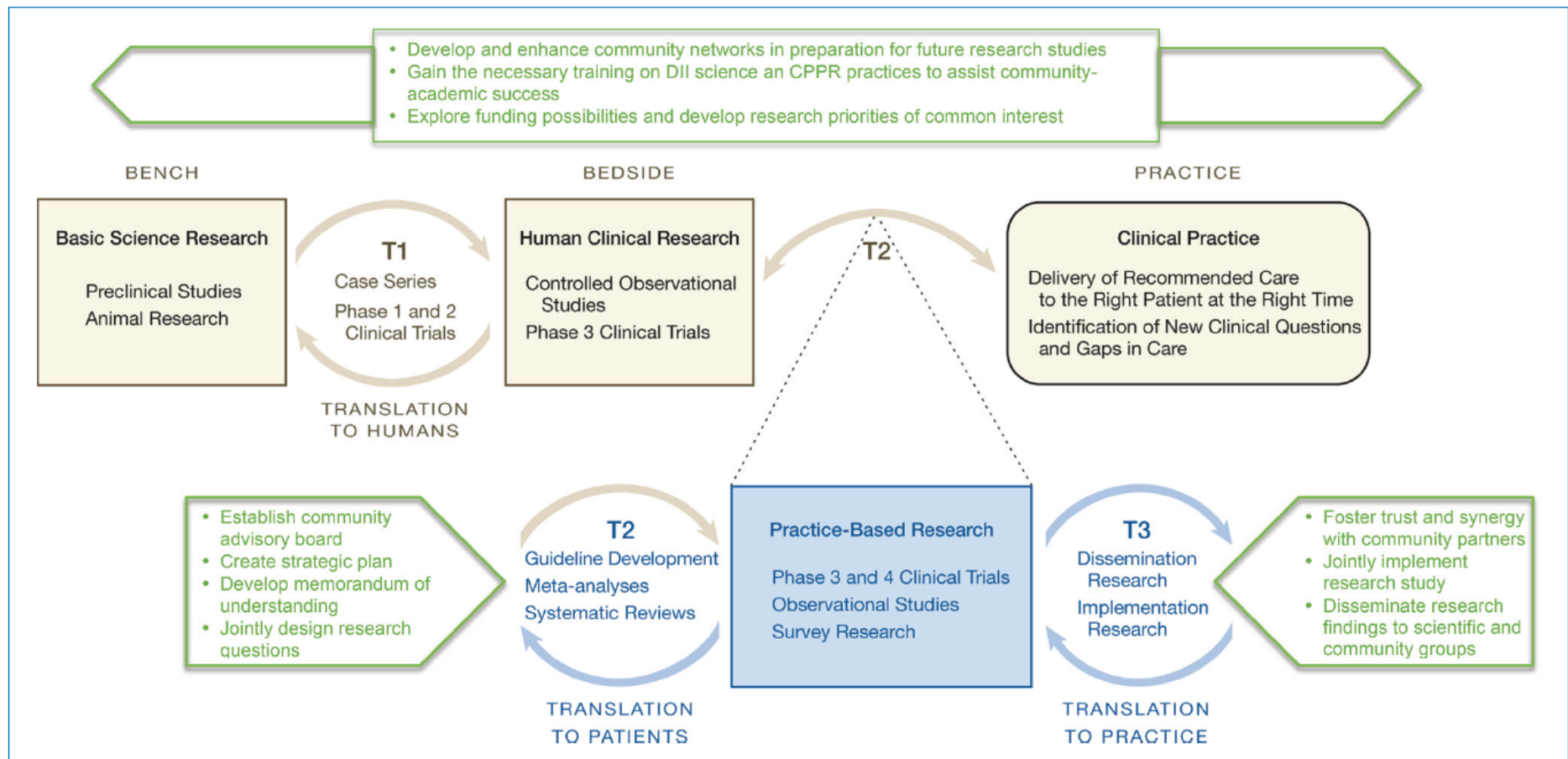Green LA, et al. The Ecology of Medical Care Revisited. *N Engl J Med* 2001; 344(26):2021-5.

"If we want more evidence-based practice we need more practice-based evidence."

L.W. Green, ORPRN Convocation Plenary Speaker, 2005

"Blue Highways" and Communities

Figure 1. Incorporation of CPPR practices during all phases of the translational Science continuum. *Adapted from Westfall JM, Mold J, Fagnan L. Practice-based research–"Blue Highways" on the NIH roadmap. *JAMA*. 2007; 294(4): 403–406.

Bodhison SC et al. Engaging the Community in the Dissemination, Implementation, and Improvement of Health-Related Research. *Clin Transl Science*. 2015: 1-6.

How is the PBRN landscape changing?

(local context shapes research interest/willingness)

Dunes Family Health Care, 1977
Reedsport, Oregon
ASPN Practice, #29

Characteristics of early PBRNs

- Led by visionary academic family physician leaders
- Network members were innovators and early adopters who wanted more out of daily primary care practice
- Face-to-face meeting at annual convocations provide critical connectivity and energy
- Simple data collection methods: card studies, weekly return, age/sex registry
- Fringe movement in the research community

see Davis et al. Characteristics and lessons learned from practice-based research networks (PBRNs) in the United States. *J Healthcare Leadership* 2012; 4: 107-116.

Data Collection Tool
Circa 1987

_____ASPPN	_____ ASPPN															OUR/MY PRAC'S SERVS WERE AVAIL:

ASPPN — Week Starting 8 A.M. Monday ___ ___ 198___ / MO. DAY YR.

ASPPN — Week Starting 8 A.M. Monday ___ (MO.) ___ (DAY) , 198 ___ (YR.) — Total Practice Encounters This Week _____

OUR/MY PRAC'S SERVS WERE AVAIL: M Tu W Th Fr Sa Su — MORNING / AFTERNOON / NIGHT

ACTIVE PID — ALL WOMEN YOU DIAGNOSE AS HAVING PELVIC INFLAMMATORY DISEASE

PATIENT'S NAME	PATIENT'S IDENTIFIER	BIRTHDATE MO	DA	YR	TEMP >100.4F >38C Y	N D	LOWER ABD PAIN Y	N D	PAST HX OF ACTIVE PID Y	N D	PAIN MOVE CERVIX Y	N D	PAIN PAL-PATE UTERUS Y	N D	PAIN PAL-PATE AD-NEXAE Y	N D	AD-NEXAL MASS Y	N D	IUD NO	YES DC	YES DPT	WBC ORD	NOT ORD	ESR ORD	NOT ORD	RX MYSELF	REFER	DISP AMBUL	HOSPIT	Visit FIRST	RET

SAB — ALL WOMEN YOU DIAGNOSE AND TREAT WHO MEET BOTH INCLUSION CRITERIA

PATIENT'S NAME	PATIENT'S IDENTIFIER	BIRTHDATE MO	DA	YR	INCLUDING THIS ABORTED PREG., NUMBER OF: PREG	SAB	IAB	ESTIM GEST AGE IN WKS	PLANNED PREG Y	N D	SITE(S) OF RX HOME	OFF	ER	HOSP	CONSULT OB-TAINED Y	N	D & C Y	N

The Primary Care Practice Landscape in 2016

- Increasing numbers of complex patients
- Fewer physician-owned practices
- Dramatic shortage of primary care physicians and a maldistribution
- Increasing role for non-physician clinicians—NPs and PAs
- Technology is here to stay—increasing access to information for the physician and the patient

Two Transformative Changes

1) The spread of electronic health records (EHRs)
   - Adoption supported by multiple federal initiatives (increase of 78% between 2009-2013)
   - Consolidation of EHR venders

2) The rise of integrated delivery systems
   - Physicians employed or under contracts
   - Competing demands with organizational missions

Carey TS et al. Practice-based Research Networks (PBRNs) in the Era of Integrated Delivery Systems. *J Am Board Fam Med* 2015; 28:658-662.

Harried Physicians

- For every hour physicians provide in direct clinical face time with patients, 2 additional hours is spent on EHR and desk work/day.

- Outside office hours, physicians spend 1 to 2 hours of personal time each night doing additional computer/clerical work.

Sinsky C. et al. Allocation of Physician Time. *Ann Intern Med*. 6 September 2016

Time Demands in Primary Care

2,500 patients
Conservative time estimates

Ten most common Chronic illnesses

Preventive care Level A and B recommendations

Well controlled
3.5 hrs/day
Poorly controlled
10.5 hrs/day

7.4 Hours per day
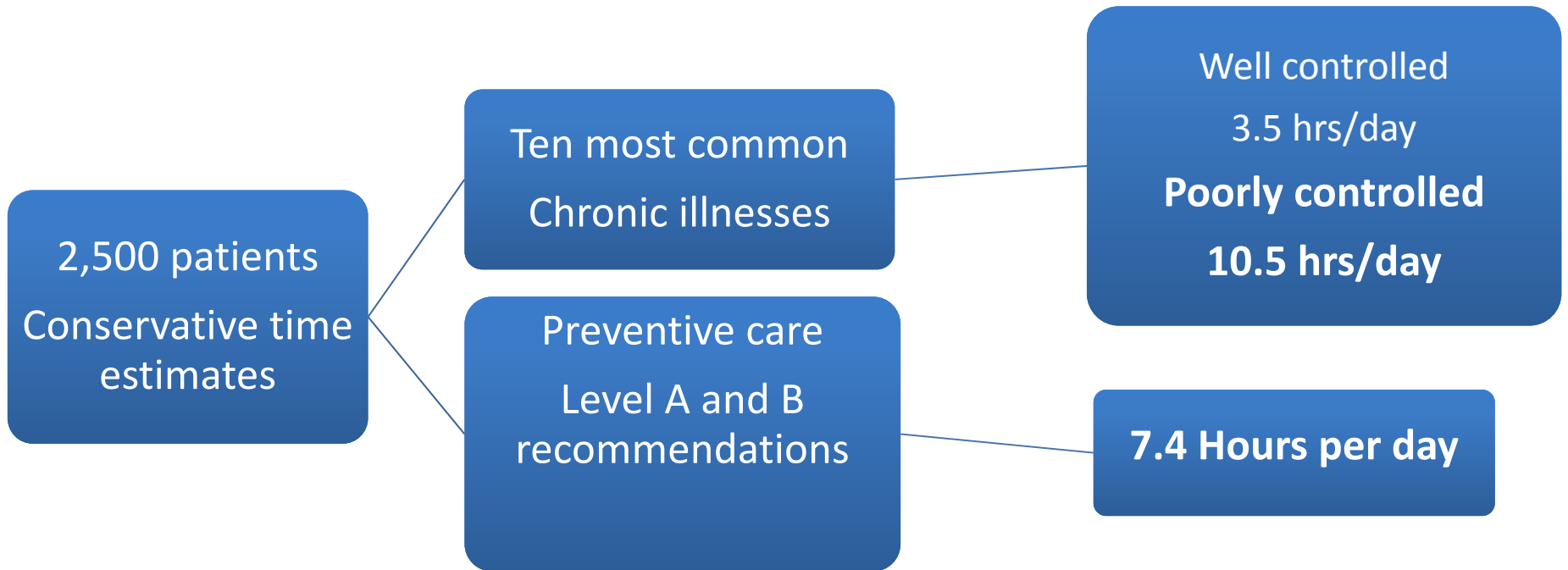
How has changing context impacted PBRN research?

PBRN Studies Blend Quality Improvement & Research

Category	Research	Quality Improvement
Intent	Discovery	Application
Driven by	Current state of knowledge	Needs of end users
Foundation	Theory-driven	Application-driven
Deviation from usual practice	Significant	Minimal
Benefit to participants	Little direct benefit to most	Direct benefit to most
Evaluation criteria	Scientific rigor	Process validity
Unit of analysis	Patient or clinician	Clinician or practice
Timeline	Years	Weeks or months

Mold JW & Peterson KA. Primary care practice-based research networks: working at the interface between research and quality improvement. *Ann Fam Med*. 2005; 1S: 12-20.

The Research Landscape in 2016

- Big Data
- Multi-component, multi-level Interventions
- Studying practice change (dissemination and implementation research)
- Patient-centered outcomes research (PCOR) and Comparative Effectiveness Research (CER)
- Context:
  - Competing initiatives (practice transformation, health system reform),
  - Clinical and translational science awards (CTSAs),
  - Factors beyond the clinic walls (e.g., health extension agents, social determinants of health)

PBRNs are also moving their research beyond the primary care clinic walls

...More in future lectures

Proportional Contribution to Premature Death
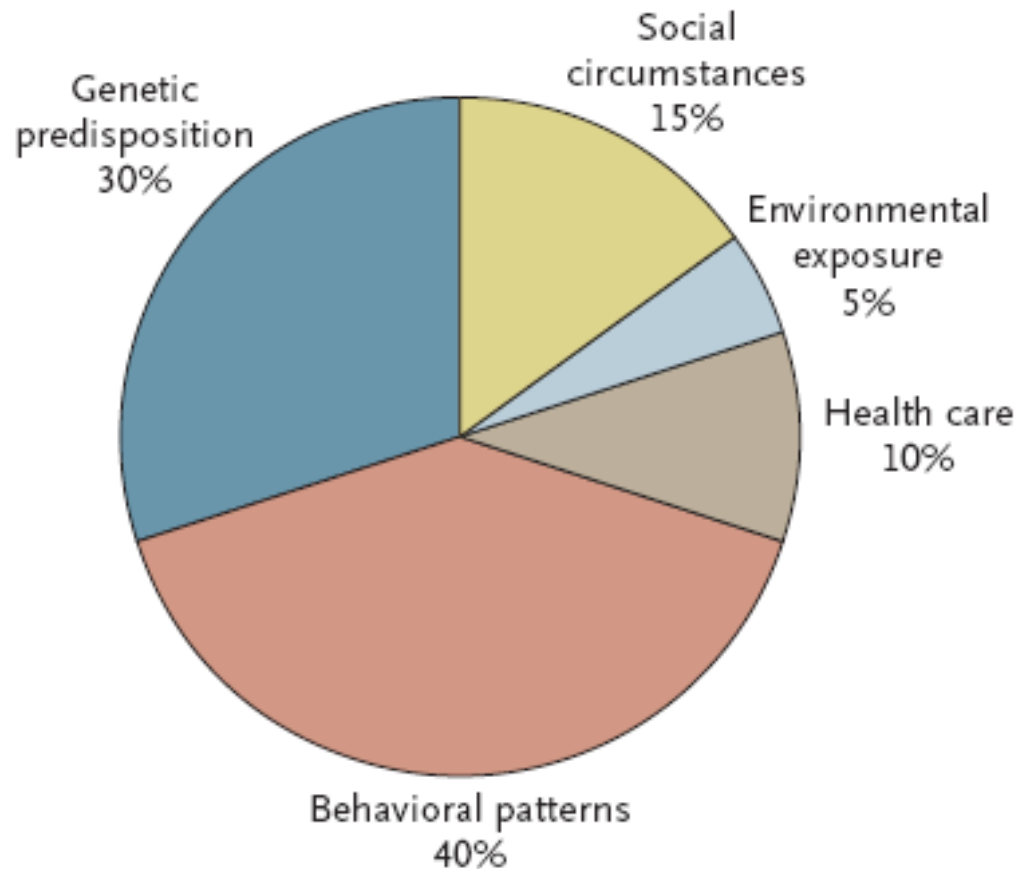
Figure 1. Determinants of Health and Their Contribution to Premature Death.

Adapted from McGinnis et al.[10]

Schroeder. *N Engl J Med* 2007; 357:1221-8.

McGinnis et al. *Health Aff (Millwood)* 2002; 21(2):78-93.

The Socio Ecological Model

PUBLIC POLICY

national, state, local laws

COMMUNITY

relationships among organizations

ORGANIZATIONAL

organizations, social institutions

INTERPERSONAL

family, friends, social networks

INDIVIDUAL

knowledge, attitudes, skills
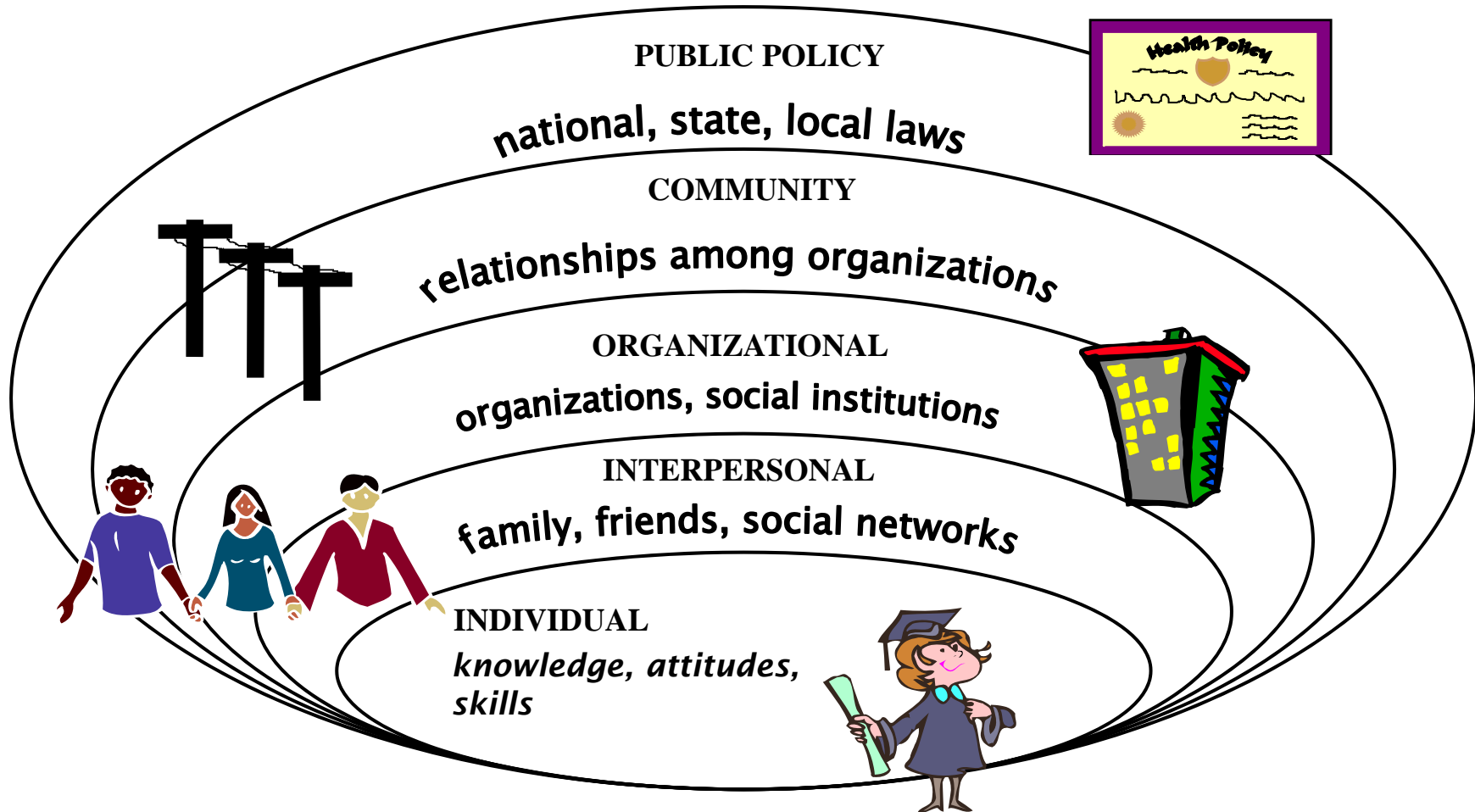
THE BIG QUESTION:

What motivates clinicians, staff, health systems, and patients to engage in research?

(and have the reasons changed over time?)

Carpal Tunnel Syndrome in Primary Care

Episodes of Care for Chest Pain

Diabetes Care by Primary Care Physicians

Diagnosed and Undiagnosed Asthma

Obstetric Referral in Family Practice

Psychosocial Problems in Primary Care

Endorsed by the American Academy of Family Physicians

Practice-Based Research Networks: The View from the Office
Linda Niebauer and Paul A. Nutting, MD, MSPH
J. Family Practice 1994; 38(4): 409-414.

Questions Explored:
- Why participate in practice-based research? What are the personal and professional rewards?
- How do patients and practice staff react to participation in research?
- What is the role of the practicing clinician in network research?
- What has been the effect of your research on the way you practice?
- What role do PBRNs play in bridging the gap between practice and academics?

ORPRN Q-Methodology Study

Research Objective: To characterize the subjective motivations to participation in practice-based research by a subset of ORPRN clinicians

- Uncovers and identifies the range of opinions regarding a specific topic under investigation
- The research instrument is called a *"Q-sample"*
- The sample is developed through the *"concourse"* process—the total range of communication around a topic
- *Q-sorting*—participant is asked to rank-order the opinion statements

Top Five Motivating Responses

Q-Statement	Mean (CI)
I want to improve the quality of care to my patients	3.46 (3.17 to 3.75)
ORPRN makes research in a rural clinic possible	1.6 (1.15 to 2.05)
ORPRN creates new knowledge regarding rural primary care	1.38 (0.92 to 1.84)
ORPRN supports research that will bring direct benefits to my practice	1.3 (0.85 to 1.75)
I want to contribute to the pool of clinical knowledge	1.18 (0.65 to 1.71)

Top Five Demotivating Responses

Q-Statement	Mean (CI)
I have sufficient time to participate	-1.94 (-2.45 to -1.43)
My staff is motivated to participate in research	-1.5 (-1.94 to -1.04)
ORPRN research does not interfere with the efficiency of my practice	-1.36 (-1.81 to -0.91)
I don't have the staff resources to support research	-1.36 (-1.97 to -0.75)
My clinical colleagues encourage my participation in ORPRN	-1.16 (-1.67 to -0.65)

NAPCRG Clinician Stories Project
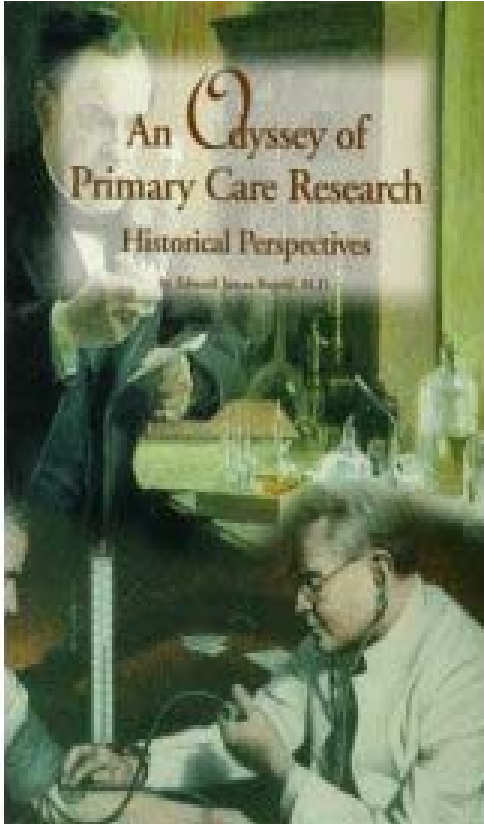
Fagnan, Handley, Rollins, Mold. Voices from Left of the Dial*: Reflections of Practice-based Research [clinician members]. *JABFM* 2010; 23(4): 442 – 451.

Clinician Stories

"I was involved in a study that illustrated the value of doing research grounded in clinical practice, the power of practice-based research to rigorously challenge conventional 'ivory tower' wisdom, and the ability of a network of practicing clinicians to make an important contribution to the practice of medicine."

Family Physician, Reedsport

Developing the Value Proposition
What's In It For Them?

Benefits (Gains) − **Costs (Pains)** = **Value**

Hartford Change Agents Conference. December 2014

Case Example: How has ORPRN engaged stakeholders in research?

Oregon!

	Oregon
Population, 2014	3,970,239
Persons 65 years and over, 2013	15.5%
Females	50.5%
Race/Ethnicity (selected), 2013	
White alone	88.1%
Black or African American alone	2.0%
Hispanic or Latino	12.3%
Persons below poverty level, 2009-2013	16.2%
Land area in square miles, 2010	95,988
Persons per square mile, 2010	39.9
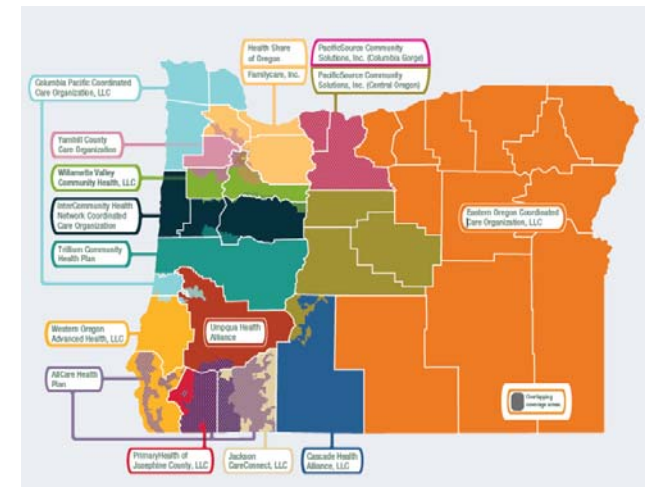
ORPRN's Mission: To improve the health of rural Oregonians by promoting knowledge transfer between communities and clinicians.
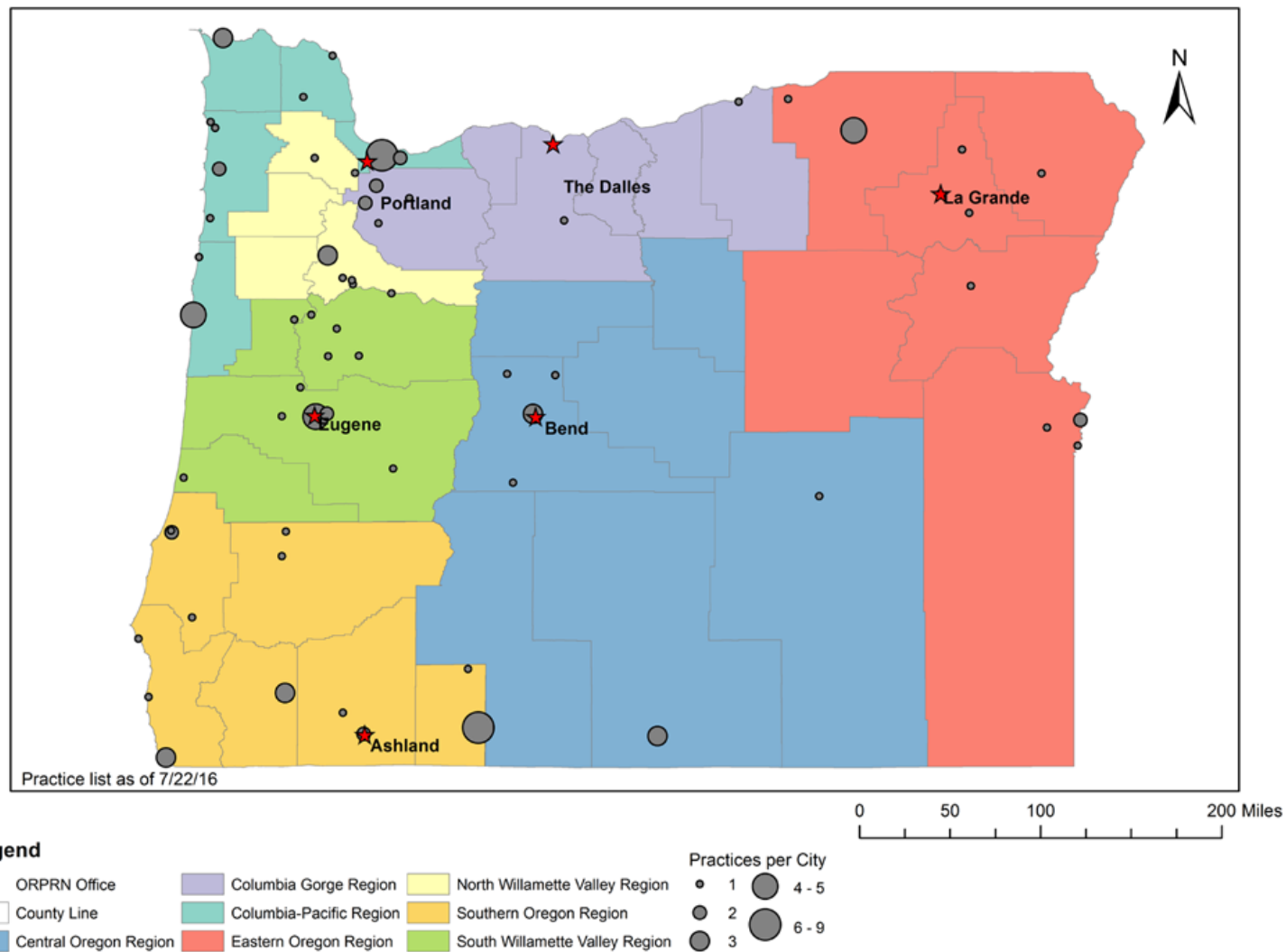
ORPRN Governance

ORPRN is governed by a Steering Committee made up of rural clinicians, practice managers, and health system leaders from around the state which meets monthly.

https://www.ohsu.edu/xd/outreach/oregon-rural-practice-based-research-network/about/steering-committee.cfm

ORPRN membership sets direction for the Network and votes on Steering Committee membership, bylaw changes, and other matters at the annual statewide Convocation

Collaborative Community Health: Outreach, Research, Health Transformation, Education

Community Engagement	Practice Transformation	Research	Education
Building Motivation and Increasing Capacity	**Connecting Practices and Delivering Services**	**Research is a Community Asset**	**Knowledge is Power**
• Nurture community collaboration and service in rural and urban areas • Health policy advocacy • Build relationships with Community Advisory Council • Build relationships with Oregon medical practices, hospitals and health systems • Community capacity building	• Patient-centered primary care home attestation • Patient advisory councils • Patient experience of care • Health systems effectiveness • Evidence-based policy	• Community-based participatory research • Practice-based research networks • Learning collaboratives • Community pilot grants	• Area Health Education Centers (AHEC) • Regional clinical education • Develop community health worker role • Create the "Learning Health System" • Health professional education

The overall goals are to implement integrated efforts for conducting community initiatives to improve population health.

- Visibility: identify & create demonstrated successes
- Identify funding to support coordination and sustainability
- Develop & implement effective measures of successful community-based engagement
- Create the infrastructure to support collaboration & sustainability

The outcomes of successful integration include:

- Build committed engagement of communities & stakeholders at all levels
- Build the academic and community capacity for successful community health
- Expand & strengthen collaborations & partnerships

ORPRN
*Oregon Rural Practice-Based Research Network*

ORPRN Structure – Hub and Spoke

- Network Director (LJ)
- Network Manager (LeAnn)
- Senior Associate Medical Director (Bruce)
- Director of Health Care Initiatives (Anne)
- Community Engaged Research Director (Melinda)
- Director of Health Disparities Research (Liz)
- 5 Project Managers, 1 Administrative Assistant, 1 Research Assistant(s)
- Our PERCS!

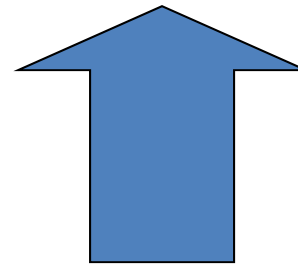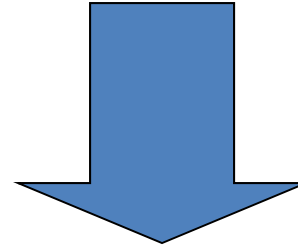# Practice Enhancement Research Coordinators (PERCs)

- Building Relationships

- Conducting Research (from the National Children's Study Pilot to SEARCH)

- Practice Facilitation
  - Meetings, huddles
  - Metrics, PDSA cycles
  - Workflow analysis
  - HIT assistance
  - Conflict resolution
  - Coach
  - Resource liaison (to academic and clinical experts)
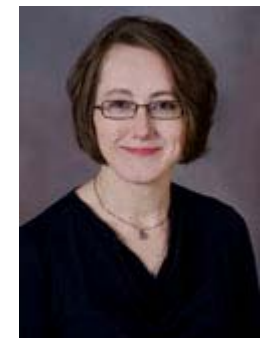
Models of Practice-Based Research

- Top-Down
  - Researcher-focused
  - Funder-focused

- Bottom-Up
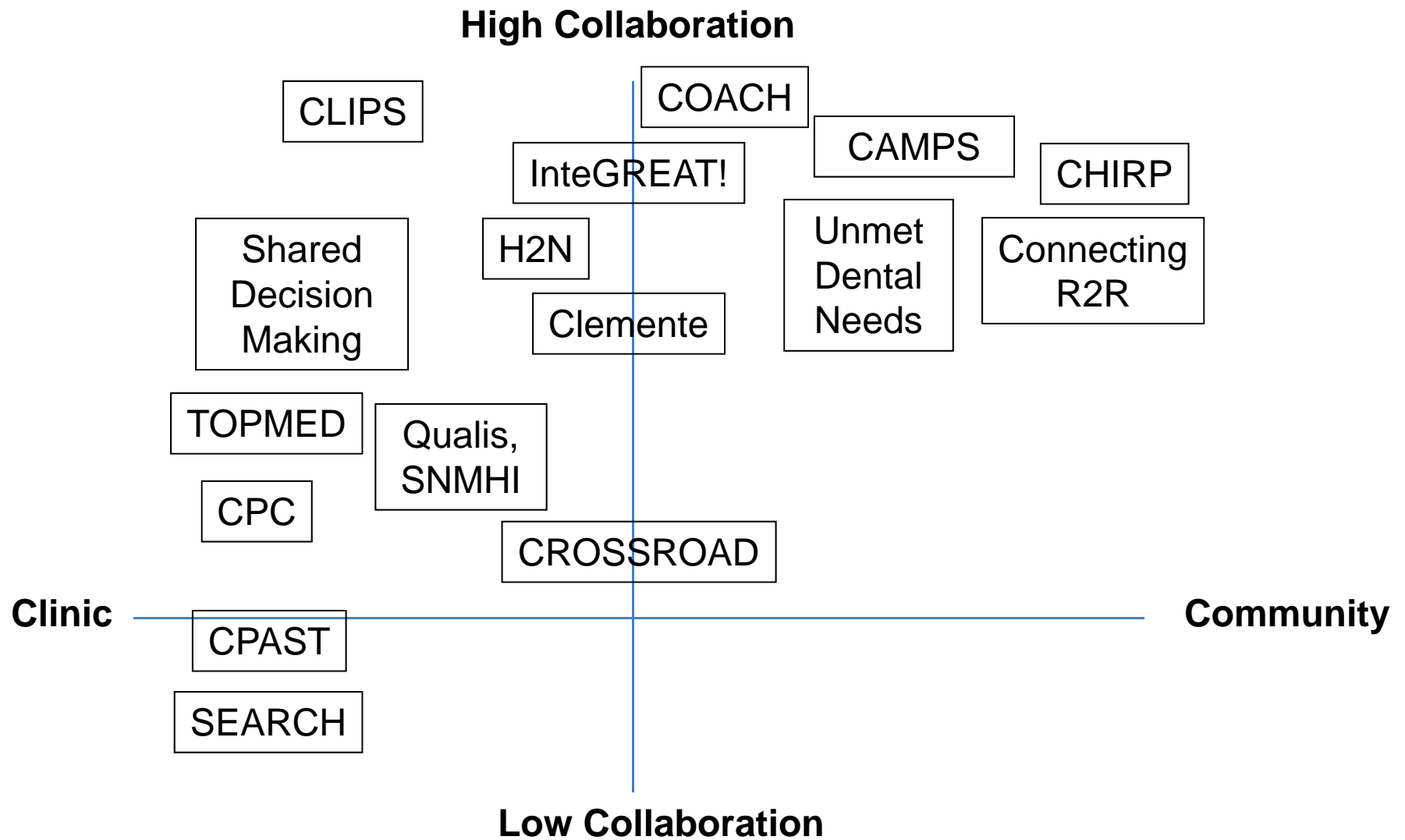 - Clinician-focused
  - Patient-focused

- Mixed (Bidirectional)

Clinician   Researcher

ORPRN's Research Spectrum

CHIP to CHIRP

Building Capacity for Community-based Participatory Research

A project of the Oregon Clinical and Translational Research Institute

http://communityresearchtoolbox.org/

Davis, Aromaa, McGinnis…Fagnan. Engaging the Underserved: A Process Model to Mobilize Rural Community Health Coalitions as Partners in Translational Research. *Clinical & Translational Science. 2014; 7(4): 300-306.*

Community Health Advocacy & Research Alliance (CHARA)
http://www.communityresearchalliance.org/

- Established in 2013 with seed funding from PCORI (Drs. Davis and Dillon)
- Supports local research, training, and evaluation
- Builds on community health development activities
  - Gorge, 2016 RWJF Culture of Health Prize Winner (see https://youtu.be/kuoz3tCn6xY)
  - Melinda, 2016 Emerging Leader Award – OPHA
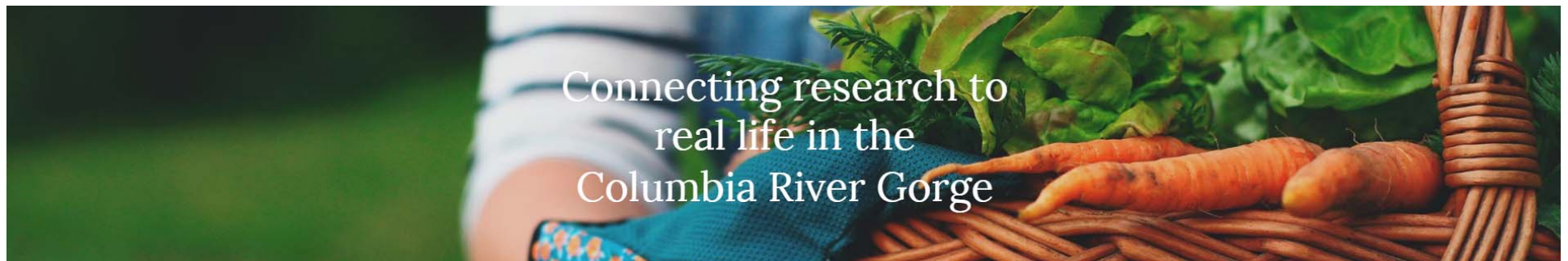
Connecting research to
real life in the
Columbia River Gorge

Panel Members

LJ Fagnan, MD
Network Director, ORPRN
Professor, Department of Family Medicine

Kelsey Branca, MPH, CCRP
Practice Enhancement Research Coordinator, ORPRN

Cullen Conway, MPH
Practice Enhancement Research Coordinator, ORPRN

You! Yes YOU!!!

Question Set 1 (LJ)

- Briefly describe your role in ORPRN

- How has ORPRN designed their activities to support stakeholder engagement?

Question Set 2 (Kelsey)

- Briefly describe the PERC's role in ORPRN

- How have PERC's supported research investigators with stakeholder (clinic, community, health system, etc) engagement and recruitment?

Question Set 3 (Cullen)

- Provide a brief overview of Healthy Hearts Northwest (H2N)

- How has the team of investigators, PERCs, and others worked to engage practices in H2N?
  - What do you do to prepare to engage a practice?
  - Who do you talk with/target outreach to?
  - Does strategy vary based on practice characteristics?
  - Who needs to be present for these conversations?

- [EvidenceNow](), an AHRQ initiative to transform health care delivery

- H2N, one of seven regional cooperatives that span 12 states, reaching 5,000 primary care clinicians serving approximately 8 million patients

H2N Overview (To whom will we spread?)

- 320 small practices

- 3 states: WA, OR & ID

- Collaborative effort
  - MacColl Center

  - Qualis Health

  - Oregon Rural Practice Research Network/OHSU

  - University of Washington: WPRN
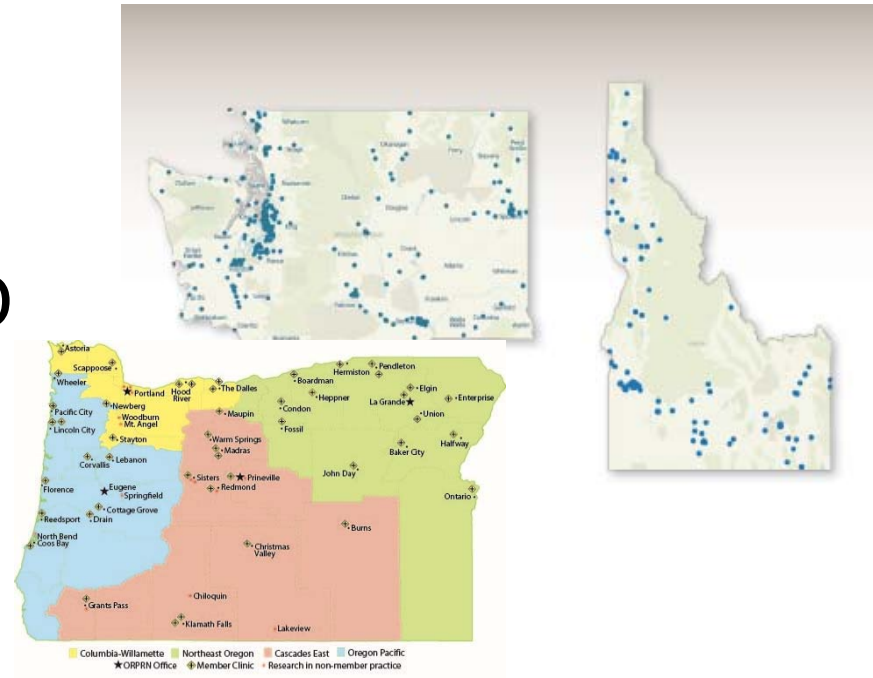
The challenge for ORPRN:
Recruiting 130 practices in a 49
member clinic network!

Background

- What are we trying to spread?
  - The adoption and routine use of the IHI Model of Improvement
    - Did they do it? (Milestone completion, CPCQ and PCMH-A)
    - Do quality measures improve? ABCS

- To Whom?
  - Highly motivated small to medium size primary care practices in WA, OR, and ID

- How Will We Spread It?
  - Practice Facilitation/Coaching
  - Learning Collaboratives
  - Academic Detailing

Yikes!

- Each practice required to report ABCS measures to us every 90 days throughout the project

Topic	Indicator	National baseline	2017 National goal
Appropriate Aspirin therapy	Aspirin use for people at high risk	47%	65%
Blood pressure control	Blood pressure control	46%	65%
Cholesterol Management	Effective treatment of high cholesterol (LDL-C)	33%	65%
Smoking cessation	Smoking prevalence	19%	17%

Selecting 130 practices in Oregon—The (Planned) Value Proposition

- Are you ready?
  - For new payment models based on quality measures, not volume?
  - For better heart health for your patients?
  - For hands-on support and resources to help your practice with quality improvement?

Selecting 130 practices in Oregon— The (Actual) Value Proposition

- Are you ready?

  – ~~For new payment models based on quality measures, not volume?~~

  – For better heart health for your patients?

  – For hands-on support and resources to help your practice with quality improvement?

Preliminary Recruitment Recommendations from EvidenceNOW

From Practices

1) Convince us that it will be worth the short term sacrifice for the long term results

2) Be very clear and upfront about what is required of me and my practice if we participate

3) Be award that we want to improve patient care, but understand our barriers (limited resources, distance, mandate overload, no financial stipend)

4) Start with the top leaders if we are part of a large organization

From Recruiters

1) Build on developed relationships (and know how to best engage with each practice)

2) Present what's in it for them, the value proposition

3) Address their concerns

4) Be pleasantly persistent

5) Use various methods for following-up

6) Be as accommodating as possible

See https://escalates.org/story/en-recruitment-lessons/

Question Set 4 (Fellows)

- What topics are you interested in doing research on?

- How (and when) are you thinking about engaging stakeholders in these research?

Question Set 5 (Mentors)

- What do investigators need to consider when designing studies for "real-world" PBRNs?
  - What strategies have worked well?
  - What "failures" can you share?

- What behaviors are critical for investigators to successfully engage with practices and/or communities?

What are the questions we haven't addressed here that are important to successful recruitment and engagement of practices and communities in research?

Thank You!

- LJ Fagnan, fagnanl@ohsu.edu
- Melinda Davis, davismel@ohsu.edu

Oregon Rural Practice-based Research Network (ORPRN)

www.ohsu.edu/orprn