

# NAPCRG's Patient and Clinician Engagement (PaCE) Project

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***Engaging Patients  
and Providers in  
Patient-Centered  
Outcomes Research***

Presenters

Ned Norman

*Cynthia Wolff*

Rebecca Borchert

*Maret Felzien*

Jack Westfall

# What is PaCE?

Objective: to develop a robust community of patients and primary care providers with knowledge and understanding of the unique features of PCOR related to primary care



***PaCE dyads speaking  
with Dr. Joe Selby,  
Executive Director of  
PCORI***

# Strategy of PaCE

## Preconferences

NAPCRG NYC 2014  
PBRN DC 2015  
NAPCRG MX 2015  
STFM MN 2016  
NAPCRG CO 2016

## Webinars

10 live webinars to further discussions, trainings, and momentum.

## Symposia

6 local symposia hosted by PaCE participants to increase PCOR knowledge and buy-in in their communities and organizations.



***PaCE Colorado  
Symposium Participants***

# Who is PaCE? Providers, Patients, Researchers, Speakers

Ed Bujold & Ray Haeme  
Kristen Dillon & Susan Lowe  
Tony Gerck & Christin Sutter  
Ned Norman & Maret Felzien  
Joseph Lemaster & Mang Sonna  
Marilyn Fraser & Ruthann Taylor  
Cleo Mavriplis & Madeleine L Champagne  
Ann Macauley & Jean Légaré  
Antoine Boivin & Jean Vocino  
Vicki Roberts & Sueann Owens  
Aimee English & Becky Emory  
Alan Pavilanis & Kirk Kelly  
LJ Fagnan & Rick Nitti  
John Epling & Carla Desalvia  
David Beaufait & David Johnson  
Diane Mckee & John MacDonald  
Hazel Tapp & Diane Derkowski  
Melanie Murphy & Willie Murphy  
Cynthia Krueger Wolff & Bethene Ross & Becky Borchers  
Amit Gupta & Nazia Munir  
David Hahn

Jack Westfall  
Linda Zittleman  
Tom Vansaghi (NAPCRG)  
Rick Glazier (NAPCRG)  
Hope Wittenberg (CAFAM)  
Cheryl Levitt (McCaster)  
Perry Dickinson (UC Denver)  
Valerie Gilchrist (Univ of Wisc)  
David Meyers (ARHQ)  
Joe Selby (PCORI)  
Nancy Mason Maclellan (CIHR)  
Marci Neilson (PCPCC)  
Jessica Sand (AAFP NRN)  
David Hickahm (PCORI)  
Tsahai Tafari (PCORI)  
Courtney Clyatt (PCORI)  
Jennifer Carroll (AAFP NRN)

***AND THE LIST KEEPS GROWING....***

*Why do we do this??*

# Recent C.A.C. Meeting

Held in the community  
On the community's schedule



***Who is the community member and who is the research team?***

# Just Check It.

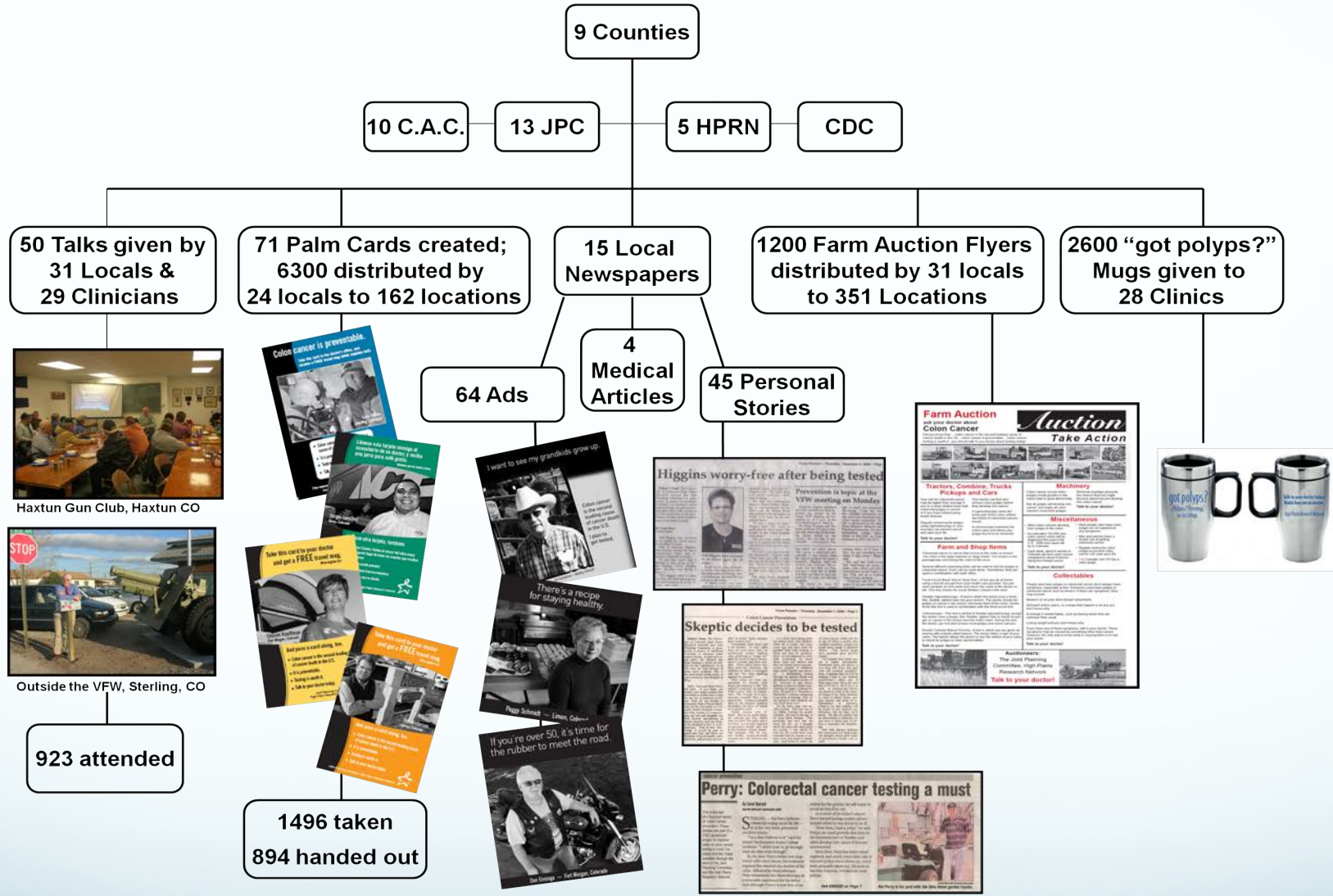
Engaging rural community members in project on high blood pressure





# HPRN C.A.C. member Garry Haynes talking about colon cancer prevention at the Haxtun Gun Club





Haxtun Gun Club, Haxtun CO



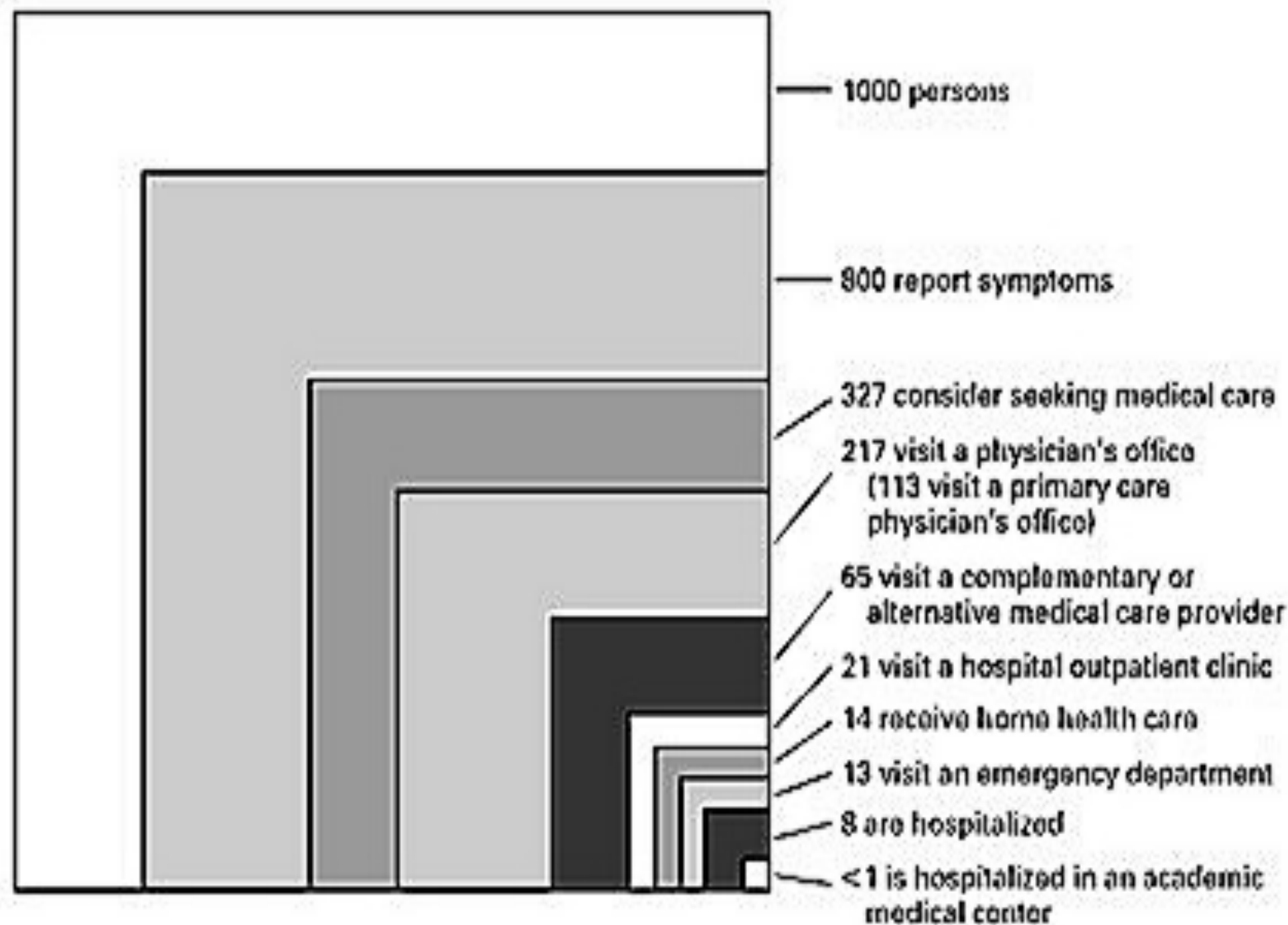
Outside the VFW, Sterling, CO



**229 local people participated in the implementation of "Testing to Prevent Colon Cancer"!**

***Making a video on CBPR study process and results.***





# The Reach of Research

- It is estimated that it takes an average of **17 years** for **14%** of original research to reach practice(s) and benefit the patients they care for.

(Balas and Boren. *Yearbook of Medical Informatics* 2000:65-70)

# Akron Mercy Medical Clinic Staff



*PCORI Pipeline Group meeting at 7am in Akron, IA  
“Addiction Treatment Integration in Rural Primary Care”*





***Babysitters at PCORI  
Pipeline Meeting on  
Addiction Integration.***

***Having fun is a rule! (Aerial  
photo of Akron, Iowa in the  
background.)***



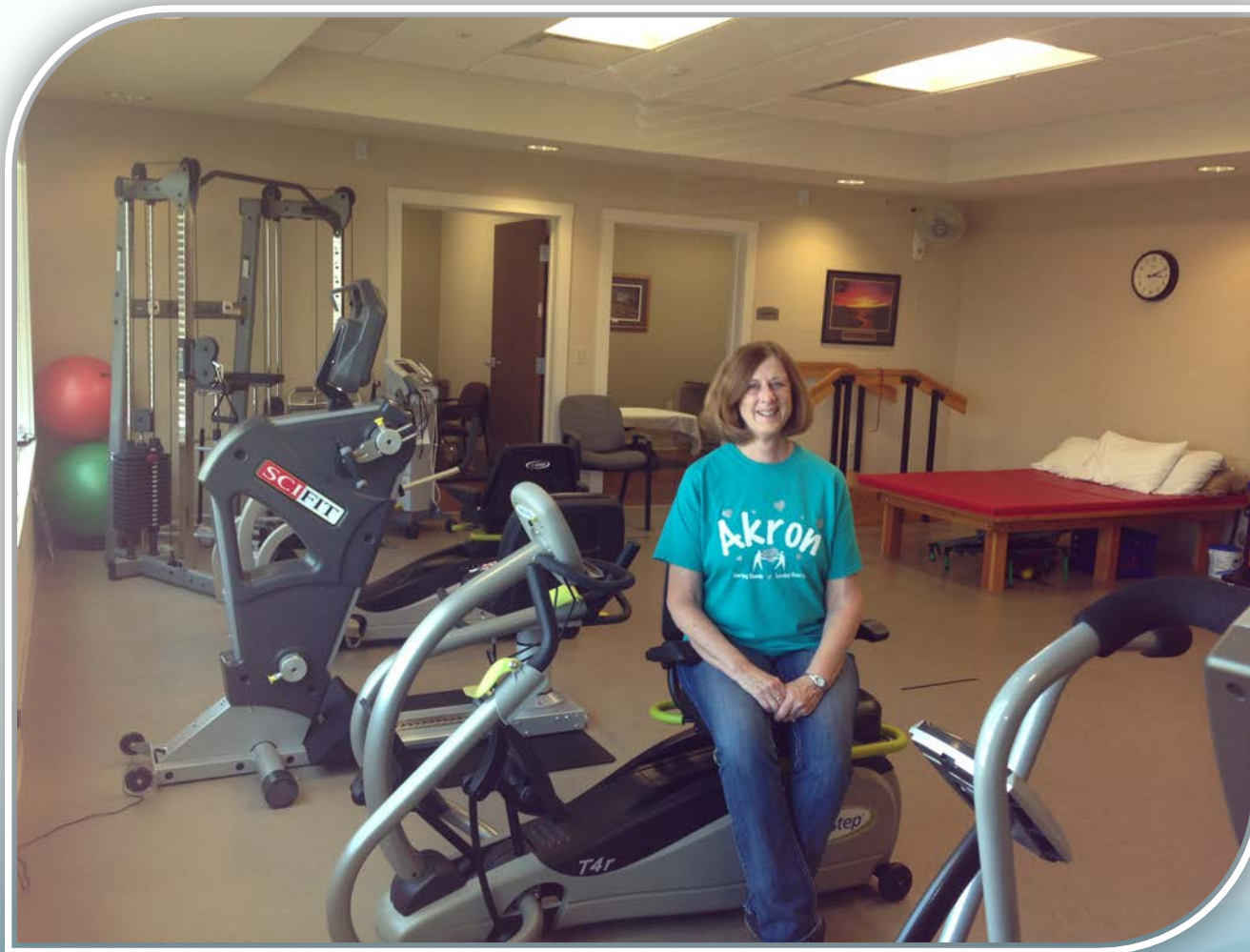
# Advocacy. We tried it alone..... It doesn't work

- Science-alone advocacy does not work
- Just telling about our cool research projects does not seem to work
  - Policy makers don't read medical journals.
- Payment reform may not sell when it's just the doctors making the sale.
  - GME reform
  - Malpractice reform
  - .....
- Begging for more appropriations does not work



There was a  
need, and we  
fixed it.

# Bringing physical, occupational, and speech therapy to the community and nursing home



# Akron's New Nursing Home



## ORIGINAL RESEARCH

# Boot Camp Translation: A Method For Building a Community of Solution

*Ned Norman, Chris Bennett, Shirley Cowart, Maret Felzien, Martha Flores, Rafael Flores, Connie Haynes, Mike Hernandez, Mary Petra Rodriquez, Norab Sanchez, Sergio Sanchez, Kathy Winkelman, Steve Winkelman, Linda Zittleman, MSPH, and John M. Westfall, MD, MPH*

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**Objective:** A crucial yet currently insufficient step in biomedical research is the translation of scientific, evidence-based guidelines and recommendations into constructs and language accessible to every-day patients. By building a community of solution that integrates primary care with public health and community-based organizations, evidence-based medical care can be translated into language and constructs accessible to community members and readily implemented to improve health.

**Methods:** Using a community-based participatory research approach, the High Plains Research Network (HPRN) and its Community Advisory Council developed a process to translate evidence into messages and dissemination methods to improve health in rural Colorado. This process, called Boot Camp Translation, has brought together various community members, organizations, and primary care practices to build a community of solution to address local health problems.

**Results:** The HPRN has conducted 4 Boot Camp Translations on topics including colon cancer prevention, asthma diagnosis and management, hypertension, and the patient-centered medical home. Thus far, the HPRN has used Boot Camp Translations to engage more than 1000 rural community members and providers. Dissemination of boot camp messaging through the community of solution has led to increased colon cancer screening, improved care for asthma, and increased rates of controlled blood pressure.

**Conclusions:** Boot Camp Translation successfully engages community members in a process to translate evidence-based medical care into locally relevant and culturally appropriate language and constructs. Boot Camp Translation is an appropriate method for engaging community members in patient-centered outcomes research and may be an appropriate first step in building a local or regional community of solution. (*J Am Board Fam Med* 2013;26:254–263.)

**Keywords:** Asthma, Cancer Screening, Colorectal Cancer, Community-Based Participatory Research, Practice-based Research, Rural Health

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***Maret Felzien and Ned Norman share patient perspectives with PCORI early on to help inform PCORI's work.***

# Helping prepare a NAPCRG pre-conference with Dr. Ann Macaulay





# STRATEGIC PLAN

## 2014-2017

### Mission

The North American Primary Care Research Group (NAPCRG) is an interdisciplinary volunteer association committed to nurturing primary care\* researchers.

### Vision

NAPCRG is the recognized leader of primary care research that improves health and health care for patients, families and communities.

### Core Values

- ◆ NAPCRG is committed to scientifically rigorous, relevant research;
- ◆ NAPCRG believes primary care research is fundamental to well-functioning health systems;
- ◆ NAPCRG is committed to embracing a safe, inclusive and supportive environment for its staff, members and stakeholders;
- ◆ NAPCRG promotes diversity in its membership, leadership, meetings, programs, research, employment, and all of its other endeavors.
- ◆ NAPCRG is committed to equitable healthcare for all;

### Strategic Areas of Focus

Capacity Building:  
Focus on Providing  
Membership Value  
through Growth,  
Retention and  
Management  
Initiatives

1

Capacity Building:  
Focus on Increasing  
Research Capacity  
and Organizational  
Capability

2

Foster Patient and  
Clinician Engagement

3

Advocate, through  
collaboration with  
strategic partners, to  
advance primary care  
practice, research  
and funding

4

Explore options and  
implications for  
NAPCRG's role in  
international primary  
care research\*

5

\*For purposes of this document, "primary care" as a term is intended to encompass primary health care, which includes a preventive system of care that is rooted within communities, governments and health care systems.



What should PBRN folks  
know about engaging  
patients and providers?

***“We’re from the (fill in the blank...), and we’re here to help!”***



**“It is inherently improbable that an academic researcher can ask a clinical question that matters to a patient.”**

*Thank you!*