NAPCRG’s Patient and Clinician Engagement (PaCE) Project

Engaging Patients and Providers in Patient-Centered Outcomes Research
Presenters
Ned Norman
*Cynthia Wolff*
Rebecca Borcher
*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

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<th>Ed Bujold &amp; Ray Haeme</th>
<th>Jack Westfall</th>
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<td>Tony Gerk &amp; Christin Sutter</td>
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<td>Ned Norman &amp; Maret Felzien</td>
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<td>Joesph Lemaster &amp; Mang Sonna</td>
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<td>Perry Dickinson (UC Denver)</td>
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<td>Ann Macauley &amp; Jean Légaré</td>
<td>Valerie Gilchrist (Univ of Wisc)</td>
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<td>Vicki Roberts &amp; Sueann Owens</td>
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<td>Aimee English &amp; Becky Emory</td>
<td>Nancy Mason Macelllan (CIHR)</td>
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<td>LJ Fagnan &amp; Rick Nitti</td>
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<td>John Epling &amp; Carla Desalvia</td>
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<td>David Beaufait &amp; David Johnson</td>
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<td>Diane Mckee &amp; John MacDonald</td>
<td>Courtney Clyatt (PCORI)</td>
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<td>Hazel Tapp &amp; Diane Derkowski</td>
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<td>Melanie Murphy &amp; Willie Murphy</td>
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<td>Cynthia Krueger Wolff &amp; Bethene Ross &amp; Becky Borchers</td>
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<td>Amit Gupta &amp; Nazia Munir</td>
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<td>David Hahn</td>
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*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
229 local people participated in the implementation of “Testing to Prevent Colon Cancer”!
Making a video on CBPR study process and results.
1000 persons

800 report symptoms

327 consider seeking medical care

217 visit a physician's office (113 visit a primary care physician's office)

65 visit a complementary or alternative medical care provider

21 visit a hospital outpatient clinic

14 receive home health care

13 visit an emergency department

8 are hospitalized

<1 is hospitalized in an academic medical center
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
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 Rodriguez, Norab Sanchez, Sergio Sanchez, Kathy Winkelman, Steve Winkelman, Linda Zittleman, MSPH, and John M. Westfall, MD, MPH

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

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

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;

Capacity Building: Focus on Providing Membership Value through Growth, Retention and Management Initiatives
Capacity Building: Focus on Increasing Research Capacity and Organizational Capability
Foster Patient and Clinician Engagement
Advocate, through collaboration with strategic partners, to advance primary care practice, research and funding
Explore options and implications for NAPCRG’s role in international primary care research*

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