



Community-Campus Partnerships for Health

Promoting Health Equity and Social Justice

The Convening Journey: Facilitating Patient & Stakeholder Engagement through Partnerships



Deep South | Midwest | Carolinas
2016 - 2017

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Community-Campus Partnerships for Health

Established in 1997, Community-Campus Partnerships for Health (CCPH) is a nonprofit membership organization that promotes health equity and social justice through partnerships between communities and academic institutions. We view health broadly as physical, mental, emotional, social and spiritual well-being and emphasize partnership approaches to health that focus on changing the conditions and environments in which people live, work, study, pray and recreate. By mobilizing knowledge, providing training and technical assistance, conducting research, building coalitions and advocating for supportive policies, we help to ensure that the reality of community engagement and partnership matches the rhetoric.

The Convening Journey

In 2016, CCPH was funded by a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EAIN-2517) to answer 3 key questions:

- ◆ How feasible is it to implement a national meeting framework that includes patients as stakeholders who actively attend and participate in meetings convened in different regions in the country?
- ◆ What key PCOR and CER priorities arise as a result of executing a regional patient-centered engagement conference framework?
- ◆ What best practices can be established for disseminating proceedings from the patient centered engagement conferences, regardless of chronic disease focus or region where meetings are convened?

CCPH convened meetings that would reflect the diversity of stakeholders, patients, patient advocates, and researchers interested in patient-centered outcomes research (PCOR) and comparative clinical effectiveness research (CER). CCPH identified 3 distinct regions of the country for these meetings—the Deep South, the Upper Midwest, and the Carolinas.

Pre-Conference Meeting: Facilitating Patient & Stakeholder Engagement Through Partnerships

The Deep South | New Orleans LA | May 11, 2017

CCPH identified and invited patient advocates from Arkansas, Louisiana, and Mississippi to form a planning committee for the first meeting. Over the course of regular meetings with this planning committee, we compiled a list of prospective participants and invited them to the first meeting – Facilitating Patient and Stakeholder Engagement Through Partnerships, held on May 11, 2016 in New Orleans, LA, as a pre-conference session to the CCPH 14th International Conference.

The purpose of this session was to build on the goal of connecting with those who are most knowledgeable of the issues that foster or impede patient engagement. We identified and invited participants from the Deep South to contribute their first-hand knowledge and experience on iss-

ues important to designing research that puts "patients first." Participants were encouraged to share ideas regarding the nature and scope of their work, what could be done to improve the health outcomes of their communities, and to help shape the research being conducted in their communities. The Deep South meeting was designed to influence and inform future meetings with key stakeholders scheduled in the Upper Midwest and the Deep South.

The meeting was strategically designed to facilitate a bidirectional exchange of information where both researchers and community contribute to the conversation, where conscious and active participation would be welcomed by those representing community and researchers, and to support the ability of patients, stakeholders, and researchers to play significant roles as partners in patient-centered outcomes research (PCOR) and comparative effectiveness research (CER).

This resulted in a didactic communication experience, fully-embraced by participants, creating an ideal environment for storytelling.

This was successful in The Deep South and subsequent meetings because community voices weighed heavily and strong. This effectively contributed to the balance of power by shifting the traditional inequity, giving respect to community voices. This exchange prompted researchers to express and find solutions that enlist the help of the communities. The ultimate benefit of this engagement strategy is it helped to ensure the results of research benefit underserved populations and achieve health equity in the communities supporting this emerging network.

It was clear at the Deep South convening that this rich environment of storytelling was used by people we identified. These were participants whose motivation was authentic. They exhibited more interest, excitement and confidence, as well as greater persistence, creativity and performance than could be accomplished by a group of participants convened randomly, who might be motivated largely by external demands and rewards.

With full engagement of all participants, three key themes emerged from the stories shared:

- ◆ Trust and Trustworthiness
- ◆ Transparency
- ◆ Partnership

At the end of this first meeting, we were left with the challenge to find ways to capture some of the dynamism that took place in the Deep South, and infuse the next two meetings with that same energy. An essential part of this was the huge finding that patients want trust and require evidence of trustworthiness. Patients want transparency. Patients want to be partners.

Agenda Items:

Welcome & Overview

Al Richmond, MSW

Research 101

Rebekah Angove, PhD

Overview of Patient-Centered Care

Larry Taylor

Freddie White Johnson

What is PCOR and CER and How it Impacts Patient-Centered Care

Lia Hotchkiss, MPH

Lunch & Guest Speaker:

“Engaging Underserved Communities in PCOR and CER”

Neely Williams, MDiv

Diverse Voices in Patient-Centered Care + Report Out

Call to Action & Closing Session

We created a practical map for marshalling that energy that included the emergence of the four themes. We focused on the themes and used them as the linchpin for the planning strategy of subsequent meetings. We wanted to ensure we brought these ideas forward, that the stories of Trust and Trustworthiness, Transparency and Partnership remained a simple and yet compelling narrative to help better understand these themes.

There was some background that we were eager to bring along from this. We wanted to bring the benefits of the respective experiences of each region but also the necessity of revealing something new. We envisioned a collaboration between these regions, the issues that surfaced and operationalizing those.

Facilitating Patient & Stakeholder Engagement in Research Through Partnerships: The Cancer Care Continuum

The Upper Midwest | Chicago IL | May 20, 2017

As of March 2017, PCORI had dedicated \$194 million to 65 cancer research studies. In addition to clinical and care process outcomes, PCORI projects assess a patient's well-being and perceptions of their care. On May 20, 2017, CCPH convened the 2nd meeting in Chicago, Illinois with stakeholders representing the cancer care/research community, Facilitating Patient & Stakeholder Engagement in Research Through Partnerships: The Cancer Care Continuum. We utilized the same strategies for recruitment in the Upper Midwest as used in the Deep South to recruit participants from the cancer community with the highest level of commitment to full engagement in PCOR and CER. Patients who had been diagnosed with cancer, clinicians, researchers, advocates and other stakeholders in the cancer community discussed the challenges they faced, lessons learned and the benefits of patient-centered cancer care research. We explored the place-region relationship, specifically, the symbolic value of the communities to their region, the strategic positioning of the communities to address key regional issues, and whether regional and disease-specific issues could be scaled up to a national level. This meeting served to deepen the understanding of the challenges and incentives needed to connect with communities disproportionately impacted by disease, and whose voices have been muted by systematic patterns of oversight.

Agenda Items:

Welcome & Opening Session

*Al Richmond, MSW
Robert Winn, MD,
Alex Zafirovski, MBA, RT(T),
ARRT*

PCORI: Progress in Patient-Centered Research

Lisa Stewart, MA

Patients as Experts: A Panel & Discussion Exploring the Needs of Patients in Research

Examples from Chicagoland: Pastors 4 PCOR

*Paris Davis, PhD
Pastors4PCOR*

Keynote Address + Q&A

*Hayley Thompson, PhD, Wayne
State University School of
Medicine*

Building a Plan to Facilitate Patient Engagement

Report + Next Steps

We conducted further exploration of the themes of Trust and Trustworthiness, Transparency and Partnership. The cancer patient stakeholder community at the 2nd convening contributed to this dialogue by defining the elements of each theme.

Lessons Learned

We learned that the success of community-research engagement activity is about much more than just healthcare. Working toward better health outcomes not only means improving our health delivery system; it also means moving policies, practices, and power dynamics to improve environmental, education, social, and economic outcomes. These “upstream” social determinants of health —like income, education, and neighborhood conditions—are often at the root of poor health and health disparities.

Participants discussed four questions framed by these themes. Through discussion surrounding these four questions, many different concepts, objectives, and recommendations emerged.

- ◆ After hearing this, how much of what you heard is similar to your experience as a patient, patient advocate or survivor?
- ◆ Is there anything you think is specific to the needs of patients with cancer, survivors, or advocates in terms of patient engagement?
- ◆ We talked a lot about patient engagement. What does it mean to you?
- ◆ In summary, what are some ways we can better engage patients in terms of cancer prevention, treatment, survivorship, and research?

Trustworthiness:

Respect
Genuineness
Commitment
Humility

Transparency:

Openness
Honesty
Full disclosure

Partnership:

Power balance
Shared Resources
Co-creation of knowledge

A Town Hall Meeting: Road Mapping the Future Work of Community- Research Partnerships

The Carolinas | Durham NC | October 24, 2017

At this point in our journey of convening, we had successfully convened two meetings using a national meeting concept that allowed for regional tailoring. In planning the final convening, held in Durham, NC, there was a prioritization of activity. We were eager to translate the lessons learned from the two previous meetings into productive activity and a plan for operationalizing the findings and dissemination. We convened stakeholders, patients and patient advocates from the cardiovascular disease community in for A Town Hall Meeting: Road Mapping the Future Work of Community-Research Partnerships.

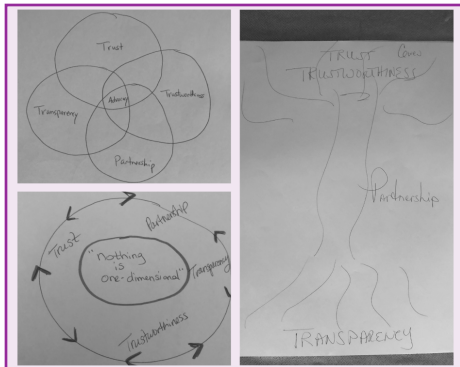
Participants eagerly received information on new and current innovation surrounding the treatment and diagnosis of cardiovascular diseases. They learned about PCORI’s work Advancing Patient Centered Research and saw firsthand how patient interest about a disease can be transformed to advocacy work. In their evaluation of this convening, these four meeting

elements were cited as appreciated for operational knowledge they could apply in their communities, programming, research and patient-care settings.

Participants were guided through the process of determining what Trust, Trustworthiness, Transparency and Partnership looks like. They were provided this drawing (below) as a reminder of the elements.



All participants drew models that reflected their personal idea of the relationship between these elements of community engagement. Below are some of those models.



Agenda Items:

Welcome & Opening Session

*Al Richmond, MSW
Cornell Wright, MPH*

Snapshot of Cardiovascular Disease in the Region

*Jacqueline Halladay, PhD
Crystal Cene, MD*

PCORI: Advancing Patient-Centered Research

Alicia Thomas, PhD, MHS,

Cardiovascular Research in the Region

*Melicia Whitt-Glover, PhD
Goldie Byrd, PhD*

Panel Discussion: Advocacy Up Close

*Mary Kay Ballasiotes
Gladys Lundy*

Building a Roadmap to Facilitate Patient Engagement and Advocacy

Melvin Jackson

DISSEMINATION PLAN

Written Dissemination	Benefit
PowerPoint Presentation Podcasts Handouts and Notes	Make the data dynamic and digestible Take-away notes
More detailed 1-2 page executive summary	To extend the engagement

One page handout or reference card	Opportunity to lead with the answers to the questions: Why should I care? What's in it for me?
Poster Presentations and promotional brochures CCPH Newsletter and other newsletters Press Releases and print media	More impact and wider distribution of findings to expand the audience
Meeting Guide	Share the meeting planning process
CCPH and stakeholder group websites	Opportunity for diversity of electronic formats including blogs, banners, and retweets
CCPH email and listserves of stakeholder groups	News blasts and invitations for further engagement
Suggestions made by participants	Demonstrate value of feedback contributed by operationalizing these ideas, capitalize on the benefit of having identified preferred methods of communication for stakeholders

IMPACT AND OUTCOME

Patient-Researcher Bidirectional Benefit

At the Upper Midwest and Carolinas convenings, participants were brought together around the diseases that impact their lives (cancer and cardiovascular disease, respectively). They received disease-specific information early in the meeting presented by experts identified as stakeholders in their focus areas. Participants were:

- ◆ Acquainted with new interventions.
- ◆ Introduced to PCORI as a resource for research.
- ◆ Provided access to a showcase of model programs.
- ◆ Introduced to a cadre of minority researchers who are focused on health equity.
- ◆ Oriented to the process of evolution from patient to advocate.
- ◆ Received information on the important role patients can play in research.
- ◆ Received validation of how important the element of patient voice is in PCOR and CER activities, and learned that patients can initiate and shape research activity.

As evidenced in the meeting evaluations, participants expressed appreciation for the space made in the convenings to present and receive this information. This was perceived as a direct, clear, and relevant benefit provided to them for their participation in the meetings. This maximization of perception of value, gained early in the meeting agenda, resulted in an enhancement of the full engagement of patients and researchers throughout the convening.

Trust, Trustworthiness, Transparency, and Partnership

Certainly, the elements of trust and trustworthiness have not gone without exploration. In March 2016, PCORI held a multi-day workshop, Building Trustworthiness in PCORnet. This workshop was designed to address the communities' questions surrounding trust and research. At the CCPH convenings, with the reiteration that patients want trust and trustworthiness in PCOR and CER activities and the addition of transparency and partnership, the meeting activities were designed to give patient voice to these concepts.

The findings of the continuous exploration and building on the themes of trust and trustworthiness, transparency, and partnership from each meeting served to deepen our understanding of each concept including their role in supporting patient engagement. We recognize that these concepts are not hierarchal in PCOR and CER; rather, each of these concepts is of equal weight and value in PCOR and CER. Additionally, each research collaboration is different and provides unique opportunities and challenges. Likewise, the formula for the implementation of these concepts should be responsive to the uniqueness of the engagement.

PCORI Support

CCPH acknowledges the resources provided by PCORI to supported the full engagement of patients in the design implementation of work and dissemination plan developed through these meetings. This includes stipends, speaker honoraria and travel support and lodging for patients to help remove potential financial barriers that would limit their participation the convenings.

KEY PARTNERS

In addition to the support a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (EAIN-2517), these convenings would have been possible without the support and guidance of our regional partners:

Deep South

- Louisiana Public Health Institute
- REACHnet
- The University of Southern Mississippi
- The Fannie Lou Hamer Cancer Foundation

Upper Midwest

- Northwestern University Feinberg School of Medicine
- Alliance for Research in Chicagoland Communities
- University of Illinois Health Cancer Center
- Northwestern Medicine Feinberg School of Medicine
- Alliance for Research in Chicagoland Communities

The Carolinas

- NC Office of Minority Health and Health Disparities
- Triangle American Heart Association
- American Stroke Association
- Gramercy Research Group
- NC American Indian Health Board