

Personalized Care Management to Achieve Outcomes Important to Patient

- **Valerie Barton**, MA, Chief Data Strategy Officer, People-Centered Research Foundation (PCRF)



PCORnet: Three Pillars



Engagement



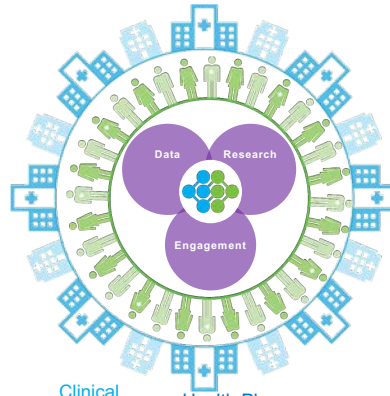
Data



Research



PCORnet Overview



PCORnet is a “network of networks” that harnesses the power of partnerships

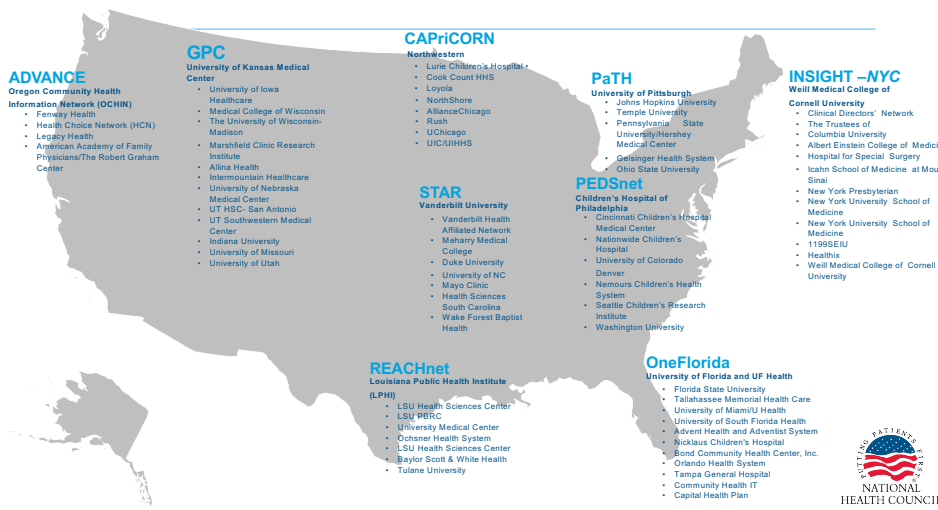


PCRF + Clinical Research Networks (CRNs) + Health Plan Research Networks (HPRNs) + Patient Partners + Coordinating Center = A national infrastructure for people-centered clinical research



PCORnet Sites

[HCARN: HealthCore-Anthem Research Network](#)
[PRACnet/Humana](#)



Bariatric Study: Overview

Study aims:

Aim 1: Assess differences in weight loss and weight regain across 3 common bariatric surgical procedures– Roux-en-Y Gastric Bypass (RYGB), Adjustable Gastric Banding (AGB), and Sleeve Gastrectomy (SG) (1, 3, 5 yrs post-surgery)

Aim 2: Analyze differences in diabetes status between 3 surgical procedures (1, 3, 5 yrs post-surgery)

Aim 3: Analyze frequency of major adverse events across 3 procedures (1, 3, 5 yrs post-surgery)

Population:

Adults, children, and adolescents < 80 years old at surgery (RYGB, AGB, or SG) between 2005 and 2015 WITH Body Mass Index (BMI) at least 35 kg/m² 1 yr prior to surgery; 11



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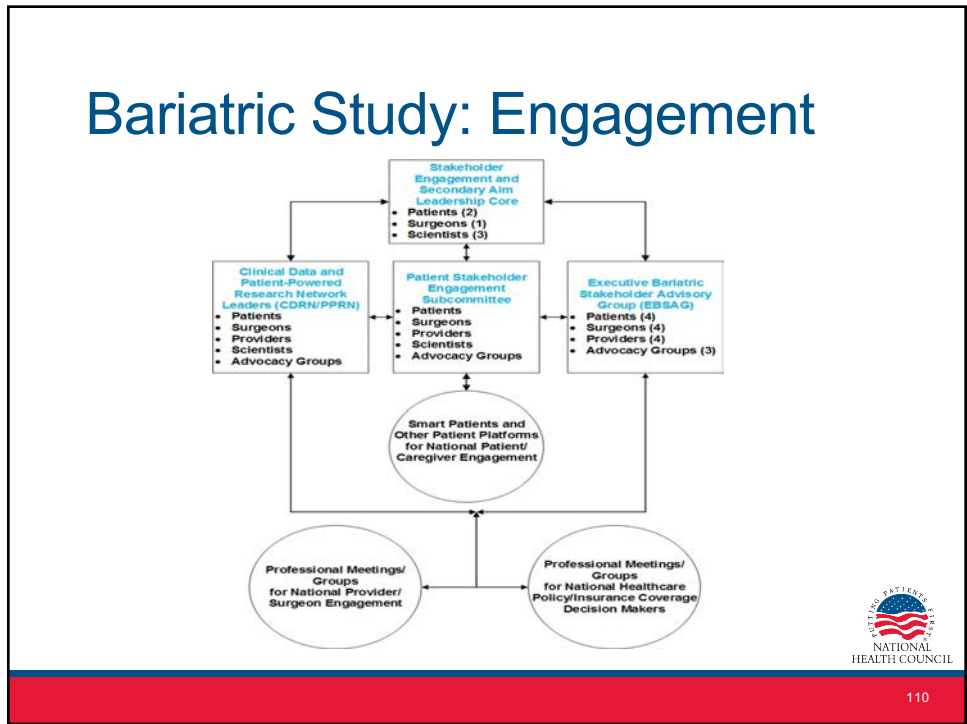
Bariatric Study: Patient Engagement Goals

- To provide a **voice equal to the scientific investigators** in the study design, implementation, and dissemination for patients and their families, providers, community/advocacy organizations, policymakers, and professional organizations.
- To create, test, institutionalize, and promote access to a **national network of bariatric patient and family engagement platforms** where patients and their families are free to exchange information and share experiences, learn about bariatric surgery, and communicate with others in a neutral environment.
- To understand the bariatric patient experience to design and implement future research studies that are **directly relevant to their concerns**.



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ADAPTABLE STUDY: OVERVIEW


Study aims:

Aim 1: Compare the effectiveness of two once-daily doses of aspirin (81 mg and 325 mg) in a secondary-prevention trial in patients with atherosclerotic cardiovascular disease (ASCVD)

Aim 2: Build an infrastructure and processes for future pragmatic trials in which a community of patients, clinicians, researchers and administrators work together to improve patient care and clinical outcomes

Population:

- Known ASCVD with a history of MI, coronary angiography showing >75% stenosis OR at least one CABG or PCI
- Age > 18
- No known intolerance to aspirin does of 325mg/day


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Engaging the ADAPTABLE Community with Participant Newsletter: *Why I Joined*

"Simple: To (maybe) be part of helping with research to find answers for treating heart problems."

Bob, KS

"It is my belief any assistance we can give to those conducting the studies who may be able to bring a better way of life is a good thing."

Terry, IA

"I want to live to see and share all the milestones that will happen in my grandchildren's lives. They are such a joy to me. Also, my wife and I are celebrating our 50th wedding anniversary this year. Our goal is 70. I hope that this dosing study will help me reach these goals."

Don, WI

ADAPTABLE Participant Community Newsletter October 2018
Volume 8

Find previous issues online: www.theapinstitute.org

Every Participant Counts from Enrollment to Study Completion

Equally important to enrollment of participants in a research study is retention. Retention is the number of patients who remain in the study until it is completed. Well-intentioned participants occasionally drop out early for a variety of reasons and, of course, they have this right. There is a fundamental principle that motivates researchers to retain participants in a study. Researchers and patients alike want to learn as much as possible from a study.

ADAPTABLE Principal Investigator Daniel Muñoz with Vanderbilt Medical Center says, "The ADAPTABLE study is only possible because each participant has chosen to join, to contribute to science, and to be part of something bigger than themselves. All of us are in this to help patients by getting closer to the truth about whether there might be a best dose of aspirin. We can only get there by understanding and following the experience of each and every participant in the study."

Read more on how participants and doctors can work together to improve retention in ADAPTABLE at www.theapinstitute.org/news

Meet an Adaptor

"When people are invited to get involved with research and bring all their experiences, we can study a question from a truly collaborative perspective, creating a culture of curiosity and the prospect of innovation. The mantra here is strength in our differences!"

The biggest value of patient-centered research is incorporating patients. This may sound obvious as patients are uniquely qualified to understand why the research matters. When answers to research questions are positive or can lead to a significant improvement in quality of life, it makes sense that patients should be meaningfully involved in the research from the beginning. ADAPTABLE patient partner, Greg Merrill, shares his perspective on the value patients bring to clinical research and how patients and researchers can work together in research and treatment. Read more from Greg at www.theapinstitute.org/news

Why I Joined - The Participant Voice

Thank you ADAPTABLE participants who responded to the survey question, "Why I joined ADAPTABLE!" We were excited to see so many participants engaged and enjoyed reading each story. Your participation helps build a community of patients, researchers, and clinicians who are actively engaged in answering important health questions. We have included a few responses below and encourage you to visit theapinstitute.org/participate to read more. We will continue to highlight your work in each newsletter on the website, and through our social media channels, if you have not had the opportunity to share your voice or have more to say, e-mail us at ADAPTABLEcommunity@vanderbilt.edu.

ADAPTABLE: An opportunity to contribute to research that may improve heart health. I am excited to be part of this study. I hope to see the results and share them with my family and friends. Thank you for the opportunity to be part of this study. Bob, KS

All in this together and we can make a difference. I am excited to be part of this study. I hope to see the results and share them with my family and friends. Thank you for the opportunity to be part of this study. Terry, IA

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ADAPTOR Patient Investigators

- Patients involved in prioritization of research topic, protocol design, and trial conduct
- ADAPTORS integral to development of participant-centric consent form and comprehension assessment
- ADAPTORS working with health systems on the development of recruitment & retention plans and materials



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The Participant Portal



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Patient Engagement

Patient Blogs



- Monthly guest blog featuring one of our ADAPTORS
- Topics will focus on why patient powered research is important
- Links to ADAPTABLE Study website

Facebook Live



- Facebook Live Event at AHA Scientific Session (November 2016)
- First Facebook Live event broadcasting about a study during AHA Scientific Sessions
- 20-minute, moderated live Q&A featuring ADAPTABLE leadership and Adaptor

Patient Engagement Pavilion



- CardioSmart Patient Panel at ACC Scientific Sessions 2017 and 2018
- Adaptor & researcher panel presentation at ACC 2017 and 2018 in the CardioSmart Patient engagement pavilion



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Engagement – Challenges & Lessons Learned

- Require continuity in stakeholder representation between proposal phase and execution
- Roles must be made explicitly clear to stakeholders
- Study teams must understand and utilize expertise and strengths
- Patients need to be provided with the tools to fully understand the study to make an impact
- Patients must be integrated into study team and early enough to co-develop vs. reacting to almost-final products
- Engagement brokers are needed to help communicate and bridge cultures

"By building these relationships, stakeholders and researchers became increasingly more comfortable with one another, which in turn made it easier to share ideas and opinions amongst all participants."

"...if there were more information given ahead of a phone call in order to be prepared. I'm still not clear as to how things are progressing overall."

"The role of [stakeholder advisory group] is not always clear...reflective of the fact that we are somewhat learning as we go how to do meaningful stakeholder engagement."

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PCORnet Engagement: Materials

[Engagement Assessment Tool](#)

[Stakeholder kickoff checklist](#)

[MOU for stakeholders](#)

[Stakeholder satisfaction survey and quality improvement tools](#)

[Key elements of engagement](#)

[Examples of study lay materials](#)



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Kicking Off: PREVENTABLE

Study Aims:

Aim 1: Determine the role of a moderate-intensity statin in preventing dementia and prolonging disability-free survival

Aim 2: Determine the role of moderate-intensity statin in preventing hospitalization for myocardial infarction/acute coronary syndrome, stroke, heart failure, revascularization or cardiovascular-related death, and preventing either mild cognitive impairment or dementia

Aim 3: Test the safety and tolerability of statins in older adults and collect bio-specimens to advance precision health

Population:

Patients 17,000 >75 years without clinically evident coronary heart disease, including those with frailty, impaired physical function, mild cognitive impairment, polypharmacy, and multi-morbidity



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New Patient Engagement Coordinating Center

- **DEFINE PCORNET PRINCIPLES OF ENGAGEMENT:** Develop principles of engagement customized to the needs and goals of the Network
- **CURATE AND FOSTER EXCHANGE OF ENGAGEMENT BEST PRACTICES:** Activate research leaders to shape PCORnet innovation in patient-partnered research, based on best practices in PCORnet
- **TRAIN AND SUPPORT:** Accelerate adoption of person-centered involvement in Network research, projects, through increasingly sophisticated levels of training.
- **DEFINE METRICS AND PROMOTE ACCOUNTABILITY FOR MEANINGFUL ENGAGEMENT ACROSS PCORNET:** Using principles from the science of engagement, define and validate performance metrics and provide tools for PCORnet to ensure accountability for meaningful engagement across the Network
- **WORK WITH PCORNET STUDY PIs AND ENGAGEMENT TEAMS:** Embed engagement science into studies and integrate patient partners into PCORnet studies



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**NATIONAL
HEALTH COUNCIL**

Presenter Contact Information:
Valerie Barton
Chief Data Strategy Officer
202.381.0855
Valerie.barton@pcrfoundation.org

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