Personalized Care Management to Achieve Outcomes Important to Patient

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

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**PCORnet: Three Pillars**

- Engagement
- Data
- Research
PCORnet Overview

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

PCORnet Sites

HCARN: HealthCore-Anthem Research Network
PRACnet/Humana

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

ADVANCE
 Oregon Community Health Information Network (OCHIN)
• Fenway Health
• Health Choice Network (HCN)
• Legacy Health
• American Academy of Family Physicians/The Robert Graham Center

GPC
University of Kansas Medical Center
• University of Kansas Health System
• The University of Kansas Hospital
• Marie State Hospital
• Wichita State University

CAPiCORN
HealthPartners
• Kaiser Permanente
• Mayo
• Medica
• Fairview
• UHC of Rhode Island

PaTH
University of Pittsburgh
• Pfizer
• University of Pittsburg
• Children's Hospital of Pittsburgh

PCRF
Intrexon

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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;

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.
Bariatric Study: Engagement

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
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

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
The Participant Portal

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
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

“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.”

“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.”

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
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

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