# PCORnet PPRN Partner Meeting

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The National Patient-Centered Clinical Research Network

# Welcome!

*Rachael Fleurence, Director*

*CER Methods and Infrastructure Program*

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The National Patient-Centered Clinical Research Network

# PPRN Practices, Challenges, and Opportunities

Sarah Daugherty, PhD MPH
PCORI PPRN Workshop
January 2014

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The National Patient-Centered Clinical Research Network

# Workshop Goal

“Create a culture between PPRNs
that fosters sharing of best practices
to avoid waste of resources and unnecessary
duplication.”

# Workshop Objectives

Objective 1
- Identify common questions and needs.

Objective 2
- Identify shared goals and objectives.

Objective 3
- Engage in peer-learning and share knowledge, resources and tools.

Objective 4
- Initiate collaborative activities that enhance the achievement of shared and individual goals.

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# PPRN Survey Informed Our Agenda

| | |
|---|---|
| **Survey questions** | Infrastructure design |
| | Patient engagement |
| | Greatest challenges |
| | Cross-collaborations |
| | Innovative designs or plans |

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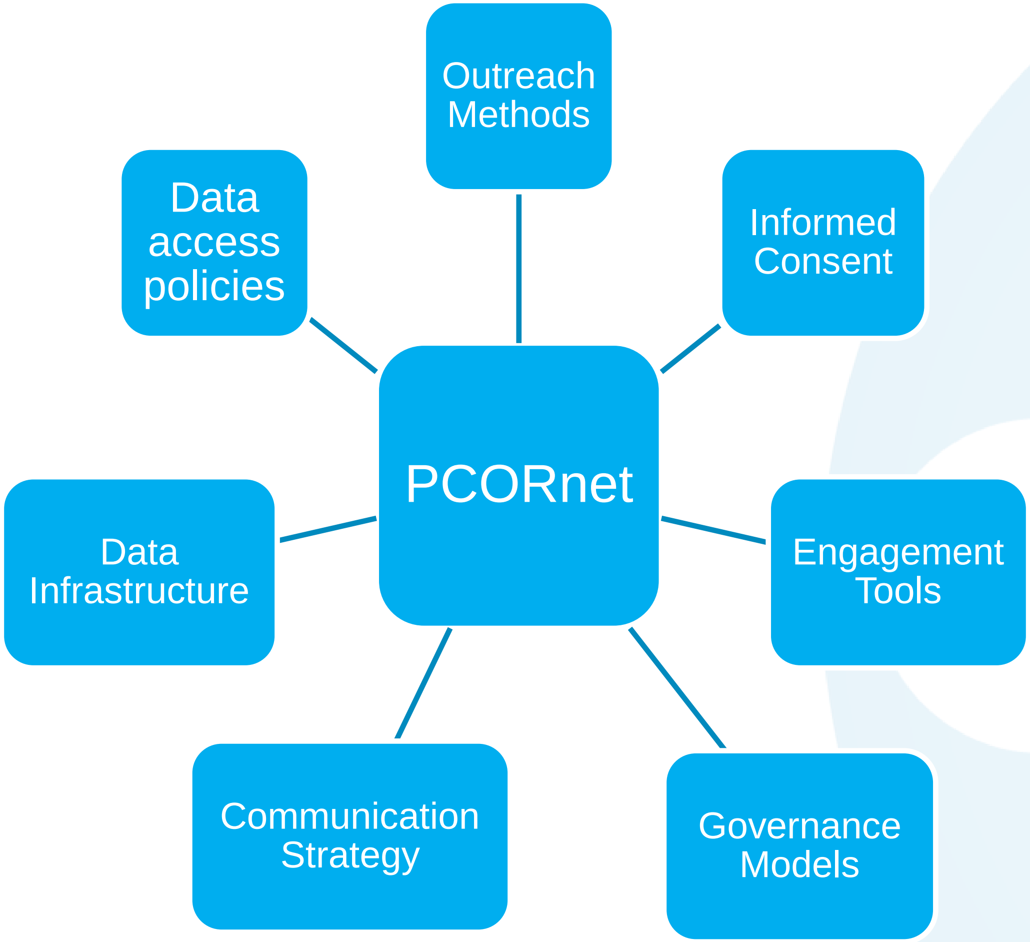
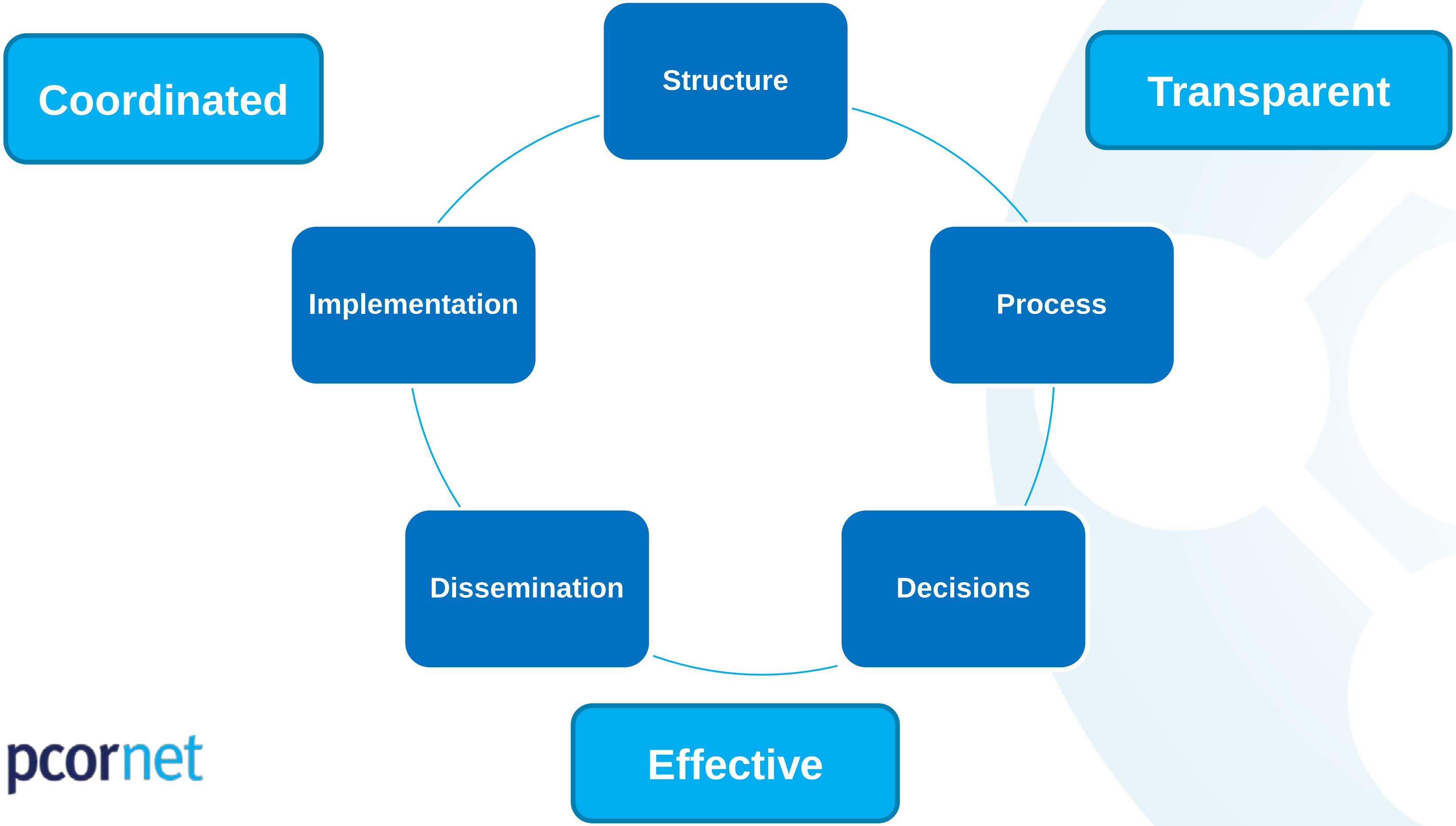
# PCORnet Synergy



# Governance

“The growth will also necessitate new systems for decision-making and prioritization within our Centers.”



Coordinated

Structure

Transparent

Implementation

Process

Dissemination

Decisions

Effective

# Outreach and Sustaining Engagement

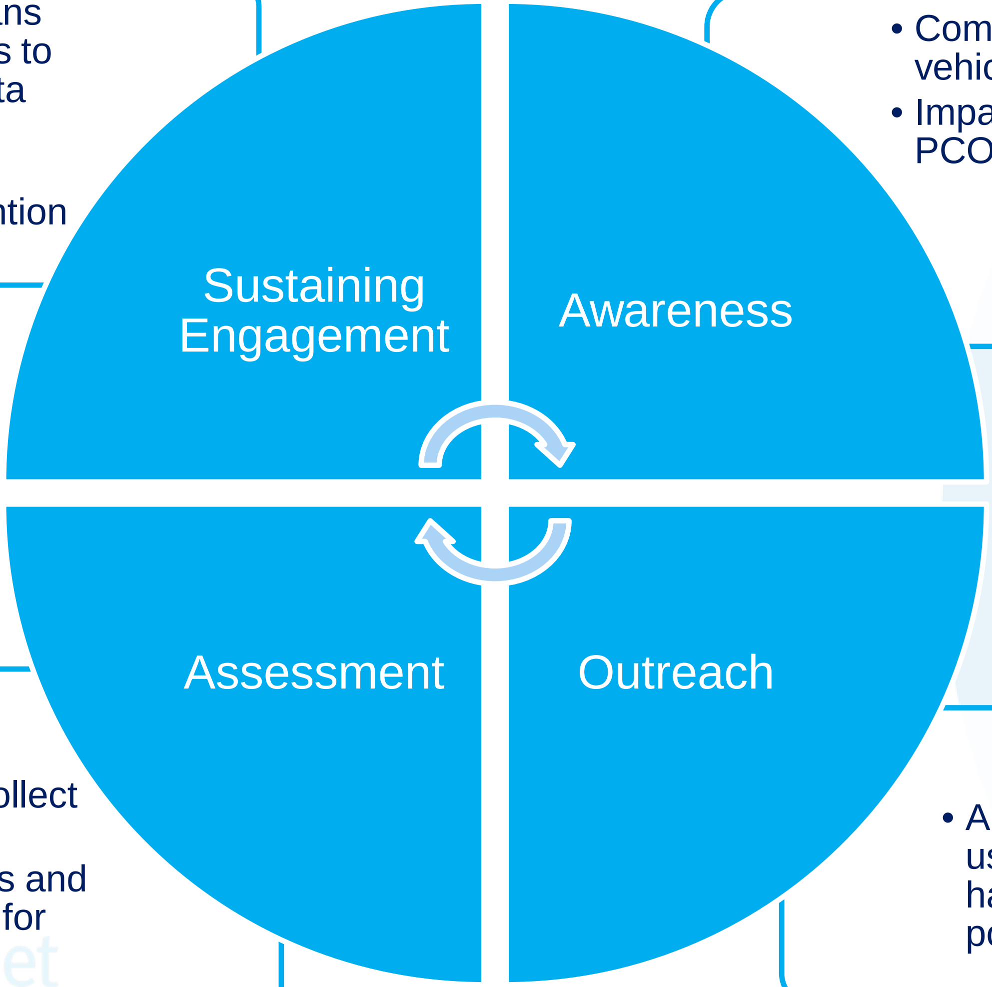
“How do you bring people up the engagement ladder so that they can get to own the whole process?”

“Do we focus on deep engagement from a smaller number of patients, or just SOME engagement from a large number of patients?”

# Outreach and Sustaining Engagement

- Optimizing plans for participants to report new data over time.
- Maximizing engaged retention

- Communication vehicles
- Impact of PCORnet



Sustaining Engagement

Awareness

Assessment

Outreach

- Methods to collect feedback
- Competencies and skills needed for effective partnership

- Approaches used to identify hard to reach populations

# Greatest Challenges

- “Translating awareness to enthusiasm to action”
- Misperceptions about privacy, security, and risks of sharing data
- Attrition of original participants
- Sustaining PPRN after month 19 and beyond

# Cross-Collaborations

- Common data model
- Co-enrollment
- Participant-friendly generic consent
- Ongoing dialogue between PPRNs and CDRNs
- Methods for collecting PRO in non-clinical setting
- Basic information about purpose of PPRNs written in generic way for all patients

# Guiding Questions for Discussion

- Common areas to address collectively?
- What resources and tools exist already?
- What resources and tools could be developed?
- Processes to leverage collective skills and knowledge?
- What are the action items needed to move forward?
- How can PCORI facilitate continued sharing?

# PPRN Workshop Outcomes

- Establish working groups
- Connect working groups to Task Force
- Identify processes to facilitate sharing

# Governance

*Alison Rein, Seth Ginsberg, Michael Kappelman, Barbara Kroner*

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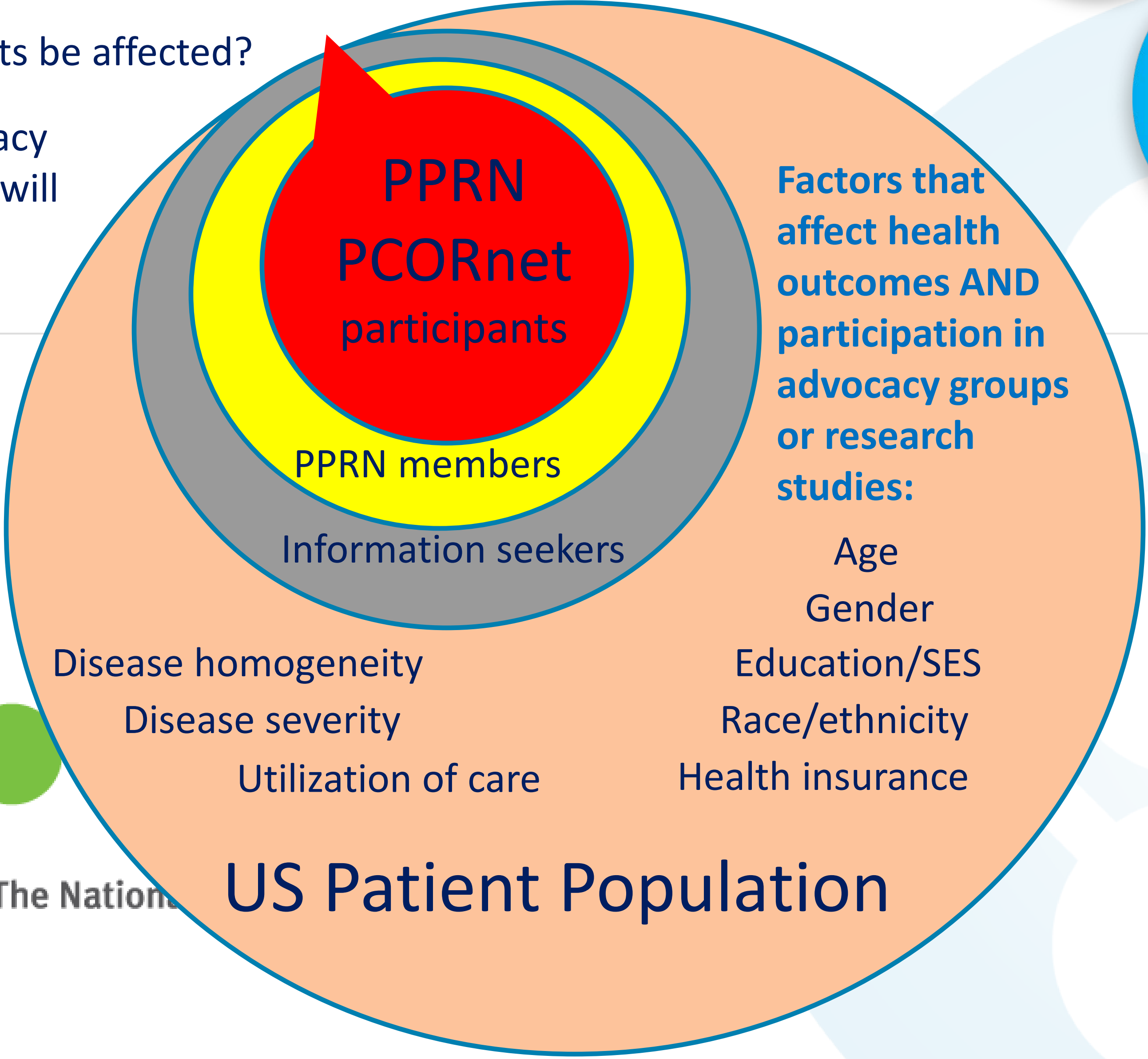
# How Will PCORnet Patients Differ From Total US Patient Pop’n?

- Why are the populations different?
- How will study results be affected?
- What role does privacy concerns play in who will participate?



PPRN
PCORnet
participants

PPRN members

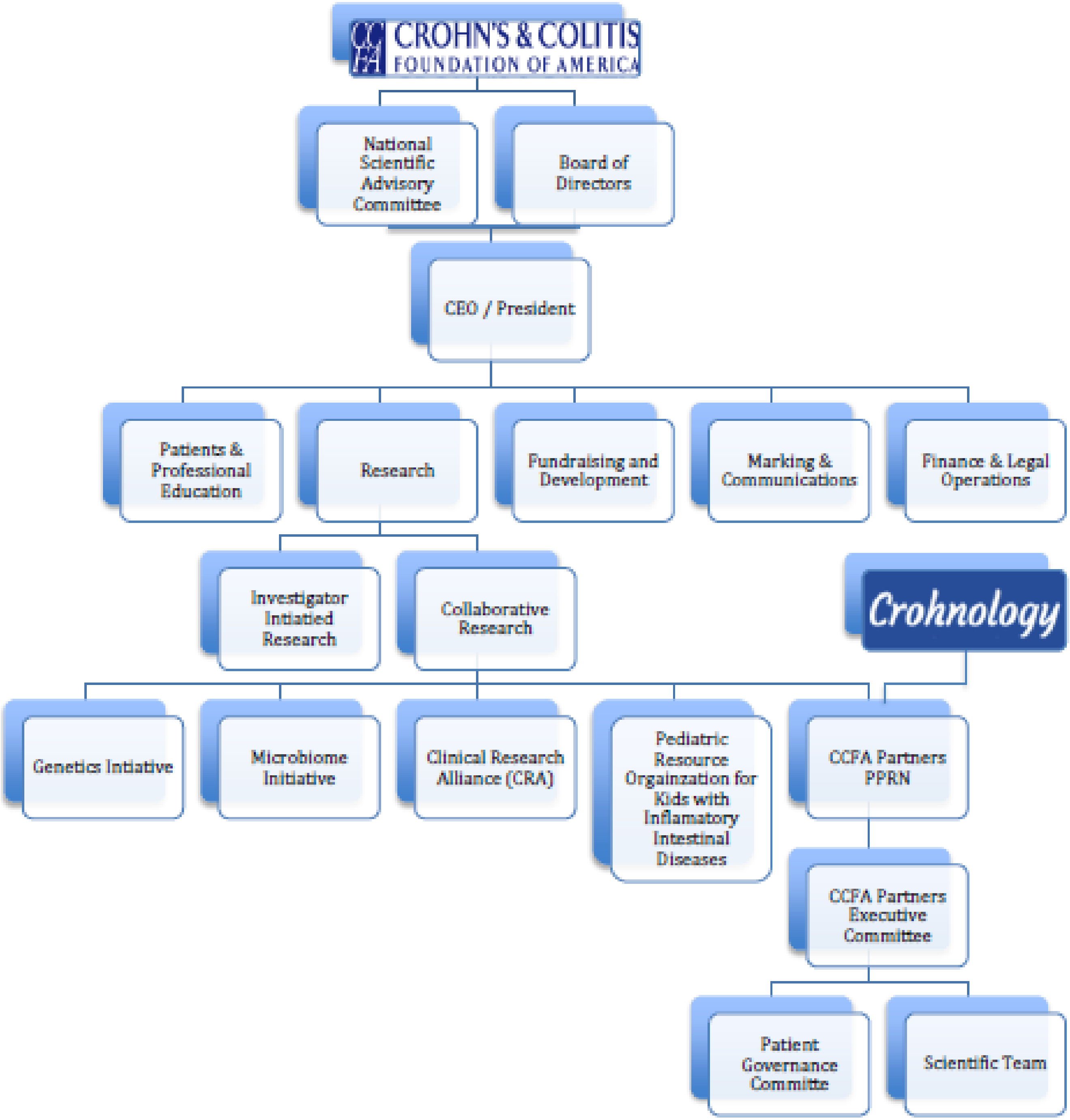
Information seekers

**Factors that affect health outcomes AND participation in advocacy groups or research studies:**

Age
Gender
Education/SES
Race/ethnicity
Health insurance

Disease homogeneity
Disease severity
Utilization of care

US Patient Population



CROHN'S & COLITIS FOUNDATION OF AMERICA

National Scientific Advisory Committee

Board of Directors

CEO / President

Patients & Professional Education

Research

Fundraising and Development

Marking & Communications

Finance & Legal Operations

Investigator Intiatied Research

Collaborative Research

Crohnology

Genetics Intiative

Microbiome Initiative

Clinical Research Alliance (CRA)

Pediatric Resource Orgainzation for Kids with Inflamatory Intestinal Diseases

CCFA Partners PPRN

CCFA Partners Executive Committee

Patient Governance Committe

Scientific Team

# 3 Levels of Patient Governance

- Scientific leadership
- Patient leadership
- Community responsiveness

# Scientific Leadership

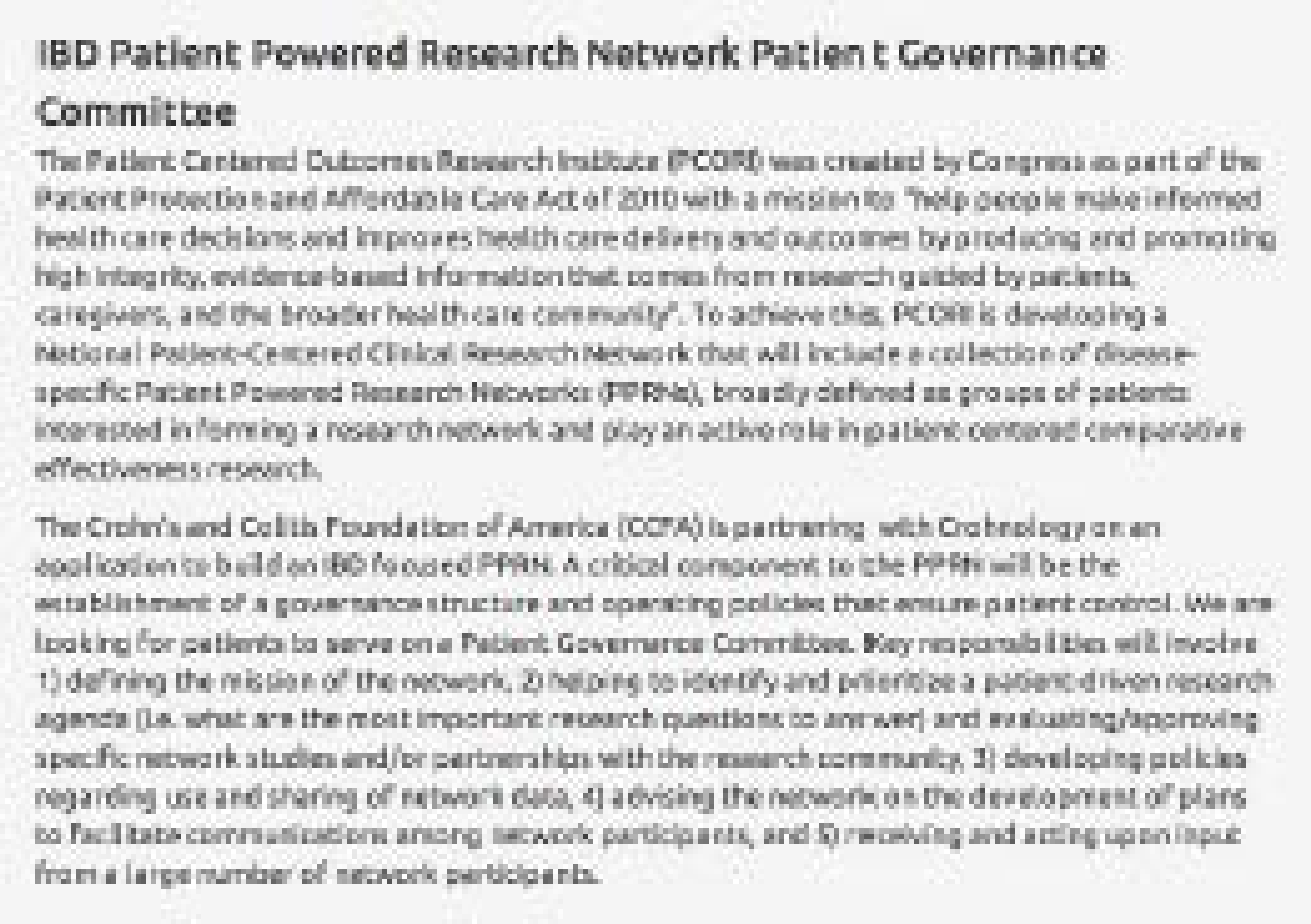
- Dr. Balfour Sartor (Network PI)
  - Adult gastroenterologist and microbiome expert
  - Chief Medical Advisor to the CCFA
  - Diagnosed with Crohn’s disease at age 21 (~40 years ago)
- Sean Ahrens
  - Founder of Crohnology
  - Computer programmer
  - Diagnosed with Crohn’s disease during childhood
- Both will serve on the network executive committee
  - Dual perspectives critical to informing policies related to data sharing and return of research findings
    - Should patients be informed of genetic results?
    - Might there be unintended consequences?

# Patient Governance Committee (PGC)

- Key responsibilities:
  - 1) Define network’s mission,
  - 2) Assist in prioritizing patient-driven research agenda
  - 3) Assist in the review of proposed network studies/partners
  - 4) Develop policies regarding use and sharing of data
  - 5) Assist in developing plans to facilitate communications among network participants
  - 6) Receive and act upon input from broader network community
- PGC will report directly to the Executive committee
  - 2 members of the PGC will hold seats on the Executive Committee (total of 4 patients)
  - PGC must independently approve all substantial changes in the direction of the network

# PGC Member Selection and Training

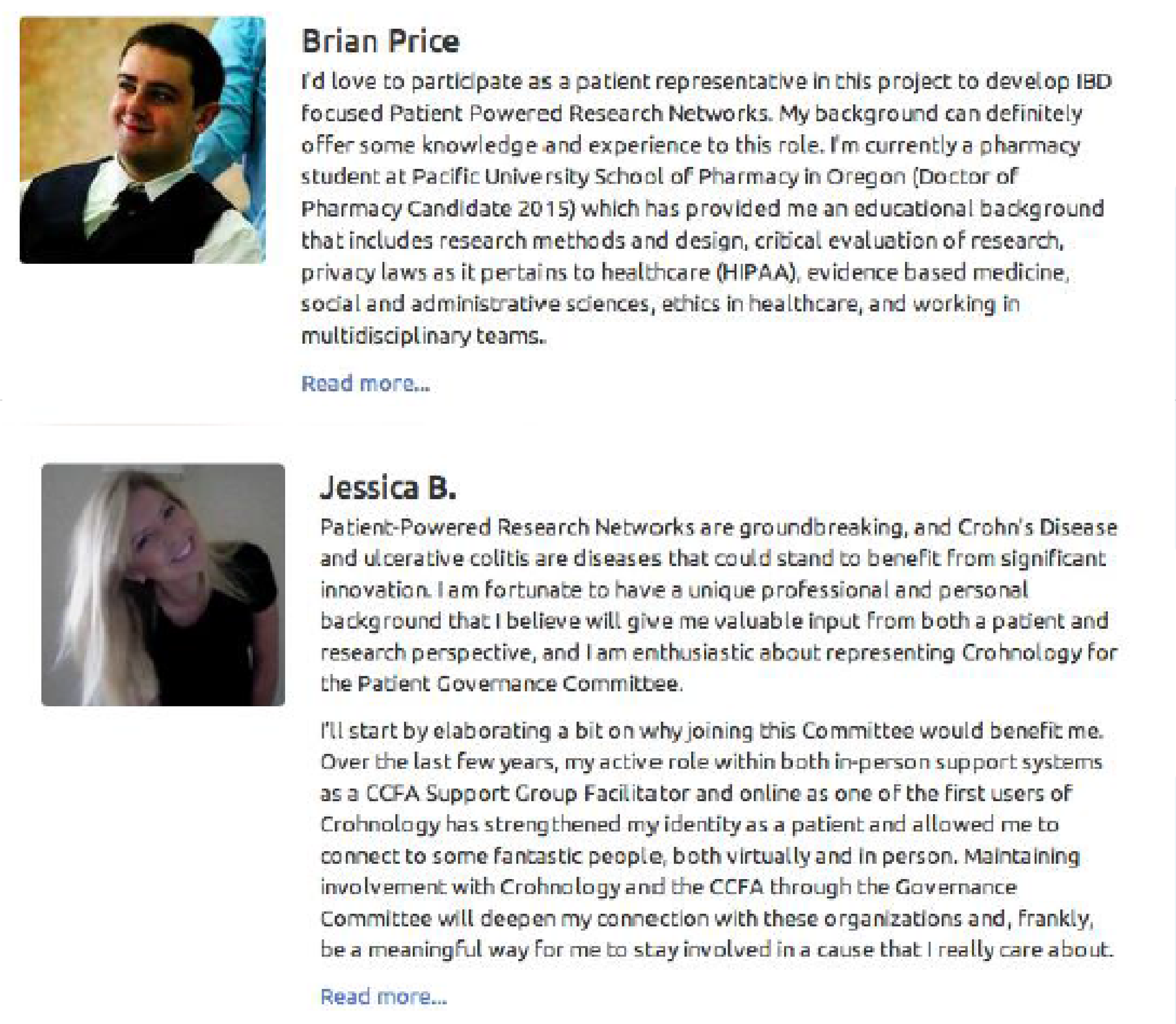
- 5 lay patients
  - 2 with prior experience serving on CCFA grant review committees
  - Former Chair of the CCFA National Council of College Leaders program
  - 2 selected by popular election by Crohnology community
    - Information about the PPRN posted on Crohnology
    - Self-nominations were invited.
    - Candidates posted description of interests and qualifications
    - On-line election
  - All will complete CCFA stakeholder training course



## IBD Patient Powered Research Network Patient Governance Committee

The Patient Centered Outcomes Research Institute (PCORI) was created by Congress as part of the Patient Protection and Affordable Care Act of 2010 with a mission to "help people make informed health care decisions and improves health care delivery and outcomes by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader health care community". To achieve this, PCORI is developing a National Patient-Centered Clinical Research Network that will include a collection of disease-specific Patient Powered Research Networks (PPRNs), broadly defined as groups of patients interested in forming a research network and play an active role in patient centered comparative effectiveness research.

The Crohn's and Colitis Foundation of America (CCFA) is partnering with Crohnology on an application to build an IBD focused PPRN. A critical component to the PPRN will be the establishment of a governance structure and operating policies that ensure patient control. We are looking for patients to serve on a Patient Governance Committee. Key responsibilities will involve 1) defining the mission of the network, 2) helping to identify and prioritize a patient-driven research agenda (i.e. what are the most important research questions to answer) and evaluating/approving specific network studies and/or partnerships with the research community, 3) developing policies regarding use and sharing of network data, 4) advising the network on the development of plans to facilitate communications among network participants, and 5) receiving and acting upon input from a large number of network participants.



**Brian Price**

I'd love to participate as a patient representative in this project to develop IBD focused Patient Powered Research Networks. My background can definitely offer some knowledge and experience to this role. I'm currently a pharmacy student at Pacific University School of Pharmacy in Oregon (Doctor of Pharmacy Candidate 2015) which has provided me an educational background that includes research methods and design, critical evaluation of research, privacy laws as it pertains to healthcare (HIPAA), evidence based medicine, social and administrative sciences, ethics in healthcare, and working in multidisciplinary teams.

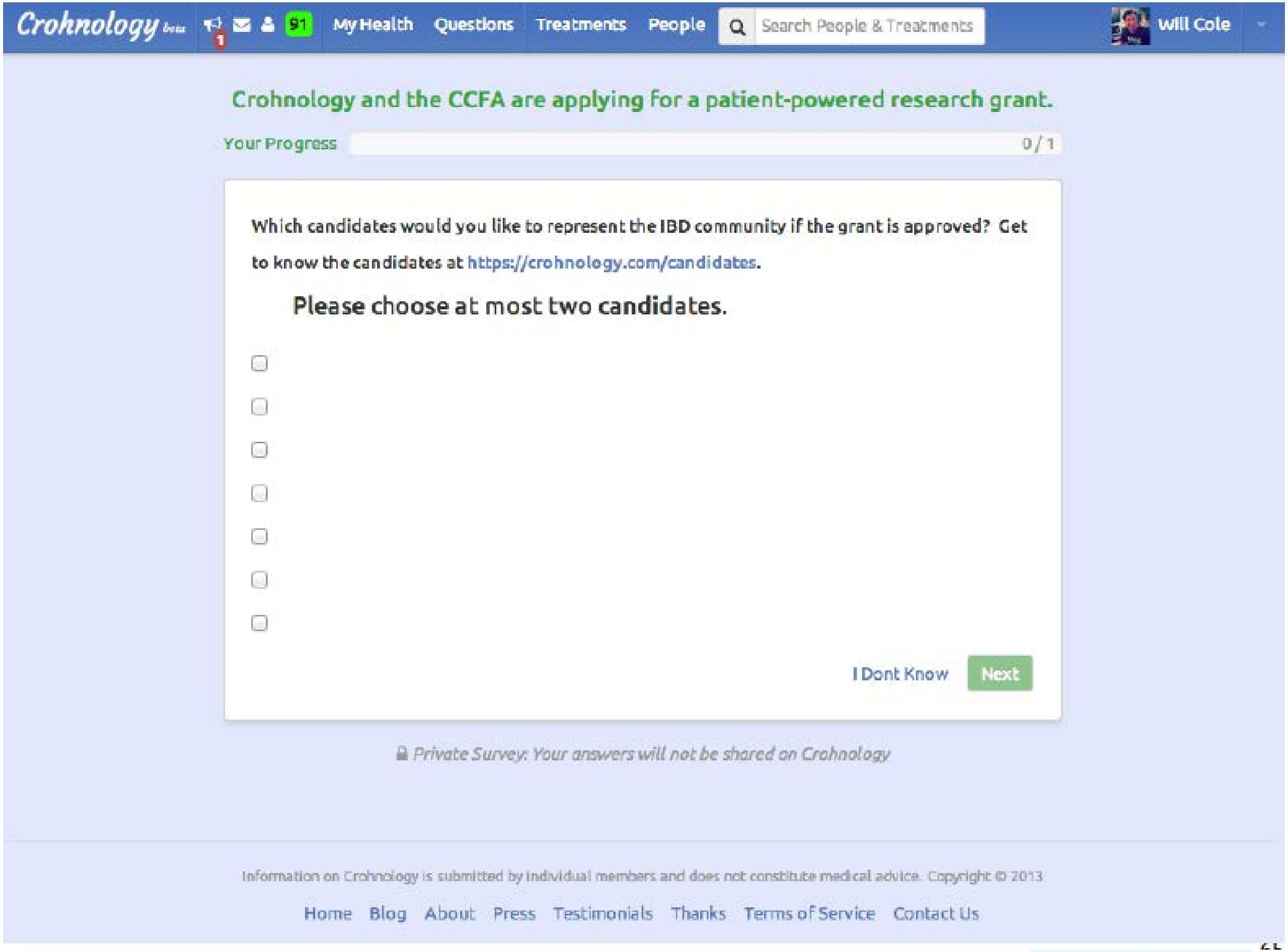
Read more...

**Jessica B.**

Patient-Powered Research Networks are groundbreaking, and Crohn's Disease and ulcerative colitis are diseases that could stand to benefit from significant innovation. I am fortunate to have a unique professional and personal background that I believe will give me valuable input from both a patient and research perspective, and I am enthusiastic about representing Crohnology for the Patient Governance Committee.

I'll start by elaborating a bit on why joining this Committee would benefit me. Over the last few years, my active role within both in-person support systems as a CCFA Support Group Facilitator and online as one of the first users of Crohnology has strengthened my identity as a patient and allowed me to connect to some fantastic people, both virtually and in person. Maintaining involvement with Crohnology and the CCFA through the Governance Committee will deepen my connection with these organizations and, frankly, be a meaningful way for me to stay involved in a cause that I really care about.

Read more...



Crohnology and the CCFA are applying for a patient-powered research grant.

Your Progress 0 / 1

Which candidates would you like to represent the IBD community if the grant is approved? Get to know the candidates at https://crohnology.com/candidates.

Please choose at most two candidates.

☐

☐

☐

☐

☐

☐

☐

Private Survey: Your answers will not be shared on Crohnology

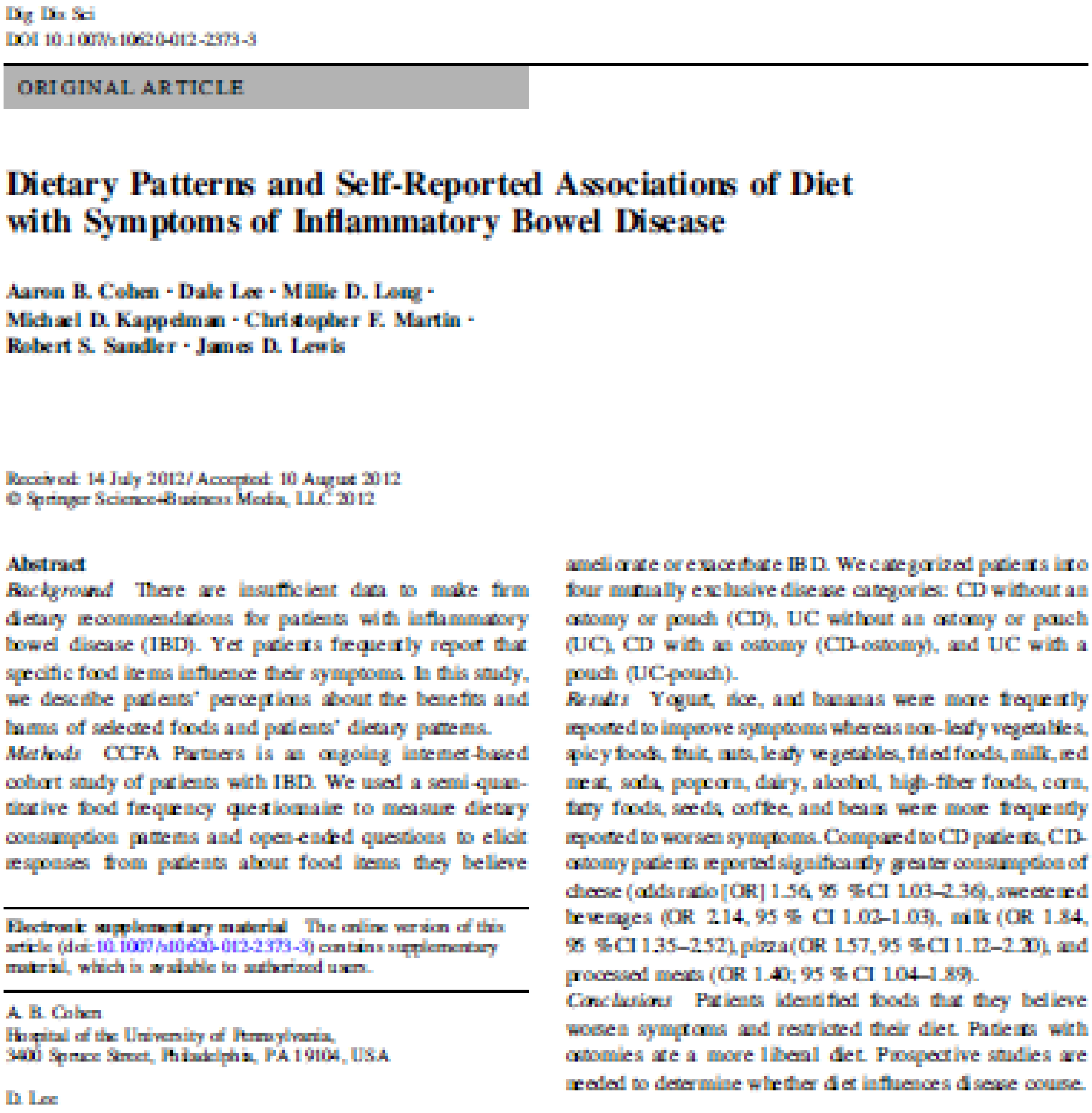
Information on Crohnology is submitted by individual members and does not constitute medical advice. Copyright © 2013

# Crowdsourcing to broaden responsiveness

- Draft policies to be posted online
- All network members will be able to comment, suggest changes, or contribute more substantially through the use of “wiki-style” editing.
- The PGC will incorporate member feedback into the final version of all policies.

# Communication and dissemination of research findings

- Network updates will be posted on discussion pages (also distributed by emails)
  - Member comments and “hearts” will be periodically reviewed by the PGC and the network’s scientific leadership
- Research findings will be communicated using lay summaries and infographics



Dig Dis Sci
DOI 10.1007/s10620-012-2373-3

ORIGINAL ARTICLE

# Dietary Patterns and Self-Reported Associations of Diet with Symptoms of Inflammatory Bowel Disease

**Aaron B. Cohen · Dale Lee · Millie D. Long ·
Michael D. Kappelman · Christopher F. Martin ·
Robert S. Sandler · James D. Lewis**

Received: 14 July 2012 / Accepted: 10 August 2012

**Abstract**

*Background* There are insufficient data to make firm dietary recommendations for patients with inflammatory bowel disease (IBD). Yet patients frequently report that specific food items influence their symptoms. In this study, we describe patients' perceptions about the benefits and harms of selected foods and patients' dietary patterns.

*Methods* CCFA Partners is an ongoing internet-based cohort study of patients with IBD. We used a semi-quantitative food frequency questionnaire to measure dietary consumption patterns and open-ended questions to elicit responses from patients about food items they believe ameliorate or exacerbate IBD. We categorized patients into four mutually exclusive disease categories: CD without an ostomy or pouch (CD), UC without an ostomy or pouch (UC), CD with an ostomy (CD-ostomy), and UC with a pouch (UC-pouch).

*Results* Yogurt, rice, and bananas were more frequently reported to improve symptoms whereas non-leafy vegetables, spicy foods, fruit, nuts, leafy vegetables, fried foods, milk, red meat, soda, popcorn, dairy, alcohol, high-fiber foods, corn, fatty foods, seeds, coffee, and beans were more frequently reported to worsen symptoms. Compared to CD patients, CD-ostomy patients reported significantly greater consumption of cheese (odds ratio [OR] 1.56, 95 % CI 1.03–2.36), sweetened beverages (OR 2.14, 95 % CI 1.02–1.03), milk (OR 1.84, 95 % CI 1.35–2.52), pizza (OR 1.57, 95 % CI 1.12–2.20), and processed meats (OR 1.40; 95 % CI 1.04–1.89).

*Conclusions* Patients identified foods that they believe worsen symptoms and restricted their diet. Patients with ostomies ate a more liberal diet. Prospective studies are needed to determine whether diet influences disease course.

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**Electronic supplementary material** The online version of this article (doi:10.1007/s10620-012-2373-3) contains supplementary material, which is available to authorized users.

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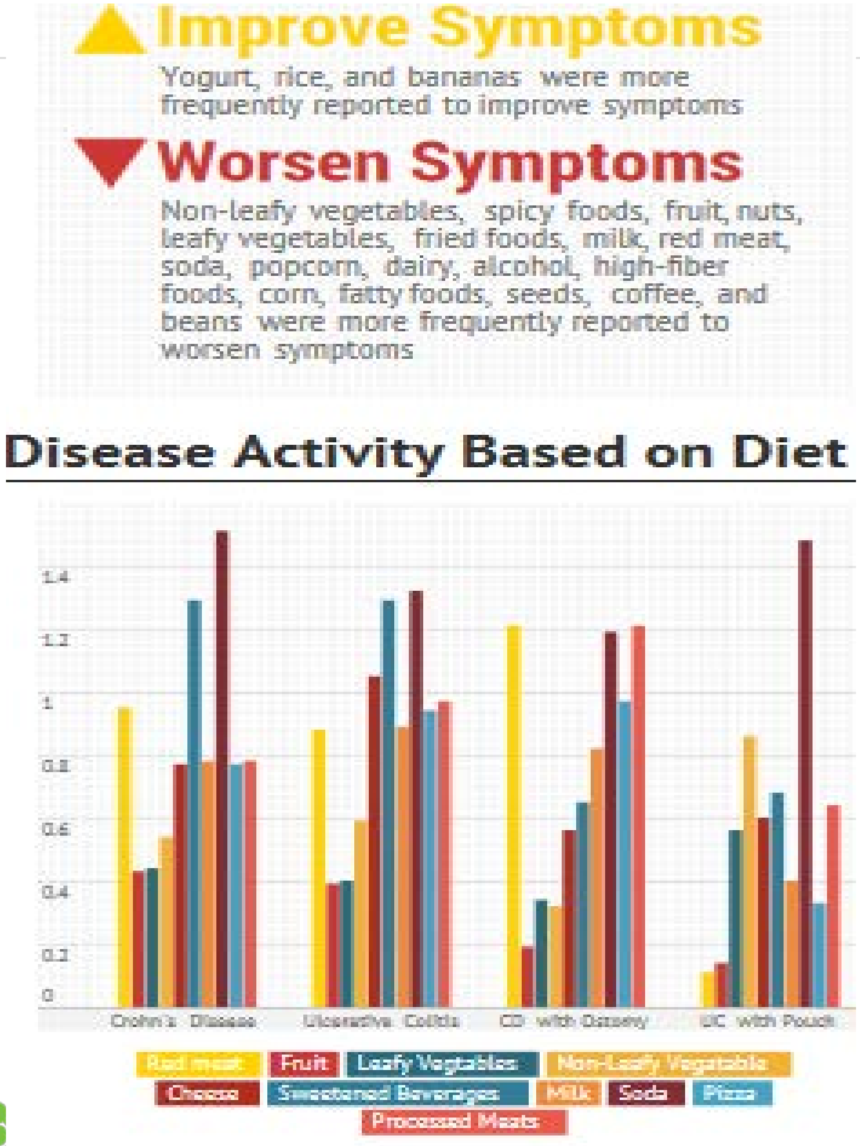


**Improve Symptoms**

Yogurt, rice, and bananas were more frequently reported to improve symptoms

**Worsen Symptoms**

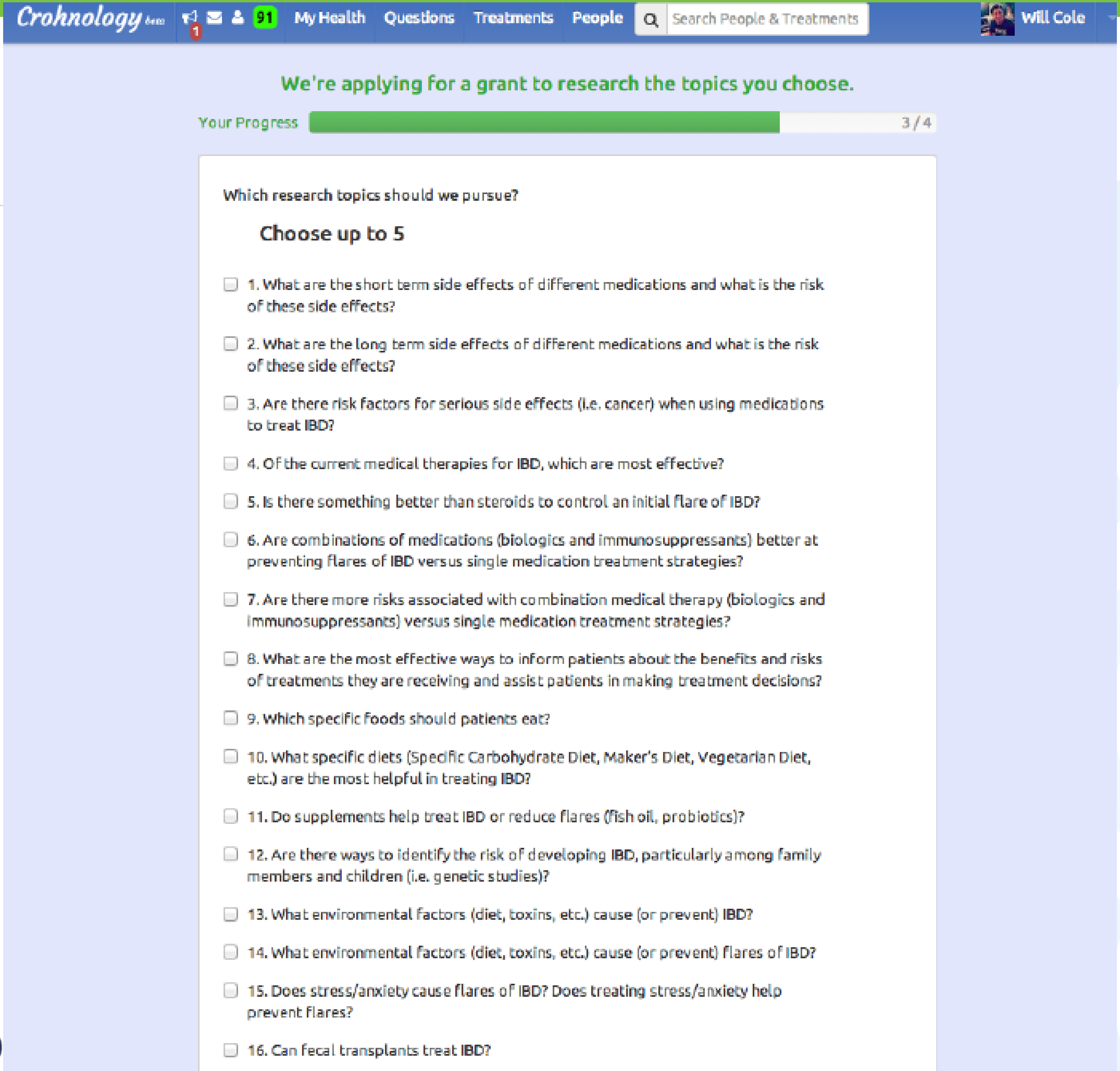
Non-leafy vegetables, spicy foods, fruit, nuts, leafy vegetables, fried foods, milk, red meat, soda, popcorn, dairy, alcohol, high-fiber foods, corn, fatty foods, seeds, coffee, and beans were more frequently reported to worsen symptoms

**Disease Activity Based on Diet**

- In 4 weeks:
  - 528 shares/views
  - 116 likes
  - 67 comments
- 92% indicated that the infographic “effectively summarized the research findings”

# Identifying and Prioritizing Research

- Crowd sourcing
- Approach Crohnology already uses to prioritize new feature development
- Pre-work
  - Candidate research topics collected from PGC, review of >2,000 questions posted on Crohnology, input from PPRN scientific team, and review of CCFA research priorities
  - Online voting through “User Voices” functionality of Crohnology



We're applying for a grant to research the topics you choose.

Your Progress 3 / 4

Which research topics should we pursue?

Choose up to 5

☐ 1. What are the short term side effects of different medications and what is the risk of these side effects?

☐ 2. What are the long term side effects of different medications and what is the risk of these side effects?

☐ 3. Are there risk factors for serious side effects (i.e. cancer) when using medications to treat IBD?

☐ 4. Of the current medical therapies for IBD, which are most effective?

☐ 5. Is there something better than steroids to control an initial flare of IBD?

☐ 6. Are combinations of medications (biologics and immunosuppressants) better at preventing flares of IBD versus single medication treatment strategies?

☐ 7. Are there more risks associated with combination medical therapy (biologics and immunosuppressants) versus single medication treatment strategies?

☐ 8. What are the most effective ways to inform patients about the benefits and risks of treatments they are receiving and assist patients in making treatment decisions?

☐ 9. Which specific foods should patients eat?

☐ 10. What specific diets (Specific Carbohydrate Diet, Maker's Diet, Vegetarian Diet, etc.) are the most helpful in treating IBD?

☐ 11. Do supplements help treat IBD or reduce flares (fish oil, probiotics)?

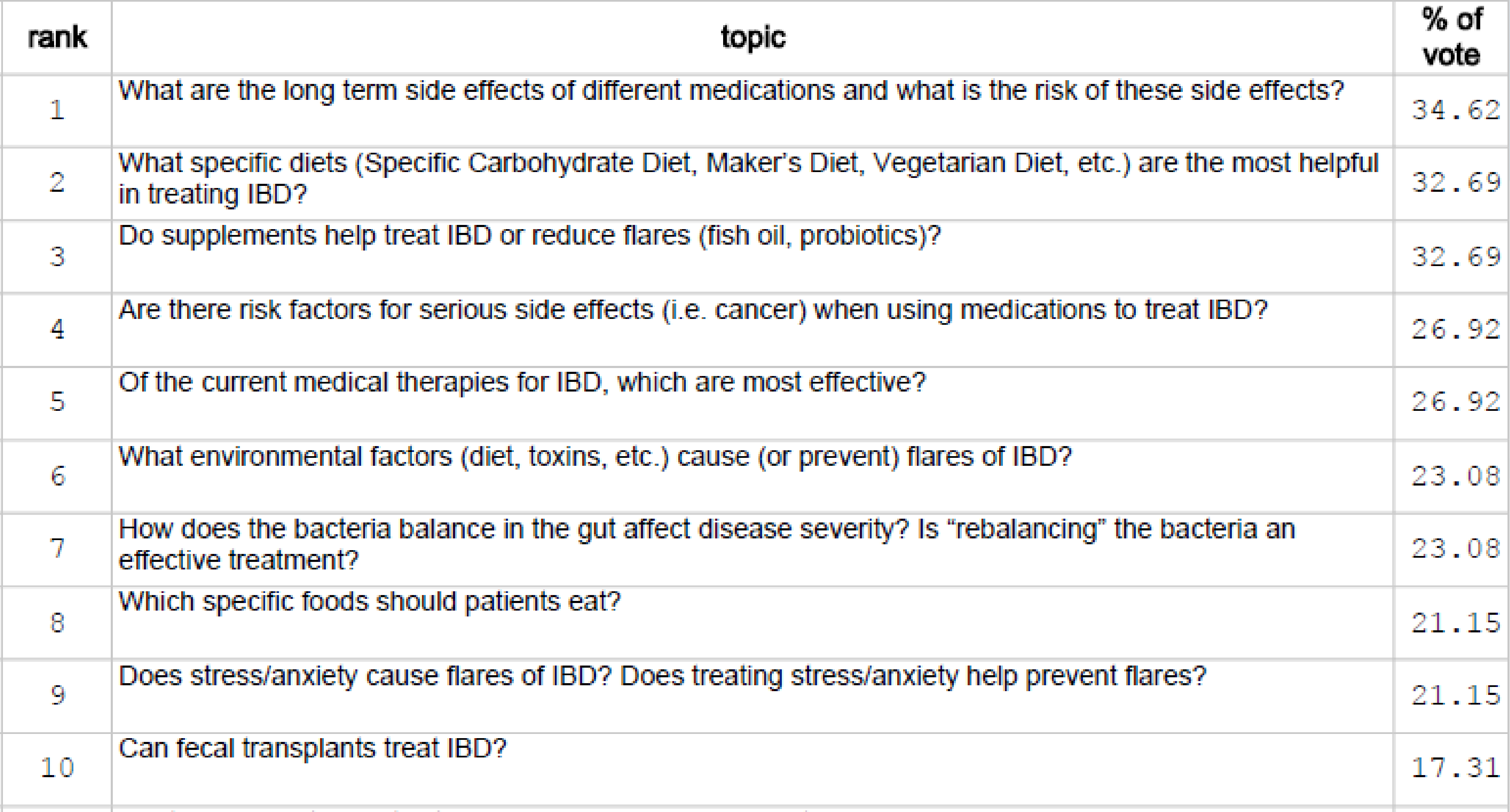
☐ 12. Are there ways to identify the risk of developing IBD, particularly among family members and children (i.e. genetic studies)?

☐ 13. What environmental factors (diet, toxins, etc.) cause (or prevent) IBD?

☐ 14. What environmental factors (diet, toxins, etc.) cause (or prevent) flares of IBD?

☐ 15. Does stress/anxiety cause flares of IBD? Does treating stress/anxiety help prevent flares?

☐ 16. Can fecal transplants treat IBD?



| rank | topic | % of vote |
|---|---|---|
| 1 | What are the long term side effects of different medications and what is the risk of these side effects? | 34.62 |
| 2 | What specific diets (Specific Carbohydrate Diet, Maker's Diet, Vegetarian Diet, etc.) are the most helpful in treating IBD? | 32.69 |
| 3 | Do supplements help treat IBD or reduce flares (fish oil, probiotics)? | 32.69 |
| 4 | Are there risk factors for serious side effects (i.e. cancer) when using medications to treat IBD? | 26.92 |
| 5 | Of the current medical therapies for IBD, which are most effective? | 26.92 |
| 6 | What environmental factors (diet, toxins, etc.) cause (or prevent) flares of IBD? | 23.08 |
| 7 | How does the bacteria balance in the gut affect disease severity? Is “rebalancing” the bacteria an effective treatment? | 23.08 |
| 8 | Which specific foods should patients eat? | 21.15 |
| 9 | Does stress/anxiety cause flares of IBD? Does treating stress/anxiety help prevent flares? | 21.15 |
| 10 | Can fecal transplants treat IBD? | 17.31 |

# Comments, Questions, Discussion?

# Outreach and Sustaining Engagement

*Sean Tunis, Andrew Nierenberg,*
*Susan Redline, Kathleen Sullivan*

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# Research Issues: Conducting Observational & Experimental Research

## *Rich Platt*

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# Research Issues: Navigating Informed Consent and IRBs

*Rob Califf, Mark Pletcher, John Walsh*

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# Pipeline to Proposal Awards & PCORI Ambassador Program

*Sue Sheridan*

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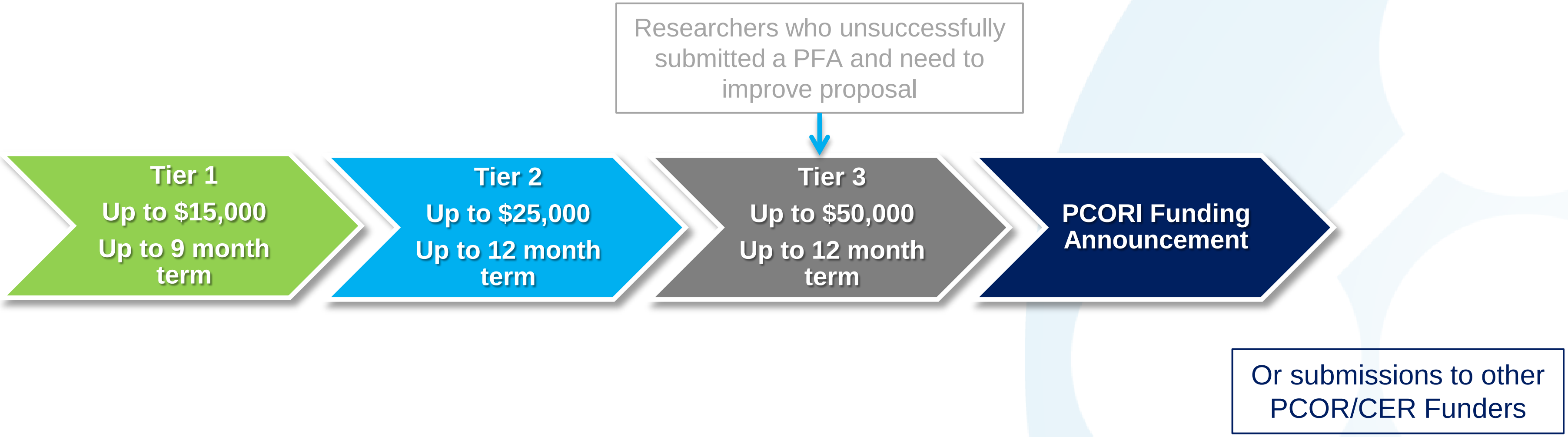
# Pipeline to Proposal Awards



Researchers who unsuccessfully submitted a PFA and need to improve proposal

**Tier 1**
**Up to $15,000**
**Up to 9 month term**

**Tier 2**
**Up to $25,000**
**Up to 12 month term**

**Tier 3**
**Up to $50,000**
**Up to 12 month term**

**PCORI Funding Announcement**

Or submissions to other PCOR/CER Funders

# Tier I Pipeline Awards
(Up to $15,000 for up to 9 months)

**Available to individuals, consumer/patient organizations, clinician(s), researcher(s) or a combination** of the above to support:

- Community building around an area of research interest to improve outcomes for patients
- Creation of structure and communication strategies
- Develop an understanding of PCORI, and “research done differently”

# Tier II Pipeline Awards
(Up to $25,000 for up to one year)

**Available to emerging research/non-research partnerships** to support:

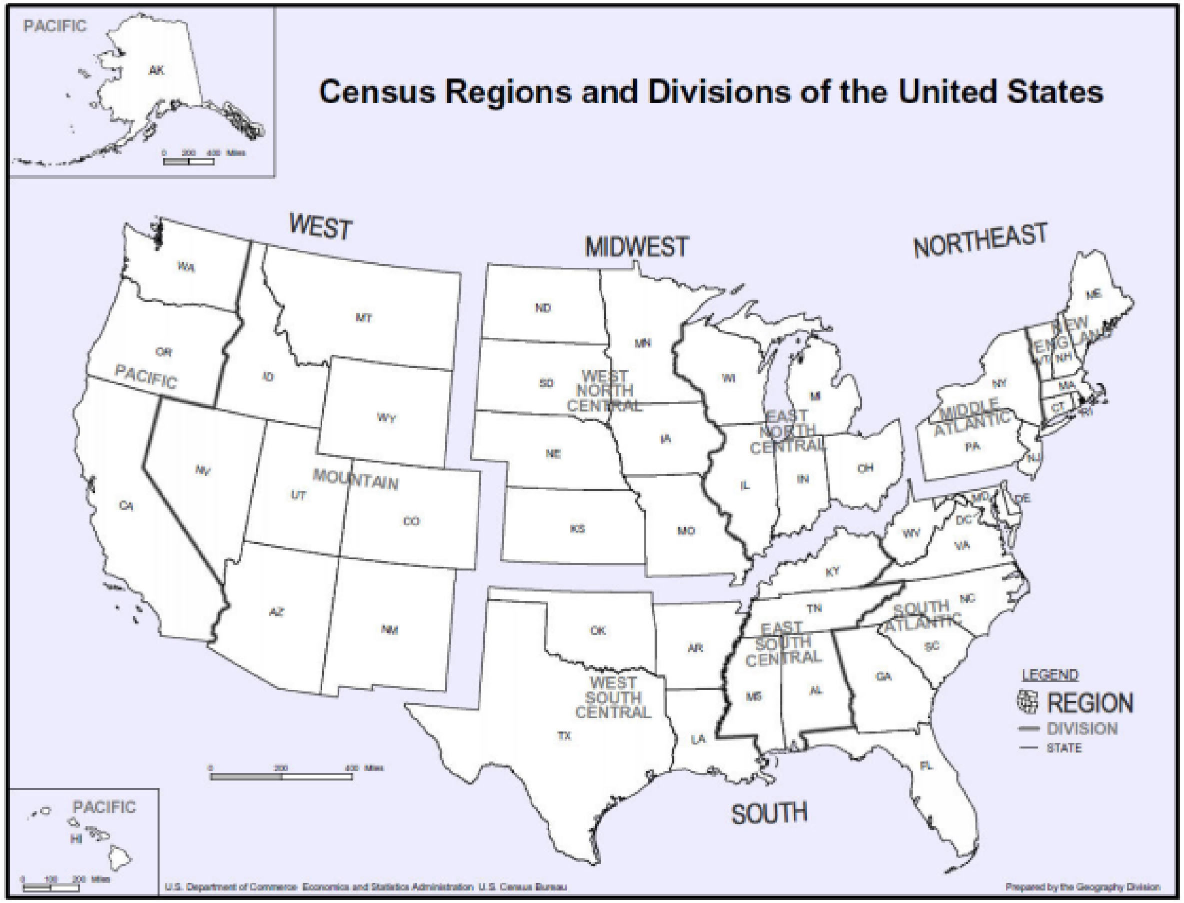
- Data network and registry development
- Development of infrastructure
- Generation and refinement of research questions through community events, town hall meetings, etc.

# **Tier III Pipeline Awards**
(Up to $50,000 for up to one year)

**Available to advanced research/non-research partnerships,** including those who submitted PCORI proposals and were not funded, to support:

- PCORI research proposal (re)submission focusing on development of engagement plan
- Research partnership skill development

# Intermediate Funders and Pipeline Regions



U.S. Department of Commerce Economics and Statistics Administration U.S. Census Bureau

Prepared by the Geography Division

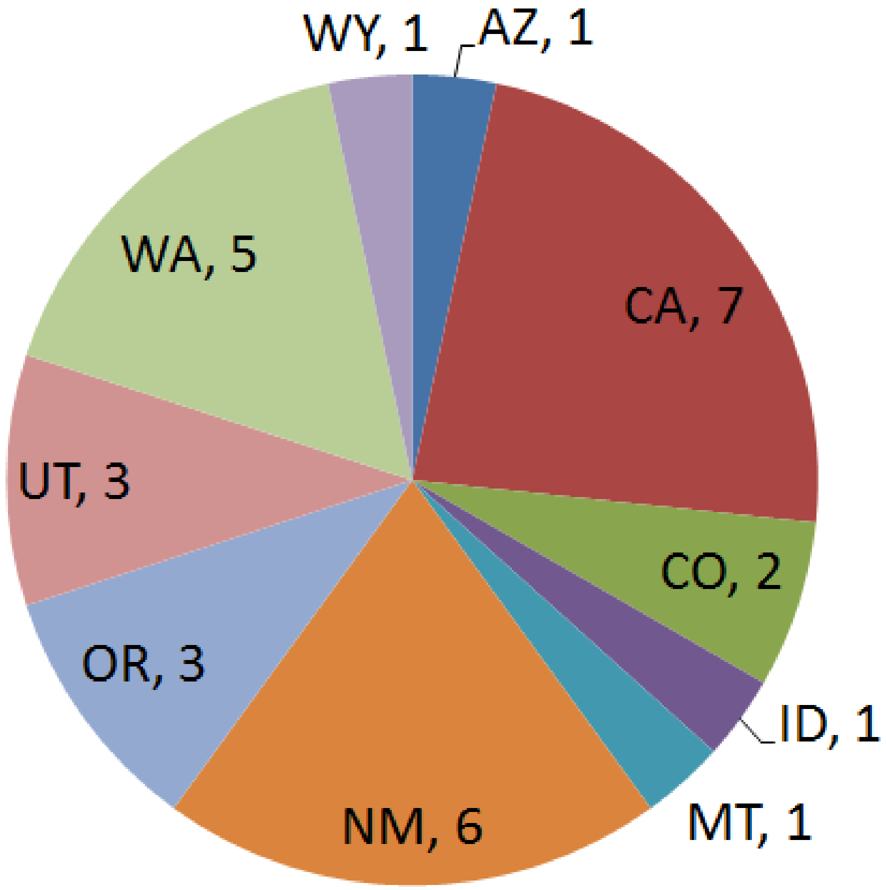
# Western Region Pilot
# Thirty Awardees Announced December 2013

- Creating Healthy Communities: Engaging Native American and Spanish-Speaking Families and Sharing Family Wisdom to Reduce Childhood Obesity
- Improving the Lives of Alzheimer's Patients and their Caregivers: A Patient Centered Statewide Approach
- Mobilizing Community Engagement for Health in a Southern New Mexico Border Region Colonia
- New Mexico LGBT Health Improvement Network
- Usefulness of Pre-diabetes Management in Breast Cancer Care
- The Hispanic Family Asthma Outcomes Research Network
- Building Capacity for Novel Screening Delivery for Chronic Conditions to Benefit Miners in New Mexico
- Culturally Appropriate Options for Diabetes Prevention and Care for Low-Income Latinos
- Citizen scientist
- Developing Infrastructure for Patient Centered Melanoma Research

# Western Region Pilot
# Thirty Awardees Announced December 2013

- Establishing a Patient-Centered Research Community for Cystic Fibrosis
- Sepsis Survivors Engagement Project (SSEP)
- Preventing Missed Appointments for HIV Patients
- Empowering Patients and Their Families to Improve Outcomes That Are Most Important to Them after Lung Cancer Surgery
- YOU COMPLETE ME! Demonstrating the Efficacy of An Innovative Medical Appointment Model to Support Aging Patients
- Healthy Outcomes for Older Foster Youth
- Addressing Obesity in Latino Adolescents with Spina Bifida
- Creating the Patient Centered Primary Care Council in the Highland Hospital Adult Medicine Clinic: Strengthening Primary Care Together
- Health Literacy and the Patient Perspective in Primary Care
- Engaging Communities in the Fight Against Preterm Birth

# Western Region Pilot, by State



- Idaho award includes New Mexico, Oregon, and Wyoming
- Two of the Oregon awards are multi-state;
    - Oregon and Utah
    - Oregon and Washington
- No awards in AK, HI, or NV

# Next Steps

- Evaluate West region Tier I pilot, revise processes as necessary
- Identify South, Midwest, Northeast, and national Intermediate Funders (IFs)
- Open first round of Tier I Pipeline Awards for South, Midwest, Northeast and national IFs
- Open first round of Tier II Pipeline Awards for all five regions
- Open first round of Tier III Pipeline Awards for all five regions

# Western Region Pilot
# Thirty Awardees Announced December 2013

- Connecting Research and Real Life: Building a Network in the Columbia River Gorge
- Taking Care of Our Parents: Improving the Coordination of Care for Elderly Community Members
- Development of Community Partnership for Patient Centered Outcomes Research in Type 2 Diabetes
- Patient-Centered Transitions for Episodes of Surgical Care
- Increasing Patient Engagement and Capacity Building between Community Stakeholders and Patients in order to Improve Diabetes Education and Management among School-Aged Children
- Puget Sound Asthma Coalition: A Community, Clinical, and Academic Partnership
- The 'CISE' Project for Family Caregivers
- Making Stomach Cancer a Health Priority among Asian Americans
- Building a Community of Safe Sleep for Infants
- Patient-Centered Outcomes for the Parkinson's Disease Community in Wyoming

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# PCORI Ambassador Program Update

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The National Patient-Centered Clinical Research Network

# Program Overview

The volunteer initiative that trains, equips, and mobilizes patients, caregivers, organizations and other stakeholders to share PCORI's vision, mission and PCOR principles with their respective communities, participate as full partners in research and to help assure the sharing and uptake of information generated from PCORI funded projects.

Train….Ambassador Training: Five modules of training focused on PCORI, their role, PCORI funding, and working in research teams

Equip….Ambassador Toolkit: Provides support material such as talking points, presentation template, social media guide

Mobilize…Ambassador Yammer Community: Online community that encourages the exchange of best practices in different communities

# Benefits of Being an Ambassador

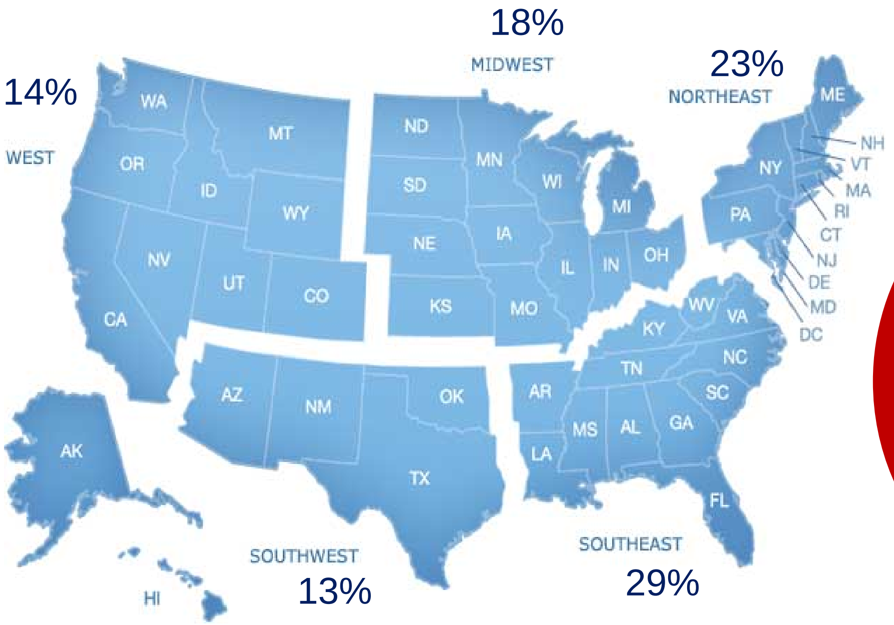
**Jacqueline Deloach Alikhaani**
**PCORI Organizational Ambassador**
Volunteer Heart Survivor Spokesperson
American Heart Association

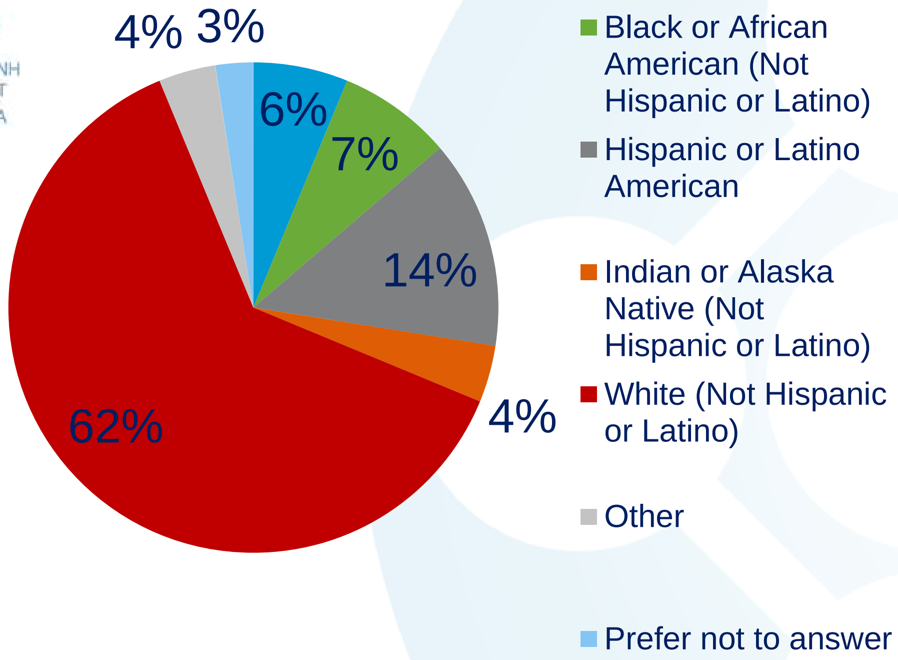
As a Congenital Heart Disease patient, I resonate with PCORI's mission and objectives to make healthcare research more

Benefits of Program:

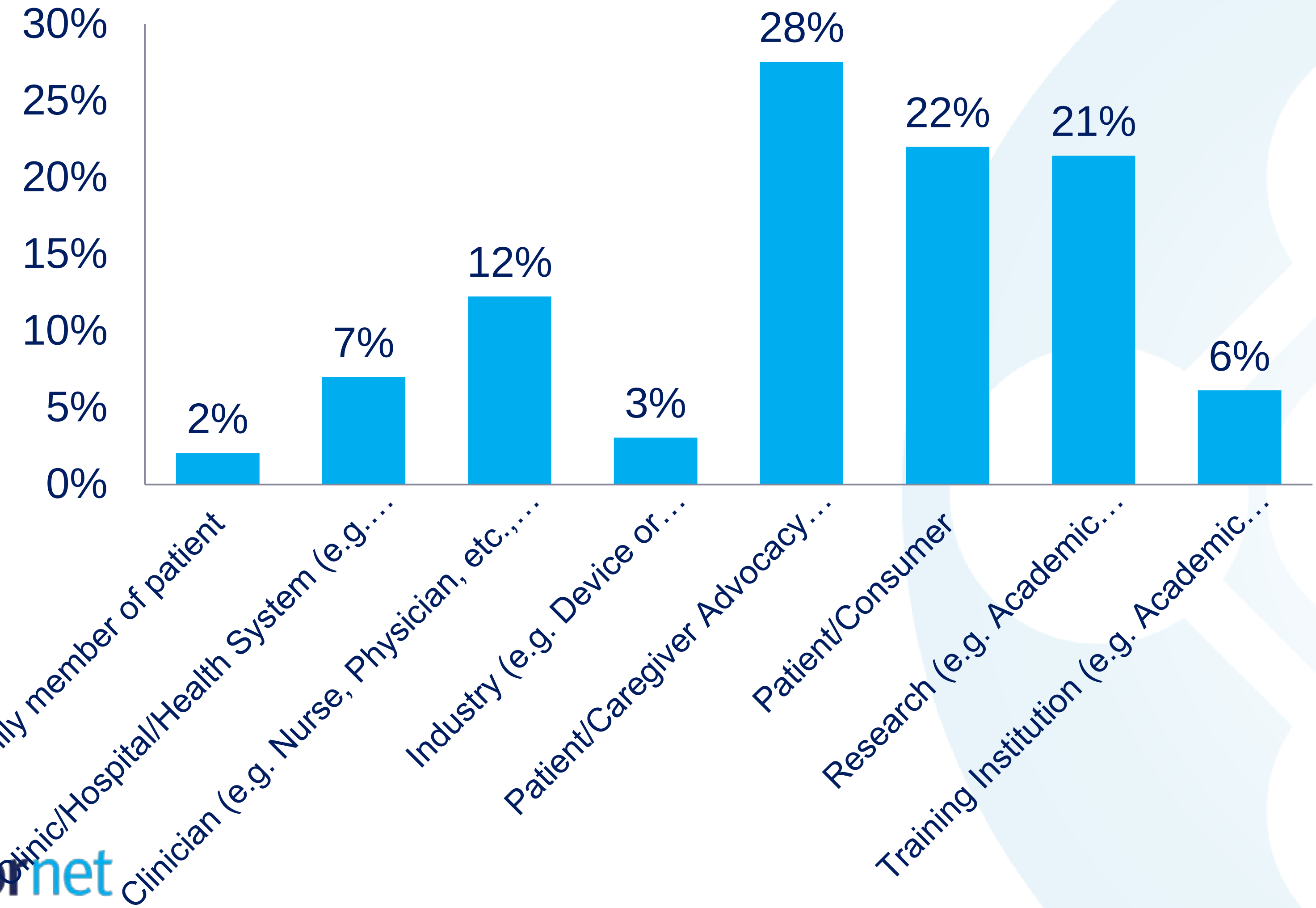
- Receiving PCORI Ambassador communications tools and PCOR training;
- Being recognized as a "PCOR Trained Ambassador" on the PCORI Ambassador webpage;
- Co-authoring publications, submitting guest blogs, or participating in other media opportunities;
- Being highlighted for work in patient-centered research in PCORI e-newsletters;
- Learning of opportunities to serve as PCORI reviewers or participate in working groups and on survey panels; and
- Collaborating and serving as a panelist with PCORI or others on events such as webinars, conferences, and panels.

# Ambassador Interest by Region and Ethnicity (total 101)

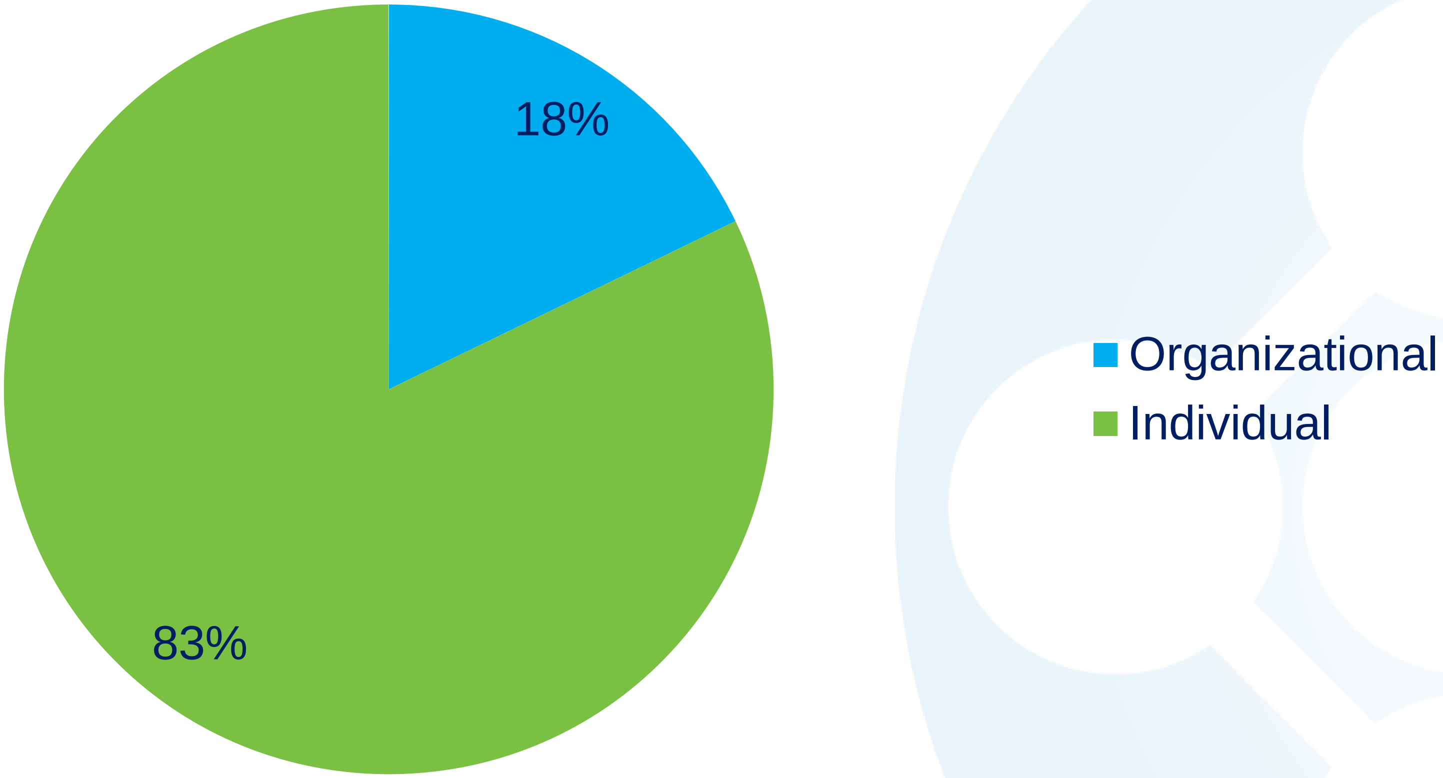




# Which of the following is your primary community? (total 101)



# Individual or Organization Ambassador (total 101)



# Facilitating Interaction & Communication Between PPRNs and CDRNs

*Sarah Greene, MPH,*

*Senior Program Officer, CER Methods & Infrastructure*

*PPRN Partner Meeting*

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# Session Objective

Open discussion about ways to optimize interaction

## Focus Questions:

1) How can PCORI help facilitate collaborations between your PPRN and the 11 CDRNs?
2) Collaboration could be driven by research focus, geography, or both. What are the pros and cons?
3) Given that the task forces will also act as incubators for collaboration, what else can PCORI do to stimulate partnerships across CDRNs and PPRNs that would add value?

# Questions & Opportunities -- PPRN Survey

Your survey responses included as reference

- Design of the common data model
- Recruiting/enrolling in multiple studies simultaneously
- Creation of participant-friendly generic consent materials
- Communication plan to open an ongoing dialogue between the PPRNs and CDRNs
- Methods for collecting PRO in non-clinical setting
- **Basic information about purpose of PPRNs written in generic way for all patients**
- Tracking of communication vehicles and response rate

# Break Out Sessions:

1) Stakeholder Engagement
2) Integrating PROs with Clinical Data
3) Standardized PCORnet Talking Points
4) Ad Hoc

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# Recap and Next Steps

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# Agenda

- Recap emerging ideas
- Identify which ideas are timely and actionable
- Channel your inner artist
- PCORI and Coordinating Center next steps

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# Emerging Ideas

## *Categories*

- Patient Engagement
- Communications / Branding
- CDRN / PPRN Collaborations
- Sustainability / Scalability
- Disruptiveness
- Engagement with non-patient Stakeholders
- Integrating PROs
- Creating Standardized PCORnet talking points
- …And More

# Emerging Ideas

## *Patient Engagement*

- Develop a patient course
- Need sufficient patient representation on Steering Committee and Task Forces
- Define patient engagement and how it is different in CDRNs and PPPRNs
- Engaging disenfranchised patients
- Provide patients with a menu of options for levels of patient engagement
- Best practices for fast tracking feedback to patients
- Ensure meaningful patient engagement in data network development.
- Understand ways to engage with persons who are overweight or obese to support the establishment of the obesity cohort

# Emerging Ideas

## *Communication / Branding*

- Develop a campaign that gets the word out to patients about why they can trust and should engage with PCORnet
- Use language that is understandable to the general public
- Use collaboration-based language
- Develop a plan to harness social media

# Emerging Ideas

## *CDRN/PPRN Collaboration*

- Create/describe the value proposition for CDRNs to work with PPRNs
  - allowing PPRNs to look for disease-specific patients within the CDRNS for enrollment
  - connecting PPRNs with clinicians at CDRNS that treat PPRN-related conditions
  - Others
- Involve PPRNs in the Health Systems Interaction task force
- Identify co-morbid conditions across networks
- Integrate into CDRN and PPRN platforms the ability to search for patients that are represented by a CDRN or PPRN
- Train clinicians in CDRNs to detect rare diseases

# Emerging Ideas

## *Sustainability / Scalability*

- Create a best practices library so networks can learn from each other and additional groups can link to PCORnet in the future
- Develop a long term, concrete, and accessible vision of success so we can plan to achieve interim success
- Develop an 18-month vision for success

# Emerging Ideas

## *Disruptiveness*

- Use novel creative strategies (music, art, visual tools, humor) to engage our partners and the general public

# Emerging Ideas

## *Engagement with Non-Patient Stakeholders*

- Connecting claims data to EHR records
- Best practices for involving health systems and communicating the value proposition for health systems to engage with PCORnet
- Expand the value proposition to address needs of all stakeholders from vendors & funders to clinicians and patients
- Link AHIP into the Health Systems Interactions TF

# Emerging Ideas

## *Integrating PROs*

- Develop group collaborations for creating standards for new PROs that are cross-cutting

# Emerging Ideas

## *Creating Standardized PCORnet talking points*

- PCORnet elevator speech

# Emerging Ideas

## *…and more*

- Create a forum to discuss research priorities
- Develop a plan to increase diversity and engage minority and underserved populations
- Create a diagram of data validation
- Incorporate rigorous methodology into data collection
- Create a unique PCORnet patient identifier
- Create a few menu options for engaging with IRB
- IRB SWAT / SWOT team
- Form mini-work groups to leverage best practices about platforms

# Emerging Ideas

## *…and more*

- Develop a mentor system
- Share best practices in tiered/ modular informed consent
- Leverage existing tools and take cues from other industries (Apple, Amazon) to make research easier and more accessible

# PCORI and CC Next Steps

- Clarify milestones and contract issues
- Clarify which work you can get started on that wont be derailed by TF decisions
- Send out information for logging onto the collaborative work space
- Invite networks to Task Force meetings
- Send updated contract language
- Post all of the CDRN and PPRN partner groups on the website
- Create and post a glossary of acronyms, research terminology, and other PCORnet specific terms (e.g., what we mean by a "node")

# PCORI and CC Next Steps, cont’d

- Map intersections among the different partner networks
- Communicate our communications plan (how we will reach out to you)
- Respond about task force co-chair
- Create a page on the collaborative work space for existing resources and best practice guides (please send us your best practice resources)
- Create a yammer community
- Clarify the rationale for and the requirements for CDRN cohorts and survey of cohorts
- Clarify logistics around TF and SC meetings

# PCORI and CC Next Steps, cont’d

- After task force kickoffs, TFs will begin to prioritize the work that needs to be accomplished over the next few months
- We will reach out to ask if you for permission to post your proposal or sections of your proposal

# Debrief and Closing Remarks

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