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Patient Engagement Advisory Panel

April 29, 2014

Alexandria, VA

Patient-Centered Outcomes Research Institute

Recap of Day 1, Overview of Day 2

Sue Sheridan, MIM, MBA
Director of Patient Engagement

Charlotte W. Collins, JD
Co-Chair
Darius Tandon, PhD
Co-Chair

Patient-Centered Outcomes Research Institute

Agenda for April 29

9:00 – 9:30 a.m.	Recap of Day 1, Overview of Day 2
9:30 – 10:30 a.m.	Evaluation Subcommittee Report
10:30 -10:45 a.m.	*BREAK*
10:45 – 11:15 a.m.	Update on Matchmaking and Partner Lists
11:15 a.m. – 12:00 p.m.	Compensation Subcommittee Report
12:00 – 12:15 p.m.	*BOXED LUNCH*
12:15 – 12:45 p.m.	Discussion on “Patient” Definition, Privacy Issues, and other Questions
12:45 – 1:30 p.m.	Update on PCORnet
1:30 – 1:45 p.m.	Wrap-up and Conclusion
1:45 p.m.	Meeting Adjourned

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PCORI Evaluation Framework: Comments from PEAP Evaluation Subcommittee

Evaluation Subcommittee

Mark Boutin, JD

Steven Blum, MBA

Sara van Geertruyden, JD

Darius Tandon, PhD

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Process for Generating Recommendations

- Committee members reviewed draft PCORI evaluation framework (February 14th version)
- Conference call to generate initial impressions from subcommittee members
- In-person meeting to generate specific recommendations for PCORI to consider

Overarching Recommendations (a.k.a. our “Top 10 List”)

1. The evaluation plan should link to the PCORI brand of “research done differently.”
2. The evaluation plan should provide information that is useful for multiple key audiences, including those making decisions about PCORI reauthorization.
    - Need to have a 3-year framework in place
3. Metrics should be created that are relevant for a 3-year evaluation framework.
4. The evaluation plan must be communicated in user-friendly language to the array of key PCORI stakeholders.
5. Stakeholder valuation of PCORI needs to be incorporated into the evaluation plan.

Overarching Recommendations

6. More metrics need to be created to understand how stakeholder engagement resulted in greater stakeholder capacity to engage in research.
7. Additional qualitative measures examining the impact of PCORI's emphasis on patient and stakeholder engagement should be developed.
8. Completion of surveys that measure attitudes toward engagement should be a contract requirement.
9. More attention should be given to how PCORI's work influences others (e.g., funders).
10. More attention should be given to how PCORI findings and products are used.

15-Minute Break

Refreshments in the upper lobby foyer.

PCOR Partner List and PCORI's Matchmaking App Challenge

Celeste A. Brown, MPH

Program Associate, Stakeholder Engagement

Patient-Centered Outcomes Research Institute

The PCOR Partner List

The PCOR Partner List

- A service on PCORI’s website, open to patients and stakeholders who want to partner on a PFA research team or on other PCORI initiatives
- PCORI’s initial approach to facilitate creation of partnerships, because engagement is something we demand from project teams
- Launch 1: March 4 – April 4
  - 112 responses
  - Sent names to researchers from pragmatic trials, obesity, and transitions in care - targeted PFAs
- Launch 2: April 23 – May 15
  - For the PCORI Matchmaking App Challenge

www.pcori.org/pcorpartnerlist

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PCORI’s Matchmaking App Challenge

Motivation for the 2014 Matchmaking App Challenge

- Researchers often ask how to find patients interested in collaborating.
- Patients and stakeholders may have an idea but not the research experience to bring it to fruition.
- Matchmaking facilitates bi-directional initiation of research partnerships.

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Goals of the 2014 PCORI Matchmaking App Challenge

- Increase the ability for all user types – patient, stakeholder, researcher – to initiate a PCOR relationship.

- Build a self-sustaining online community interested in patient-centered outcomes research.

- Spread the method of patient engagement in research across the country.

PCORI Matchmaking App Challenge

- Polished, ready-to-publish apps
- Total Prizes: $150K
  - 1st Place: $100K (60/40 payment schedule)
  - 2nd Place: $35K
  - 3rd Place: $15K
- Must work with patients and/or stakeholders in product design

Required Features

- Facilitates creation of partnerships among **all user types**: researchers, stakeholder, patient
- Users must be able to **self-select the user type(s)** with which they primarily identify
- Internal (user-only) communication platform
- Ability to **translate** from English, or have a plan to translate the app into other languages
- Section 508 compliance
- Interoperability/ability to integrate with **preexisting research networks** (such as, clinicialtrials.gov, and the PCORnet CDRNs and PPRNs)
- A clear designation that **participation** in the application (web or mobile version) is **voluntary** and, therefore, disclosing personal medical information is the app user's choice and responsibility

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Suggested Features

- **Social media integration** for external networking
- Robust **user profiles**
- Advanced **search** options (e.g. geocoding)
- **Customizable displays**, which allows users to filter and display their network by category (disease condition, geography, individual. Consider the features LinkedIn uses to display existing relationships and suggested connections)
- An **admin dashboard**, which allows users to pull data about the reach and depth of their network
- An **analytics dashboard,** or feature, that other funders and research institutions could access to retrieve data and the existing network (displays such information as, where users access the network from, user concentration by geography, frequency of use, etc.)

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Judging Criteria and Definitions

- **Creativity**: uniqueness and innovation in approach to fulfilling the mandatory requirements; the variety and value of additional features
- **User interface and user experience (UI/UX)**: overall look and feel of various displays and ease of use of all features
- **Evidence of co-design**: the inclusion of patients and stakeholders in the app design and development process
- **Sensitivity**: demonstrated cultural awareness; consideration of the variety of potential users (PCORI's priority populations)
- **Incentive**: impetus users have to download the app and return to use it frequently
- **Past performance**: evidence of the volume and quality of the app developer's previous experience (judged only from the "Past Performance" slide in the .PDF submission)

Timeline Overview

Challenge Development Period

Challenge Launch Date	March 17, 2014
PCORI Webinar for Promotion	March 20, 2014
PCORI Webinar	April 30, 2014
Application Submission Deadline	Aug. 15, 2014

Judging Period

Virtual Judging Begins	Aug.15, 2014
Judging Completed	Aug. 31, 2014
Winner Announced	Sept. 2014

Questions?

matchmaking@pcori.org

www.pcori.org/pcorpartnerlist

www.pcori.org/challenge

PCORI Principles of Compensation Parity

Compensation Parity Subcommittee

Charlotte Collins, JD

Sara van Geertruyden, JD

Regina Greer-Smith, MPH, FACHE

Lorraine Johnson, JD, MBA

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PCORI Patient Engagement Rubric

- Time and contributions of patient partners are valued and demonstrated in fair financial compensation as well as reasonable and thoughtful time commitment requests.

Issues That Matter

- Who is compensated?
- Who is providing the compensation?
- For what level of activities?
- How much?
- Mandated or suggested?

Who Is Compensated

- Patients
- Caregivers
- Patient Organizations

NOTE: Research subjects (study participants) are not included in this topic.

Cover Reasonable Expenses

- Travel
- Accommodation
- Meals
- Childcare
- Internet/telephone
- Conference fees
- Training participation
- Prompt, and even advance, reimbursement

Level of Activities

Research Subject

I. Simply informing
II. Consulting on decision
III. Deciding together
IV. Acting together
V. Encouraging independent initiatives

Fully Engaged Partner

Compensation Alignment with Activities

Parity reflects -

- commitment
- dedicated time
- skills
- expertise
  - level of patient engagement expertise
- commensurate with contributions by other collaborators

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Other Considerations

- Align with level of activities
- Flexible – consider choice
- Non-cash incentives
- Opt-Out
- Consult with the patient/caregiver/organization
  - Public benefits eligibility risk
  - Organization’s internal policies
- Formal contract
- Mandatory vs. permissive

Boxed Lunch Break

Boxed Lunch is served in the
Upper lobby foyer.
We reconvene at 12:15 pm.

Discussion on “Patient” Definition, Privacy Issues, and other Questions

Compensation Parity Subcommittee
Charlotte Collins, JD
Sara van Geertruyden, JD
Regina Greer-Smith, MPH, FACHE
Lorraine Johnson, JD, MBA

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PCORnet Update

April 29, 2014

Jaye Bea Smalley

National Urban Fellow and Special Assistant to the Chief Engagement and Dissemination Officer

Sarah Daugherty, PhD, MPH

Senior Program Officer, CER Methods and Infrastructure

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The National Patient-Centered Clinical Research Network

PCORnet Update

- Revised Infrastructure Rubric
- PCORI Patient Engagement Webinars
- Strategic Portfolio Management
- The ENACT Tool
- Common Data Model Version 1.0
- Update on Patient Engagement Activities

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PCORI Network-Led Patient Engagement Webinars

Building on recent feedback to create a continued dialogue and a sharing of promising practices, the goals for the engagement webinar series are to:

- Promote PCOR readiness
- Encourage the development and sharing of promising practices among PCORnet
- Foster collaboration among networks
- Identify existing resources
- Identify issues and challenges in patient-engaged network development

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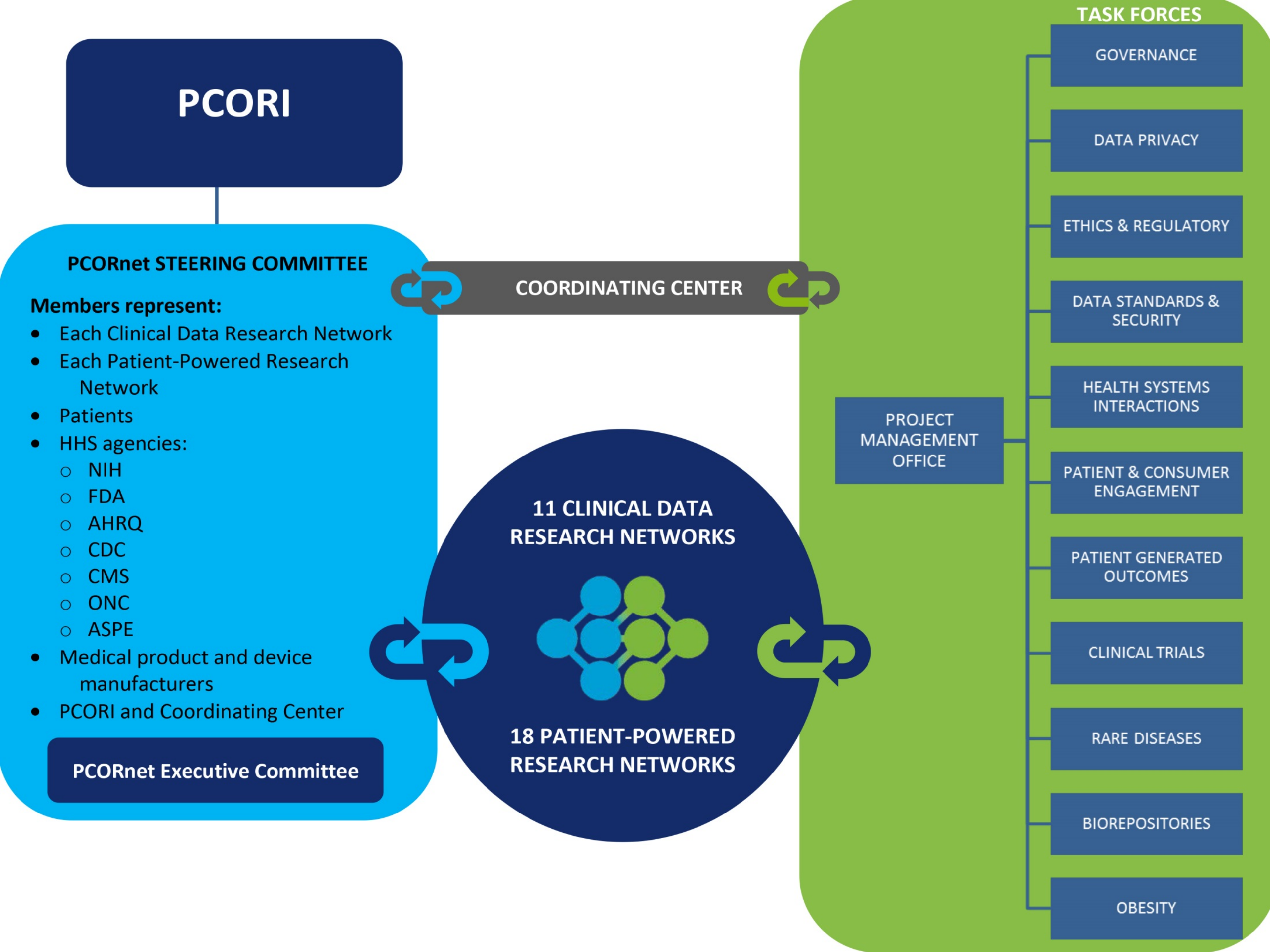

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PCORnet STEERING COMMITTEE

Members represent:

- Each Clinical Data Research Network
- Each Patient-Powered Research Network
- Patients
- HHS agencies:
  - NIH
  - FDA
  - AHRQ
  - CDC
  - CMS
  - ONC
  - ASPE
- Medical product and device manufacturers
- PCORI and Coordinating Center

PCORnet Executive Committee

COORDINATING CENTER

11 CLINICAL DATA RESEARCH NETWORKS

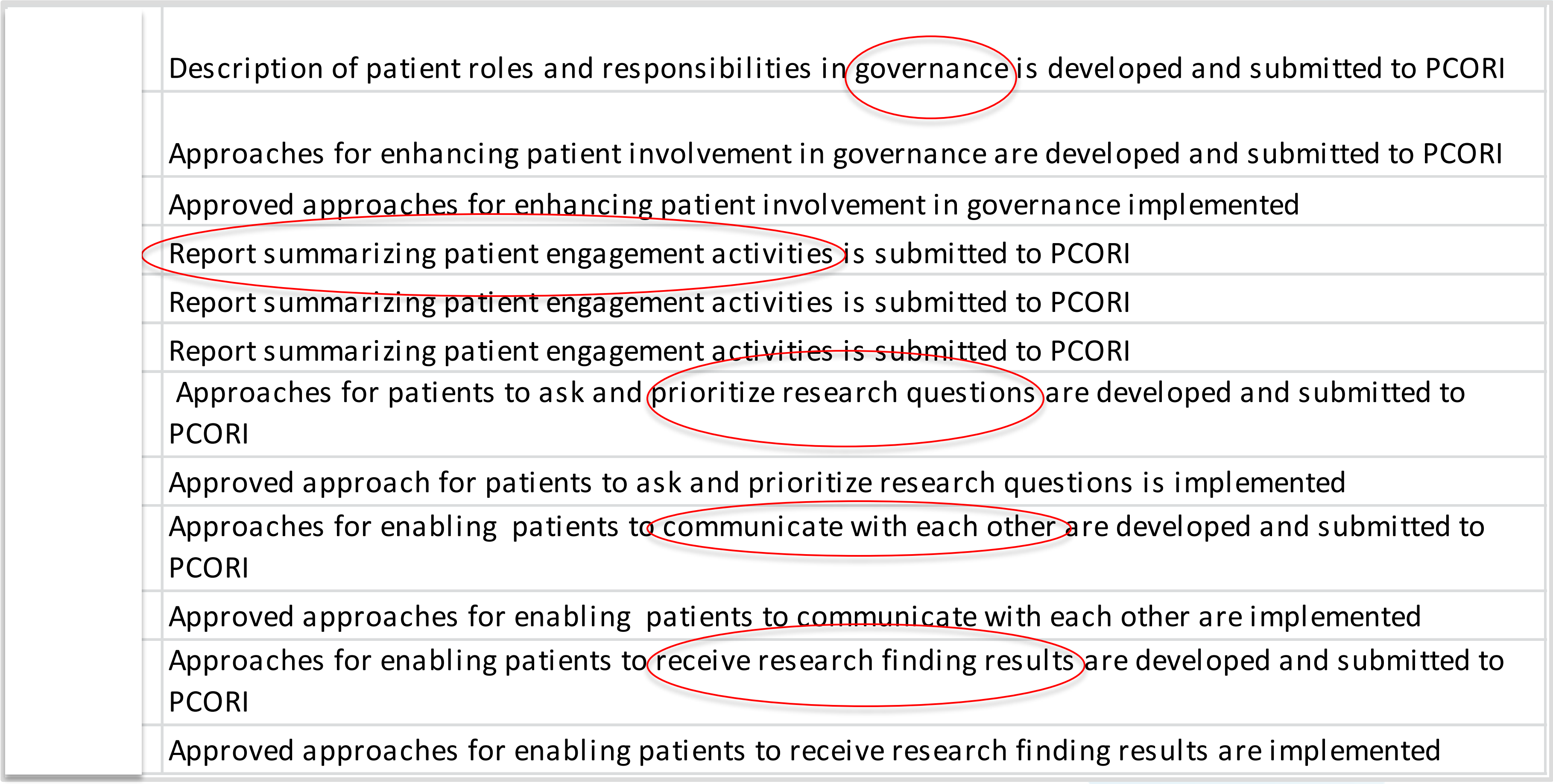
18 PATIENT-POWERED RESEARCH NETWORKS

PROJECT MANAGEMENT OFFICE

TASK FORCES

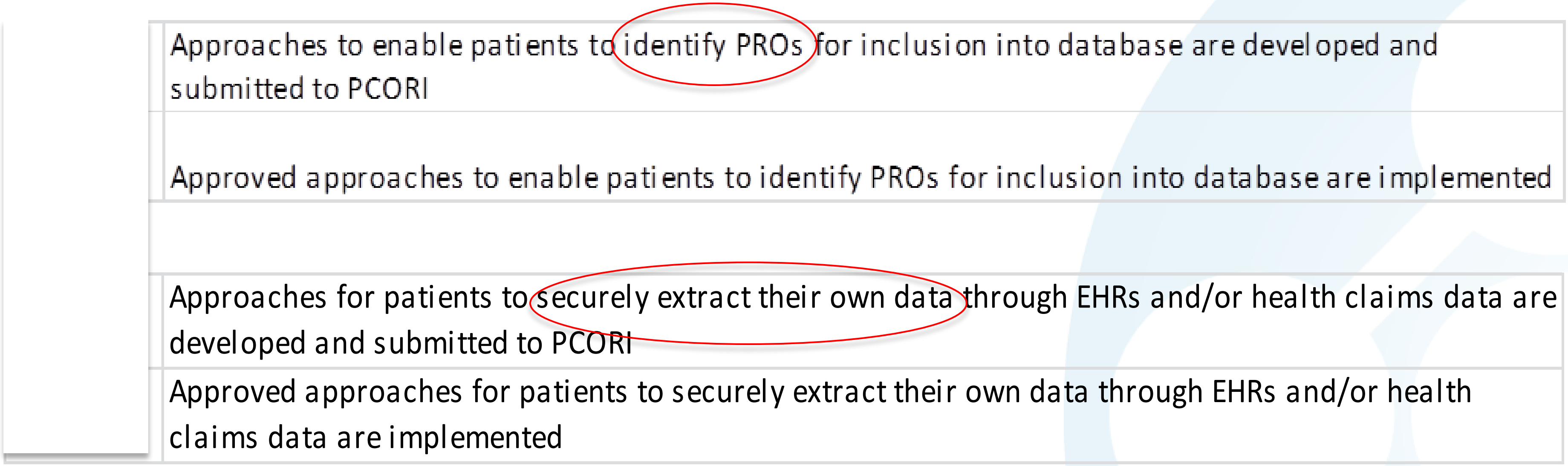
- GOVERNANCE
- DATA PRIVACY
- ETHICS & REGULATORY
- DATA STANDARDS & SECURITY
- HEALTH SYSTEMS INTERACTIONS
- PATIENT & CONSUMER ENGAGEMENT
- PATIENT GENERATED OUTCOMES
- CLINICAL TRIALS
- RARE DISEASES
- BIOREPOSITORIES
- OBESITY

PCORnet Patient Engagement Milestones



	Description of patient roles and responsibilities in governance is developed and submitted to PCORI
	Approaches for enhancing patient involvement in governance are developed and submitted to PCORI
	Approved approaches for enhancing patient involvement in governance implemented
	Report summarizing patient engagement activities is submitted to PCORI
	Report summarizing patient engagement activities is submitted to PCORI
	Report summarizing patient engagement activities is submitted to PCORI
	Approaches for patients to ask and prioritize research questions are developed and submitted to PCORI
	Approved approach for patients to ask and prioritize research questions is implemented
	Approaches for enabling patients to communicate with each other are developed and submitted to PCORI
	Approved approaches for enabling patients to communicate with each other are implemented
	Approaches for enabling patients to receive research finding results are developed and submitted to PCORI
	Approved approaches for enabling patients to receive research finding results are implemented

PCORnet Patient Engagement Milestones

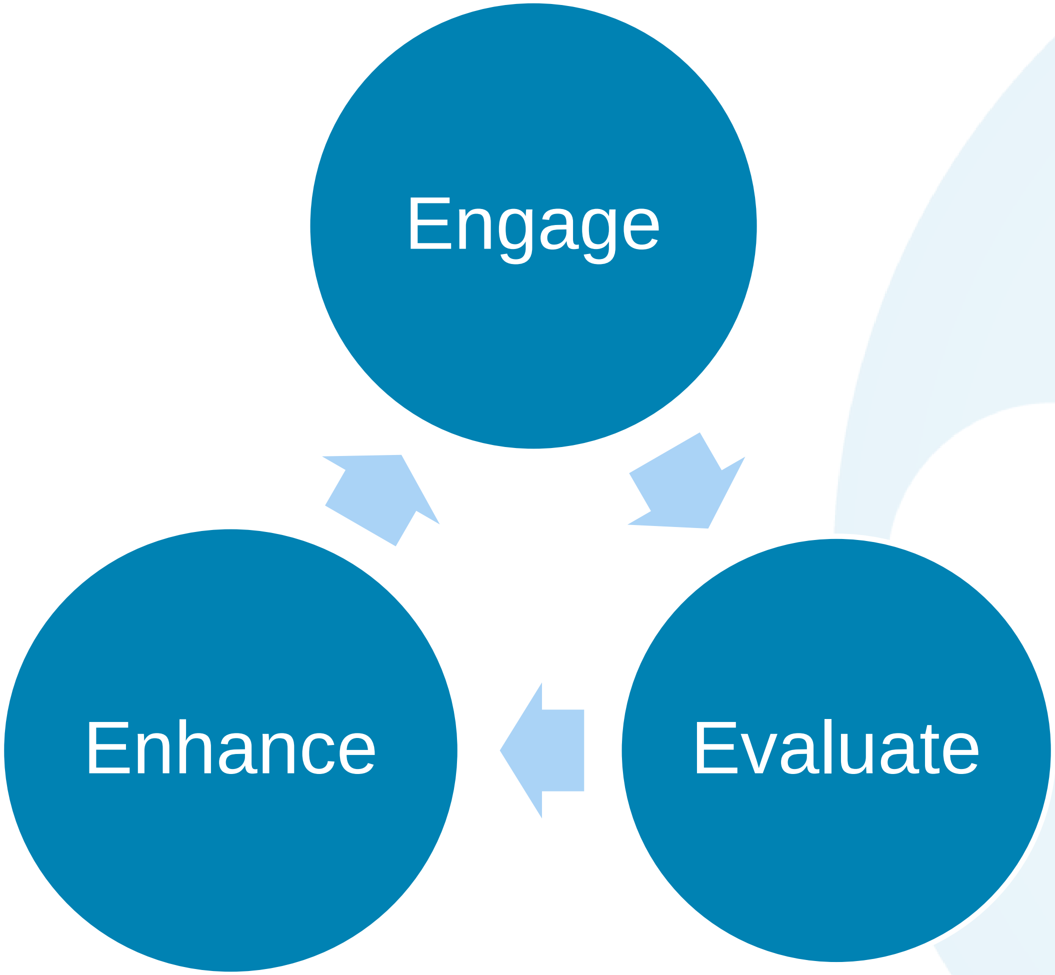


	Approaches to enable patients to identify PROs for inclusion into database are developed and submitted to PCORI
	Approved approaches to enable patients to identify PROs for inclusion into database are implemented
	Approaches for patients to securely extract their own data through EHRs and/or health claims data are developed and submitted to PCORI
	Approved approaches for patients to securely extract their own data through EHRs and/or health claims data are implemented

Strategic Portfolio Management

- Monthly calls with awardee teams
- Quarterly progress reports
- Completion of ENACT tool is required as part of progress report
- Summative analysis at 6, 12, 18 months
- Site visits
- Monthly assessment of technical assistance provided

Engaging Patients in Infrastructure



Engage

Evaluate

Enhance

PCORnet ENACT Tool Protocol

- Integrate end-users into developing assessment tool, interpreting findings, and disseminating results
  - Patient and Consumer Engagement Task Force
  - Evaluation working group established

- Timing: Baseline and 6-month assessments

- Respondents: PI, lead patient representative, clinical partners

- Dissemination: aggregate results to network partners

PCORnet Common Data Model Version 1.0

- Demographics
  - Date of birth
  - Sex
  - Race
  - Hispanic
- Enrollment data, including dates
- Encounter data, including inpatient and outpatient; visit type, provider type
- Vital signs
  - Weight
  - Length (0 to 2-3 y)
  - Height (2-3 + y)
  - Blood pressure, position taken
- Codes for diagnoses, procedures

Thank you!

Safe travels home!