Patient Engagement in Research and Infrastructure Development

Grand Rounds March 7, 2014

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Meaningful Patient Engagement in: Clinical Research (PCOR) and Infrastructure Development

Sue Sheridan, MIM, MBA

Director of Patient Engagement

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Our Mission

PCORI helps 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.

Patient Engagement Priorities and Long Term Goals

Develop PCOR Community…

to successfully establish an infrastructure for patients, caregivers, and other stakeholders to increase CER information and engage them in research, dissemination and evaluation

Engage Community in Research Process…

to influence research and establish trust and legitimacy for successful uptake of research findings

Promote Dissemination and Implementation…

so that patients, caregivers and other stakeholders have CER information they can use to make decisions that reflect their desired health outcomes and to speed implementation of our findings

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Why Engage Patients in Research or Infrastructure Development?

- Lived experience of condition or disease
- Research questions that are important to patients
- Outcomes important to patients such as quality of life and PROs
- Power of data (new currency)
- Focus on patient-centeredness, ethics and safety
- Sense of urgency
- Greater likelihood of trust and patient participation in research networks when patients are involved in infrastructure development
- Greater likelihood of uptake of research findings when patients are involved as partners in the design and conduct of the research

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What does patient engagement look like in the conduct of research?

Rubric: Patient and Family Engagement in Patient-Centered Outcomes Research (PCOR)

Planning the Study

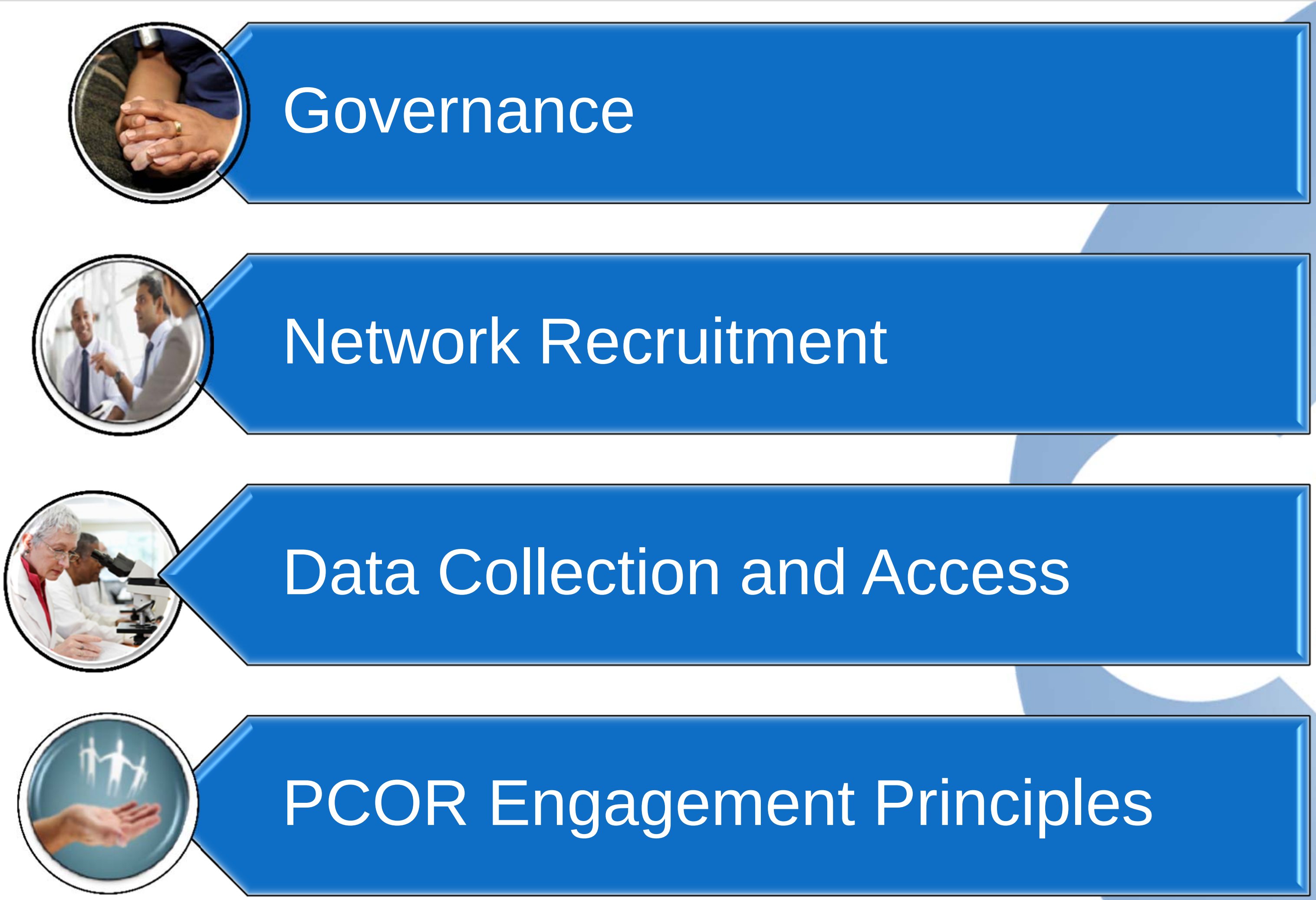
Conducting the Study

Disseminating the Study Results

PCOR Engagement Principles

What does patient engagement look like in Infrastructure Development?

Rubric: Patient and Family Engagement in Infrastructure Development - PCORnet



- Governance
- Network Recruitment
- Data Collection and Access
- PCOR Engagement Principles

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Patient and Family Engagement in Infrastructure Development

Establishi

Develop resea
structure, poli
procedures

Development of research network structure, policies, procedures and bylaws

Patient partners participate in:

- Governance of network development
- Developing policies for data sharing and implementing data sharing and data linkage agreements
- Plans for cross-network collaboration and influencing patient engagement across a large national distributed research network

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Patient and Family Engagement in Infrastructure Development

Network Recruitment

Patients participate in:

Developing plans for increasing the size, diversity, and representativeness of the network

Develop Research Network Infrastructure		
Network Recruitment	Patien Patie involv incre divers repre netwo	ach diversity plan was developed icity, rural or urban locale, disability pulation ofile Survey, homepage, consent ate in the network
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Patient and Family Engagement in Infrastructure Development

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Data Collection and Access

Patients participate in:

The development of data collection tools, strategies to minimize missing data from patient reported data, and the establishment of patient-centered elements

Patient and Family Engagement in Infrastructure Development

Develop Research Network Infrastructure		
Network Recruitment	Patien Patie involv increa divers repre netwo	each diversity plan was developed icity, rural or urban locale, disability pulation rofile Survey, homepage, consent ate in the network
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Data Collection and Access

Patients participate in:

The development of plans and budgets to support patients in obtaining their data through standards-based approaches to download and view data, or in using blue button functions

PCOR Engagement Principles

PCOR Engageme

Reciprocal Relationsh

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Reciprocal Relationships

The roles and decision-making authority of all research partners, including patient partners, are clearly stated

PCOR Engagement Principles

PCOR Engageme	
Trust, Transparency Honesty	d honesty are stated in escriptions of how the ch other frequently, and ensus.

Trust, Transparency, Honesty

- Major decisions are made inclusively and information is shared readily with all research partners

- Patient partners and research partners express commitment to open and honest communication with one another

- The study team commits to communicate the study’s findings back to the study community in a meaningful and usable way

PCOR Engagement Principles

PCOR Engageme

Co-learning

Co-learning

The project includes plans to ensure that the patient partners will understand the research process and the researchers will understand patient centeredness and patient engagement

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better communication

PCOR Engagement Principles

PCOR Engageme

Partnership

Partnership

- Time and contributions of patient partners are valued and demonstrated in fair financial compensation, as well as reasonable and thoughtful time commitment requests
- When the patient partners represent unique populations, the research team proposes to accommodate their cultural diversity and/or disability

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are accessible.

Have Questions?

We welcome your questions and comments at getinvolved@pcori.org

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Matching Engagement Methods to Different PCOR Activities

Sean R. Tunis MD, MSc
Co-lead, PCORnet Patient Engagement Task Force
March 7, 2014

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PCOR/CER Activities

- Establish / manage research Infrastructure
- Topic Identification
- Priority Setting
- Framing Study Questions
- Protocol Development
- Study Implementation
- Review and Interpret Results
- Dissemination
- Implementation

Models / Methods of PCE

- Social media, crowdsourcing
- Mailed or online surveys
- Telephone interviews
- Advisory boards / steering committee / task forces
- Focus Groups
- Multi-stakeholder meetings
- Formal group techniques
  - e.g. modified Delphi, nominal group technques

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Sub-types of Patients and Consumers

- People with specific acute/chronic conditions
- Members of general public
- Reps from patient advocacy organizations
  - With wide range of agendas
- Individuals with deep knowledge of disease, methods, other technical training, policy experience
- Family members and caregivers

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Patient Engagement Task Force Charter

To ensure active and effective engagement of patients and consumers in the design and implementation of all components of PCORnet by serving as a technical resource for innovative problem solving, cross-project communication, and application of cutting edge methods.

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Primary Task Force Activities

1. Agree on the overall philosophy behind Patient & Consumer Engagement (PCE) and develop a guiding conceptual framework and language for PCE in PCORnet
2. Identify, refine, and/or create practical, implementable strategies to ensure effective patient engagement and patient leadership
3. Provide a forum for collective problem solving, obtaining feedback on specific challenges encountered
4. Serve as a resource to support the Coordinating Center and other PCORnet task forces with regard to patient engagement and leadership issues
5. Emphasis on developing strategies for engaging minority, vulnerable, and under-represented populations
6. Serve as an internal patient engagement advocate and "conscience" within PCORnet

More Reasons to Engage Patients/Consumers

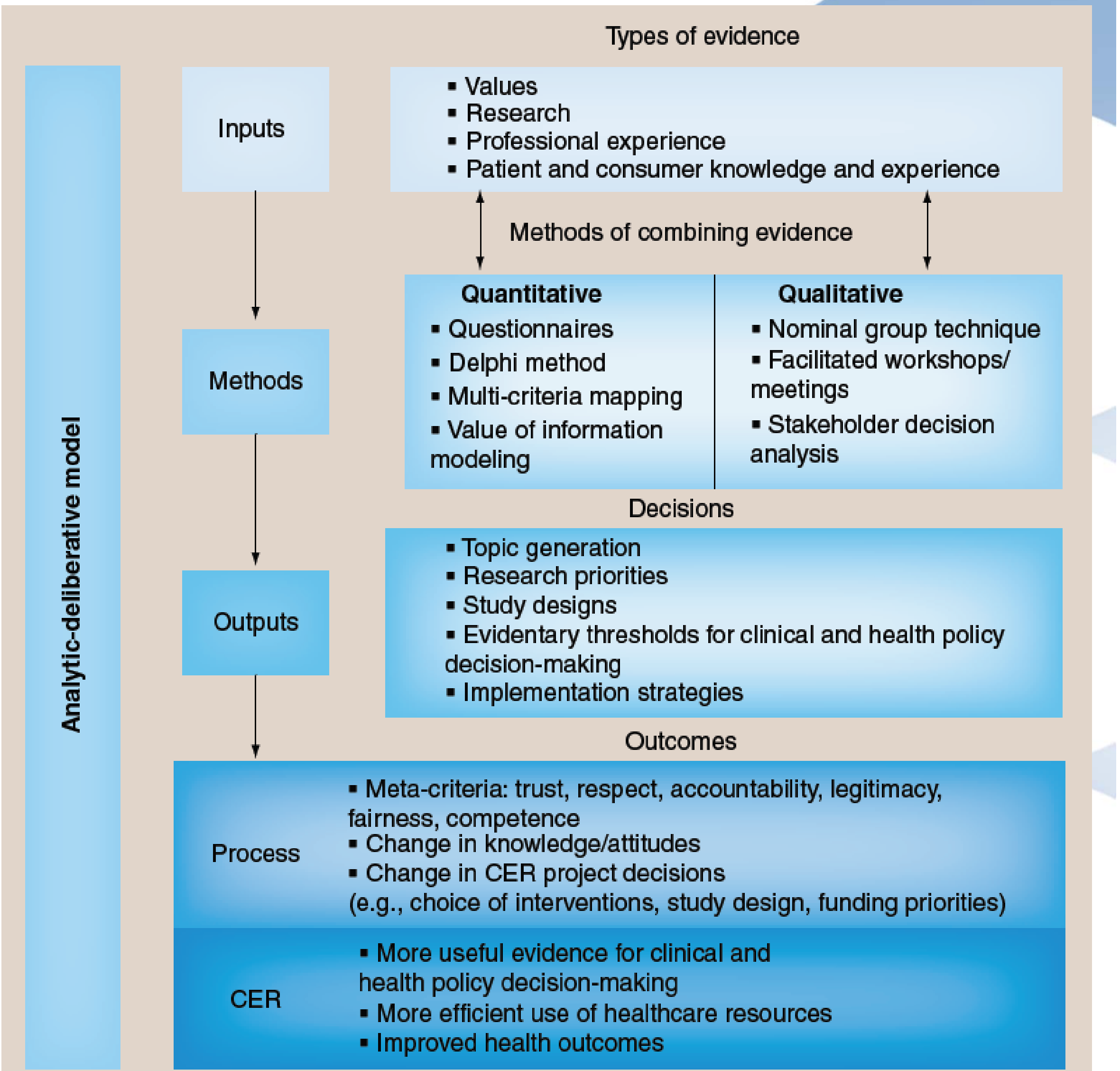
- Patients and other stakeholders bring unique perspective, insights, experience and expertise
- Building trust - easy to underestimate patient/public fears that research results will be used to limit care
- Sustainable infrastructure depends on compelling value-proposition from patient/public perspective
- Not a bad idea to err on the side of over rather than under-inclusion

Conceptual model for stakeholder engagement in comparative effectiveness research

Source: Deverka, Lavallee, Desai et al., JCER 2012

***<u>Stakeholder</u>*: Individuals, organizations or communities that have a direct interest in the process and outcomes of a project, policy or research endeavor – including patients and consumers, healthcare providers, payers and purchasers, policy-makers and regulators, industry representatives, researchers and research funders.**

***<u>Stakeholder engagement</u>*: An iterative process of actively soliciting knowledge, experience, judgment and values of individuals selected to represent a broad range of direct interests in a particular issue for the dual purposes of creating a shared understanding and making relevant, transparent and effective decisions.**



Analytic-deliberative model

Types of evidence

Inputs

- Values
- Research
- Professional experience
- Patient and consumer knowledge and experience

Methods of combining evidence

Methods

Quantitative

- Questionnaires
- Delphi method
- Multi-criteria mapping
- Value of information modeling

Qualitative

- Nominal group technique
- Facilitated workshops/ meetings
- Stakeholder decision analysis

Decisions

Outputs

- Topic generation
- Research priorities
- Study designs
- Evidentary thresholds for clinical and health policy decision-making
- Implementation strategies

Outcomes

Process

- Meta-criteria: trust, respect, accountability, legitimacy, fairness, competence
- Change in knowledge/attitudes
- Change in CER project decisions (e.g., choice of interventions, study design, funding priorities)

CER

- More useful evidence for clinical and health policy decision-making
- More efficient use of healthcare resources
- Improved health outcomes

Laying Down Track while Moving at Full Speed

Ref: Wallace and Gromit:
“The Wrong Trousers”

Patient Perspective on Patient Engagement in Infrastructure Development

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Patient Representative, Executive Leadership Committee
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Patient Stakeholder Roles & Associated Verbs

Co-Investigators

Designers

Advisory Board Members

Influencers

Focus Group Members

Testers

Research Participant

Experiencers

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Desirable Qualifications of Patient Partners for Research Infrastructure Development

- Previous experience representing patient constituencies at a national level in multi-stakeholder groups
- Understanding of PCOR research and informed consent
- Well-positioned within the patient community both to gather input for research initiatives and to communicate progress to stakeholders
- Ability to represent the patient perspective, but also collaborate and compromise to reach solutions that can be embraced by many
- Ability to act in an unbiased manner for the greater good of all patients and not just one disease

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Thank You!

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