

# Evaluating the Quality of Your Patient/Stakeholder Engagement

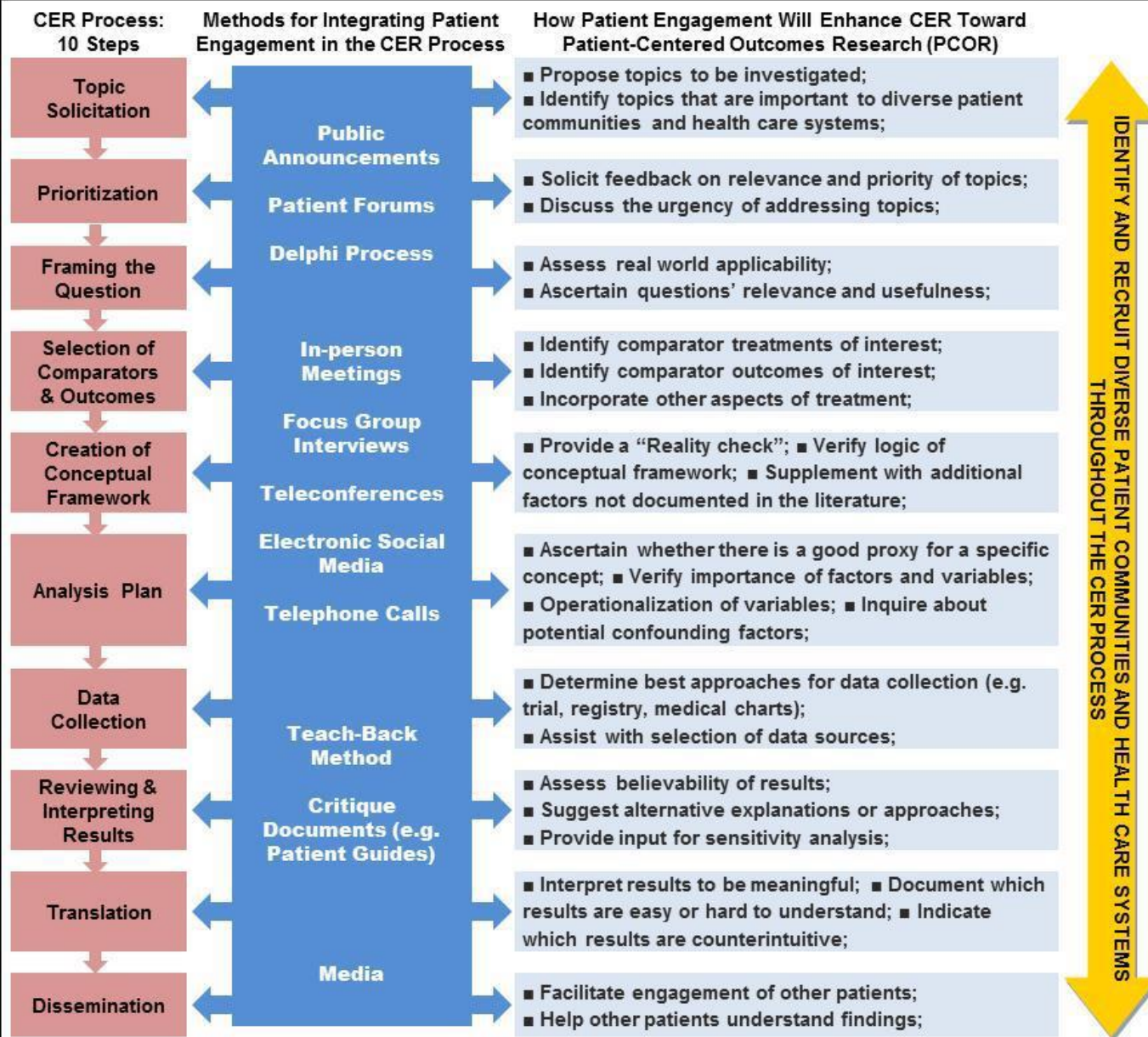
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# 10 Step Framework for Continuous Patient Engagement in Comparative Effectiveness Research (CER)

## THE COMPARATIVE EFFECTIVENESS RESEARCH (CER) PROCESS IS ENHANCED THROUGH CONTINUOUS PATIENT ENGAGEMENT...



...LEADING TO MODIFICATIONS BASED ON FEEDBACK FROM PATIENTS.

# What is a stakeholder?

Any entity which has contact with or impact on the patient's care:

- Patient
- Caregiver
- Hospital
- Hospital Administrator
- Insurer
- Provider
- EMS

# Problems Inherent in Evaluation of Patient Participation

- Concept is complex and value laden
- No criteria for judging success or failure
- No agreed upon evaluation methods
- Few reliable measurement tools

# Ways of Evaluating

- Process Evaluation
- Change in Outcomes
- Impact Evaluation

# Process Evaluation

Was the process inclusive?

Were patients invited to meetings?

Did patients attend meetings?

Did they participate?

# Process Measurement

Number of patients/stakeholders involved

Number of meetings patients/stakeholders  
attended

Actual participation by patients/stakeholders





# Change in Outcomes

Did the participation of the  
patient/stakeholder change any elements  
of the study?



# Outcomes Evaluation Measurement

Did the research question change?

Were the outcomes more patient centered?

Did the patient participation lead to changes  
in analytic plan?

Did the patient participation lead to changes  
to dissemination plan?

# Impact Evaluation

What impact did the process have on participants?

- Researchers
- Patients
- Stakeholders

# Other possible effects

Was the researcher made aware of **stigma**?

Did patient participation lead to clearer, or more appropriate **language**?

Were patients/stakeholders able to assist with **recruitment**?

# What is “PATIENTS”?

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“PATIENTS: PATient-centered Involvement  
in Evaluating effectiveness of Treatments”

PI: C. Daniel Mullins, Ph.D.  
(AHRQ: R24HS022135)

# Our Vision

Patients and stakeholders are **heard, inspired, and empowered** to co-develop patient-centered outcomes research (PCOR).



# Our Mission

The PATIENTS Program partners with patients and care providers to answer questions about the best treatment options to improve health and quality of life. We engage people from all communities, especially those from underserved and minority populations, in every step of the patient-centered outcomes research (PCOR) process. Through our collective efforts, we create an effective learning healthcare community.

We **listen to patients' voices** so that we ask relevant and meaningful questions

We **align research priorities** with the values of patients and communities

We **transform research** to make it more relevant and patient-centered

We **train patients, stakeholders, and researchers** to become co-developers of PCOR



# Evaluation for PATIENTS

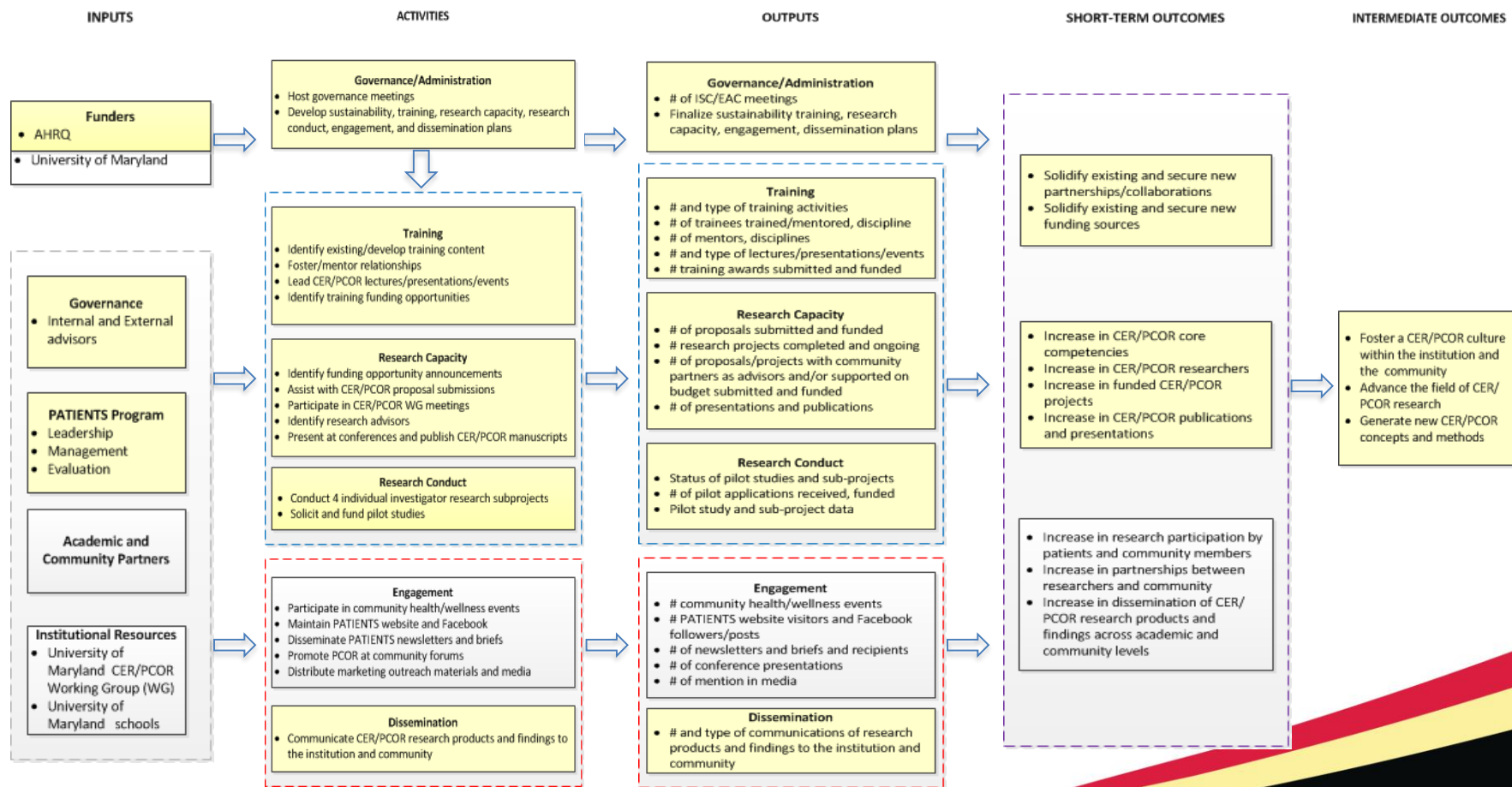
- Identify needs of PATIENTS investigators, patients, healthcare delivery systems, and our partners
- Collect indicators of how well PATIENTS has achieved its objectives
- Understand how barriers and facilitators influence the conduct of PCOR from the perspective of PATIENTS stakeholders

# Program Logic Model

- A picture of how your organization does its work
- Illustrates the linkages between program activities with outcomes
- Tool to facilitate effective program planning, implementation and evaluation
- Serves as a roadmap for staff, stakeholders and funding agencies



# PATIENTS Logic Model



# Evaluation Methods

- Online surveys
- Key informant interviews
- Data abstraction/document review

# Evaluation Constructs & Activities

Evaluation Constructs	Activities
Governance/Administration	Meetings, programmatic plans
Training	Training resources, mentorship, CER/PCOR events
Research Capacity	Assist with CER/PCOR proposals, identify research and patient advisors
Research Conduct	Conduct research subprojects, fund pilot studies
Engagement	Health/wellness events, media, newsletters
Dissemination	Promote CER/PCOR research products and findings

# Short-term Outcomes

Increases in:

- New partnerships/collaborations/funding
- CER/PCOR core competencies, projects, publications and presentations
- Research participation by patients and community members
- Partnerships between researchers and community
- Dissemination of CER/PCOR research products and findings across academic and community levels

# Intermediate Outcomes

- Foster a CER/PCOR culture within the institution and community
- Advance the field of CER/PCOR research
- Generate new CER/PCOR concepts and methods



# Questions?

The PATIENTS Program:

<http://patients.umaryland.edu/>

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