Engaging Patients and Families in Patient-Centered Outcomes Research on Care Transitions

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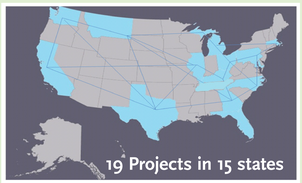
TC E2AN Transitional Care Evidence to Action Network

What is the "Transitional Care Evidence to Action Network?"

Transferring from one health care setting to another or to home can be a vulnerable time for patients and those who care for them, prompting researchers and policy makers to identify and validate strategies that improve transitions of care (TC). For this reason, the Patient-Centered Outcomes Research Institute (PCORI) has invested more than $62.7 million in TC research. However, PCORI's investment does not end there; through its Transitional Care Evidence to Action Network (TC-E2AN), it also connects PCORI-funded investigators to facilitate collaborative learning and share key lessons learned.

In aggregate, the 19 projects currently comprising the TC-E2AN seek to reduce readmissions, improve patient experience, and improve outcomes important to patients. Most focus on patients discharged from the hospital to home. Facilitated by PCORI and its contractor, Westat, the TC-E2AN connects these geographically dispersed research teams via an annual in-person meeting, periodic Webinars and Network-wide conference calls, and one-on-one calls, fostering engagement and cross-learning among awardees.



Locations of PCORI Transitional Care Evidence to Action Network Projects by State

What is PCOR and How does it Include Patient Perspectives?

Patient-centered outcomes research (PCOR) helps patients and their caregivers make informed healthcare decisions, allowing their voices to be heard in assessing the value of healthcare options. A key component of all PCORI-funded research is the engagement of patients, families, caregivers, and other stakeholders in all aspects of the research process. This poster highlights the various engagement strategies employed by TC-E2AN research teams.

According to PCORI's "About Us" page on its website: "We incorporate patients and other stakeholders throughout the process more consistently and intensively than others have before. We call this 'research done differently.'" To help researchers, PCORI published the Engagement Rubric,[1] which incorporates key principles of meaningful engagement in research, identifies opportunities for engagement in research, and provides concrete and replicable examples of engagement in research.

What are the Roles of Patients, Families, and Caregivers in TC-E2AN Studies?

PCORI/Westat conducted an analysis of critical project documents, including initial proposals and contract modifications, and conducted interviews with each research team to understand the engagement practices employed by each. We found that all 19 projects include patients, families, and caregivers in their research studies in various ways, including:

- Extensive use of patient advisor groups (e.g., in developing and vetting interventions, as a sounding board during design, implementation, and/or evaluation phases).
- Use of patient peers in the intervention.
- Measurement development and refinement.
- Patients and other stakeholders as co-investigators.

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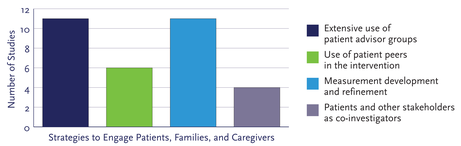

Patient Advisory Groups

Many projects employed patient/caregiver advisory groups early in the process, often through focus groups or as ongoing advisory bodies. Researchers:

- Relied heavily on patient and caregiver input during their first year intervention development and refinement stages, often using focus groups to gather insights.
- Engaged patient advisory group/steering committees even prior to submitting the PCORI application to ensure engagement from the project's inception.
- Used a Patient and Family Advisory Council to guide intervention design, including patient-facing data collection instruments.
- Convened advisory groups more frequently during the first year of their projects.
- Created a stakeholder advisory group portal and monthly newsletter to connect geographically dispersed advisors.
- Heavily relied upon focus groups of patients and caregivers during the initial proposal and project development phases.

Many advisory boards provide input throughout the life of the project. Some meet weekly, monthly, or less frequently (e.g., some advisor groups meet every 4-6 weeks or on a quarterly basis).

Patients as Peers

Several research teams include patients as "peers" in the following ways:

- A peer-led telephone information line or a "peer mentor" intervention.
- In one project, patient advisors are leading focus groups and interviews for the qualitative data collection component of the study.
- In studying ways to improve upon TC for patients with serious mental illness, one project hired a peer counselor to help patients understand their role in shared decision-making.

Patient/Caregiver Involvement in Measure Development, Refinement, and Collection

- The primary outcome measure of one study was selected by the research team based upon input from its Survivor and Caregiver Advisory Group.
- In one project, patients provided input on survey question and prompt wording.
- Patients in one study adjusted wording in several key instrument questions, educating researchers about insufficient cultural and economic sensitivity of original language.
- In another project, patients helped develop questions for the in-depth interview complexity assessment, and then pilot tested these tools.
- Patients helped develop educational materials and have actively aided in developing and testing a patient portal.
- Input from patients and families informed how the researchers operationalized data collection.

Overview of Projects

Number	Name of Principal Investigator	Name of Project	Location
1	Aboumatar	An Integrative Multilevel Study for Improving Patient-centered Care delivery Among Patients with Chronic Obstructive Pulmonary Disease	Maryland
2	Bettger	Comparative Effectiveness of Rehabilitation Services for Survivors of an Acute Ischemic Stroke	North Carolina
3	Boulware	Putting Patients at the Center of Kidney Care Transitions	North Carolina
4	Brooks	Specialized Community Disease Management to Reduce Substance Use and Hospital Readmissions	Pennsylvania
5	Carden	An Emergency Department-to-Home Intervention to Improve Quality of Life and Reduce Hospital Use	Florida
6	Collins	Get With the Guidelines Interventions to Reduce Disparities in AHF Patients Discharged from the ED (GUIDED HF)	Tennessee
7	Duncan	Early Supported Discharge for Improving Functional Outcomes After Stroke	North Carolina
8	Fratantoni	Peer Support After NICU Discharge: Can Parent Navigation Improve Parental Mental Health and Infant Outcomes?	Maryland
9	Jones	A patient-centered approach to successful community transition after catastrophic injury	Georgia
10	Kiefe	Improving Measurement of Health Care Transitions through Key Stakeholder's Eyes	Massachusetts
11	Krishnan	PATient Navigator to rEduce Readmissions (PArTNER)	Illinois
12	Reeves	Improving care transitions for acute stroke patients through a patient-centered home based case management program	Michigan
13	Schnipper	Relative patient benefits of a hospital-PCMH collaboration within an ACO to improve care transitions	Massachusetts
14	Seekins	Rural Options At Discharge Model of Active Planning (ROADMAP)	Montana
15	Shah	Improving post-discharge outcomes by facilitating family-centered transitions from hospital to home	Ohio
16	Velligan	Improving transitional care experience for individuals with serious mental illness	Texas
17	Whooley	Improving Delivery of Patient-Centered Cardiac Rehabilitation	California
18	Williams	Project ACHIEVE (Achieving Patient-Centered Care and Optimized Health In Care Transitions by Evaluating the Value of Evidence)	Kentucky
19	Zatzick	A Comparative Effectiveness Trial of Optimal Patient-Centered Care for US Trauma Care Systems	Washington

Remuneration for Patients and Caregivers

PCORI guidance states that "any research proposal submitted to PCORI will include a plan and related budget for fairly compensating patients, caregivers, and patient/caregiver organizations engaged as partners in the project."[2] Each TC-E2AN project, therefore, offers compensation for patient and caregiver team members. Some offer funding for stakeholder engagement in the initial project stages, while others provide remuneration on an ongoing basis. Remuneration strategies include:

- Compensation for transportation to meetings.
- Consulting fees.
- Incentives/honoraria.
- In at least one study, patients are paid the same hourly rate as physicians.
- Patient advisors are such an invaluable asset that some research teams are pursuing additional funding to sustain their efforts beyond the initial funding period.

What can we Learn from the TC-E2AN About Patient, Family, and Caregiver Involvement in Research?

- Researchers integrate patients and other stakeholders into their processes using a variety of techniques, from guidance on study design to defining operational issues to interpreting results.
- Patient advisory groups are cited as an efficient approach to garner input throughout the life of the research projects.
- Effective stakeholder engagement requires thoughtful agenda and meeting planning; teams reported a strong correlation between levels of planning and resultant patient engagement.
- Principal investigators consistently report that patient, family, and caregiver input profoundly changed the way the envisioned and executed study elements have helped study teams overcome unanticipated barriers in project execution, including patient recruitment efforts.
- Aided by PCORI's recent guidance,[2] researchers are able to offer meaningful compensation to recruit, retain, and support ongoing involvement of patients and other stakeholders.

[1] "PCORI Engagement Rubric for Applicants." Published 02/04/2014 and updated 06/06/2016. Available at: http://www.pcori.org/sites/default/files/Engagement-Rubric.pdf

[2] Financial Compensation of Patients, Caregivers, and Patient/Caregiver Organizations Engaged in PCORI-Funded Research as Engaged Research Partners. Available at: http://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf

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