Overview

On July 12, 2013, PCORI’s Improving Healthcare Systems program convened a multidisciplinary workgroup meeting in Washington, DC, to identify unanswered questions that are important to patients and other stakeholders when deciding whether to participate in programs of transitional care. The workgroup included patients, researchers, providers, stakeholders. The meeting was open to the public via webinar, and comments were welcomed before, during, and after the meeting.

The workgroup concluded that building on large-scale research programs with new research has the potential to develop a broad base of evidence in the short term that may guide clinical decision making and the successful widespread adoption of transitional care programs. This supplementary research should include a specific focus on outcomes that matter to patients and caregivers, as well as an assessment of the facilitators and barriers to successful adoption of transitional care models. To guide this activity, workgroup members recommended survey and research questions (see Tables 1 and 2, pages 6 and 8).
Background

PCORI is interested in identifying research questions that evaluate important choices faced by patients and that have a good chance of providing evidence that can reduce uncertainty, support decision making, change practice, and improve patients’ health outcomes. PCORI views gaps in the evidence base on transitional care as an opportunity where we can contribute to improving health outcomes.

There are several steps in the process that leads to the final selection of specific topics for our targeted funding announcements. A full description of the topic generation and research prioritization process\(^1\) is available on the PCORI website. In April 2013, the Advisory Panel on Improving Healthcare Systems\(^2\) recommended models of transitional care as one of five topics for potential development into PCORI Funding Announcements (PFAs).\(^3\) The topic of transitional care was reviewed by the Board of Governors and approved for further topic refinement in May 2013, and the Improving Healthcare Systems team subsequently performed a literature review.

The number of individuals with chronic conditions is expected to reach 125 million by 2020, and each of these individuals may each see up to 16 physicians in a given year.\(^4\) Those with multiple chronic conditions are particularly vulnerable to medication errors, inefficient or duplicative care, inadequate patient/caregiver preparation, and rehospitalization. According to one study, one in five patients discharged from hospital to home experienced an adverse event within three weeks of discharge; 60 percent of these errors were medication related.\(^5\) Moreover, 19.6 percent of all Medicare beneficiaries were rehospitalized within 30 days, nearly 90 percent of these readmissions were unplanned, with an estimated cost to the Medicare program of $17.4 billion.\(^6\) In this environment, transitional care—a set of care strategies designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of case—may have a positive impact. For additional information, see Topic Brief: Models of Transitional Care.\(^7\)

The PCORI Improving Healthcare Systems team convened a workgroup to help identify research gaps and questions in this topic area. Workgroup participants were selected on the basis of their affiliation with professional organizations that represent the broad spectrum of perspectives involved in care transitions. Patients, caregivers, clinicians, researchers, and other stakeholders attended the meeting. PCORI Science and Engagement staff also. A list of participants\(^8\) and detailed biographies\(^9\) are available on the PCORI website. The workgroup met from 9:00 am to 4:00 pm (ET) on July 12, 2013, in Washington, DC. Public comments were welcomed before, during, and after the meeting via email (transitionalcare@pcori.org), webinar chat, and Twitter.

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1. Available at pcori.org/funding-opportunities/funding-announcements/from-research-questions-to-research-funding-about-our-topic-generation-and-research-prioritization-process/
2. Available at pcori.org/get-involved/pcori-advisory-panels/advisory-panels-on-improving-healthcare-systems/
3. Available at pcori.org/funding-opportunities/funding-center/
8. Available at pcori.org/assets/2013/07/PCORI-Transitional-Care-Workgroup-Participant-List-071213.pdf
9. Available at pcori.org/assets/2013/07/PCORI-Transitional-Care-Workgroup-Biographies-071213.pdf
Meeting Summary

Dr. Chad Boult, Program Director of the Improving Healthcare Systems (IHS) team opened the meeting with an overview of PCORI’s mandate and its process for selecting targeted research topics. The moderators of the workgroup, Dr. Trent Haywood, Chief Medical Officer of Blue Cross and Blue Shield, and Dr. Doris Lotz, Medicaid Medical Director of the State of New Hampshire, introduced themselves and each workgroup member. Dr. Lynn Disney, Senior Program Officer of the IHS team, provided background on the process of prioritizing research topics at PCORI and the evolution of the Transitional Care Workgroup. Next, topic experts presented current research on transitional care and the process of patient-centered outcome measure development. Then, the moderators presented a patient vignette and guided the workgroup participants in a discussion with the goal of creating a list of high-priority survey questions related to transitional care that are most significant to each of the stakeholders (see Table 1, page 6). In a later discussion, the participants developed additional research questions (arranged by thematic area in Table 2, page 8).

Research Presentations

The presentations below are available online here.10

- **Setting the Stage—Current State of Evidence**, Mary D. Naylor, PhD, FAAN, RN, Marian S. Ware Professor in Gerontology and Director of the NewCourtland Center for Transitions and Health, University of Pennsylvania, School of Nursing

  Transitional care is distinguished from case management in that it refers to the range of time-limited services and environments that are designed to ensure healthcare continuity and avoid preventable poor outcomes among at-risk populations as they move from one level of care to another, among multiple healthcare team members, and across settings such as hospitals to homes. A majority of published studies on transitional care focus on chronically ill older adults. Effective transitional care models tend to extend from the hospital to home; offer multiple, customizable solutions; and rely on a team (including the patient and often caregivers) with nurses as the hub or coordinators. In addition, 9 out of 21 studies reported that transitional care has a positive impact on health outcomes and reduces preventable rehospitalizations. Dr. Naylor listed unanswered questions that, if answered, could build upon the existing evidence.

- **Measuring Patient-Centered Outcomes**, Sara J. Singer, PhD, MBA, Assistant Professor, Harvard University, School of Public Health, and Erin Rand-Giovannetti, PhD, MPH, Research Scientist, National Committee for Quality Assurance

  Dr. Singer presented an overview of the process through which a survey question becomes a measure. The first step of the survey-development process is to identify unanswered questions through literature scan and stakeholder discussions. The next step is to organize these unanswered questions into measurable components that form a framework. Each piece of the framework should be comprehensive and mutually exclusive. To develop specific surveys to measure unanswered questions, researchers will

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10 Available at pcori.org/assets/2013/07/PCORI-Transitional-Care-Workgroup-PPT-071213.pdf
borrow or construct new question items that address the framework. These questions must be attributable and actionable, thereby allowing providers to learn and improve. Before using a survey, researchers must test the questions to ensure that survey recipients will understand the intended meaning of the questions. This is typically done through a pilot test, during which the survey is administered to a small group of patients. The process of testing, refining, and using the survey will repeat.

Dr. Rand-Giovannetti reviewed important considerations in measure development, including the health of the population, whether measures are important to an individual, and whether the outcome will lead to increased well-being for individuals. In addition, the measure results must be scientifically sound. This means that measure results are repeatable (reliable) and correct (valid). Lastly, the population must be able to provide the information being measured (feasibility), and the information gathered should be usable and worth the cost of measurement (usability).

### Participant Perspectives on Information Gaps

After the presentations, the workgroup participants provided their perspectives on research and information gaps. These perspectives are summarized below (also see Table 2 for a detailed list of questions).

- The components of an effective transitional care program remain unclear. It is also important to better understand the level of care-transition assistance needed for different types of patients, with respect to both demographics and complexity of conditions.

- There is a need to better understand the most effective mechanisms of communication between stakeholders, including the role of health information technology interventions. For example, existing information systems often make it difficult for primary care providers to access transitional care recommendations and discharge summaries from the hospital. There is also a need to improve communication between providers and patients after discharge.

- Patient representatives suggested that for transitional care programs to be effective, they must take into account the patient’s lifestyle and circumstances before the medical episode and the resources available to him or her after the episode. Primary care providers are not necessarily aware of all of the community services that may be available.

- It will be important to determine the optimal composition of a transitional care team for patients with varying levels of need. Transitional care requires an interdisciplinary team, which may include family or paid caregivers, community services, pharmacists, hospitalists, specialists, and primary care providers. Research is also needed to understand the characteristics of effective teams and how to get teams to work together most effectively and efficiently.

- There is a need to understand how to best educate and empower patients and caregivers and how to make transitional care patient-centered.
- It is critical to link hospitals’ efforts to reduce readmissions to the development and improvement of transitional care programs. In many cases, these efforts only exist in silos.

- There remains a need to determine how best to scale models for transitional care programs for which there is evidence of effectiveness. We also need to study strategies for enabling stakeholders to understand the evidence base. Most large studies of transitional care focus on 30-day readmissions. Additional evaluation metrics for transitional care programs are evolving and require further research and refinement.

Next Steps

A number of national studies and local trials across the country are evaluating different models of transitional care. Building on large-scale research programs with new research has the potential to develop a broad base of evidence in the short term that may guide clinical decision making and the successful widespread adoption of transitional care programs. This supplementary research should include a specific focus on outcomes that matter to patients and caregivers, as well as an assessment of the facilitators and barriers to successful adoption of transitional care models. To guide this research, workgroup members recommended questions to ask all key stakeholders involved in or impacted by the implementation of transitional care programs (Table 1, page 6) and formulated potential research questions (Table 2, page 8).
# Table 1: Survey Questions Posed by Stakeholder Groups

<table>
<thead>
<tr>
<th>Stakeholder</th>
<th>Prioritized Survey Questions</th>
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| **Patient** | - Did your transitional care program actively involve you on the team? Provide you with 24/7 access? Link you with community support? Focus on your goals? Provide comprehensive attention to all your needs?  
  - Did you know who to call?  
  - How confident were you about doing what you needed to do?  
  - How well would you rate your understanding of your health issues?  
  - Did the program increase your stress? Increase your satisfaction? Give you a sense of continuity in care? Improve your ability to function? Meet your personal goals?  
  - Are you able to access and impact electronic health records to the same extent as the care team? |
| **Caregiver** | - What is your role as a caregiver? Did you have the opportunity to play the role you preferred?  
  - What effect did transitional care program have on your out-of-pocket costs? On your time available for work or other pursuits?  
  - What effect did the program have on your stress level? Health?  
  - Did you have the information you needed to help your family member be successful when he or she went home?  
  - Did the nurse care manager understand the patient’s functional culture? Role for family members?  
  - Did you have peer support? Are you connected with peers? |
| **Home health agency (including community services)** | - Is your level of training adequate for the role you are playing?  
  - Who pays?  
  - If you were involved earlier, how would that have affected patient outcomes?  
  - Did you get the information you needed in a timely way to take care of the patient?  
  - Did your action as a home health agency prevent readmission within the first [time period]?  
  - What gaps did you see in the transition process?  
  - To whom do you presenting their findings? Patient? Caregiver? Someone else?  
  - Was the home health agency given time or access to the patients to present all options for caregiving services even those not typically covered under insurance? |
| **Pharmacist** | - How good was the communication with the rest of the team?  
  - How good was access to hospital records and treatment goals?  
  - At what site did you provide services?  
  - What would be good metrics for pharmacist performance?  
  - How were you paid for your services?  
  - How did the program impact the process for medication reconciliation? |
| **RN case manager** | - Did the transitional care team work as one?  
  - What are your credentials?  
  - Did you consider bringing on a pharmacist to be part of the team? |
| **IT manager** | - Were information-exchange capabilities adequate?  
  - Were the appropriate technologies available? |
| **Hospitalist** | - How would you describe various characteristics related to functioning of the transitional care team?  
  - What were the effects of the transitional care program on hospitalist workflow?  
  - How did the program impact interaction with primary care providers?  
  - Do you participate in structured, interdisciplinary bedside rounds?  
  - Did you consider bringing on a pharmacist to be part of the team? |
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<tr>
<th>Primary care provider</th>
<th>How would you describe your sense of inclusion on the transitional care team?</th>
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<tbody>
<tr>
<td></td>
<td>How would you rate your confidence that the team would fulfill its role?</td>
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<td></td>
<td>Do you have adequate information about care, communication, and equipment?</td>
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<td>Are you equipped to do what you need to do?</td>
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<td></td>
<td>Who pays for your time required for transitional care?</td>
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<td></td>
<td>How much time does it take?</td>
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<td>What do your patients think about transitional care?</td>
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<td></td>
<td>How satisfied are you with the transitional care program?</td>
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<td>What does it do for your sense of efficiency?</td>
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<td>Were you notified your patient was admitted into a hospital? Were you notified when your patient was discharged?</td>
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<td></td>
<td>Did you consider bringing on a pharmacist to be part of the team?</td>
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<td>Hospital</td>
<td>Does the transitional care program begin in the hospital, including privacy review, dietician assessment, etc.?</td>
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<td>What is the effect of the transitional care program on communications with providers (primary care providers, hospitalists, home health agency, etc.) and the community? What about purchasers?</td>
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<td>Purchasers</td>
<td>What outcomes would the transitional care program have to achieve for you to pay for it?</td>
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<td></td>
<td>What are your considerations for making decisions about providers?</td>
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<td>Payer</td>
<td>What approaches are you currently taking to reduce readmissions and utilization cost?</td>
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<td>Do you know how to find providers that are working on transitional care?</td>
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<td>How often were you asked to provide transitional care?</td>
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<td>All</td>
<td>What IT tools helped you? Hindered you?</td>
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<tr>
<td>Topic Area</td>
<td>Questions</td>
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| Components of an effective transitional care program | ▪ What are the best structures and designs for transitional care programs?  
▪ How much care transition assistance do different types of patients need? How can we deliver the right amount of support?  
▪ What are the logistics of the transitional care program? Will the family caregiver be the main decision maker?  
▪ How comprehensive is the transitional care program? Should it provide information about community services, use of medical equipment, medication information, etc.?  
▪ Should the transitional care program offer any supportive services? Who offers supportive services?  
▪ How would e-prescribing help with compliance and knowledge?  
▪ Could personal health devices be beneficial and show true incentives and impact in the way patients do exercise?  
▪ What are the best approaches to connect transitional care with community care and to facilitate collaboration and coordination with health care professionals and the family caregiver?  
▪ What program components are of the highest value?  
▪ What are the interventions in transitional care that have influence on patient outcomes? |
| Effective mechanisms of communication between stakeholders | ▪ What information needs to be sent and to whom? What is the best way to send it?  
▪ How do patients receive relevant information? Will the information be online? Presented in person? Both?  
▪ What information is usable? How do we get people to use it?  
▪ Can a patient portal that is also accessible by caregivers/family members help facilitate communication and provide a source of additional information on discharge information?  
▪ Would measurement of patient follow-up be useful? Should this be included in Meaningful Use stage 3?  
▪ What are the elements of successful public reporting of information for deciding among providers? |
| Patients’ circumstances | ▪ Does the transitional care program take into account recent conditions of the patient other than the hospitalized conditions?  
▪ How confident is the patient that he or she can implement a transitional care program when they go home? |
| Transitional care team | ▪ Who is on the team? When is the team necessary? How can it be continuous and flexible?  
▪ Who is primarily responsible for facilitating transitions of care at each patient encounter with the health care professional?  
▪ How do you measure team function? How do you measure team cohesiveness (e.g., transitioning a patient from inpatient to outpatient)? |
| Patient education and empowerment | ▪ What are the best strategies to enable stakeholders to understand the evidence base?  
▪ What is the patient’s understanding of the transitional care program?  
▪ How do you keep patients from feeling lost? |
| Integration of transitional care programs and other programs to reduce readmissions | ▪ How do we facilitate or promote collaboration of teams within the hospital?  
▪ How can we ensure that hospital teams addressing readmissions make use of appropriate patient information? |
| Evaluation and scalability | • As we compare models of transitional care, which ones are the best?  
• What are the best metrics to evaluate transitional care programs? Financial? Dollars saved? Quality of life? Patient satisfaction?  
• What are the patient risk factors that suggest need for a transitional care program? Is it based on social support? Complexity of diseases?  
• How do you demonstrate good execution of transitional care programs? |
| --- | --- |
| Other | • Can we compare ways in which electronic medical records can be useful? What makes them useful?  
• What are the elements of successful decision making by patients?  
• What are the unintended consequences of transitional care programs? |