Engaging Family Caregivers as Partners in Transitions

TC–QuIC: A Quality Improvement Collaborative

CAROL LEVINE
DEBORAH E. HALPER
JENNIFER L. RUTBERG
DAVID A. GOULD
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CAROL LEVINE
Director, Families and Health Care Project

DEBORAH E. HALPER
Vice President, Education and Program Initiatives

JENNIFER L. RUTBERG
Senior Program Manager, Families and Health Care Project

DAVID A. GOULD
Senior Vice President for Program
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ISBN 1-933881-34-8
Free electronic copies of this report are available at
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Acknowledgments

TC–QuIC was a major undertaking involving the efforts of a strong leadership team, expert faculty, and the able support of United Hospital Fund program staff. A complete list appears on page 4.

This collaborative is a direct outgrowth of Next Step in Care, United Hospital Fund’s campaign to change practice so that family caregivers are routinely involved in planning, decision making, and coordinating care, particularly related to transitions from one care setting to another.

The Next Step in Care website, www.nextstepincare.org, offers field-tested guides and checklists—in English, Spanish, Chinese, and Russian—that are simple, accurate, and task-oriented. Topics include medication management, assessing one’s needs as a caregiver, and planning for discharge. The campaign’s efforts also include outreach to organizations that directly serve family caregivers.

Funds to support the development of the Next Step in Care campaign were provided by Aetna Foundation, The Altman Foundation, The Bloomingdale’s Fund of the Macy’s Foundation, The Margaret A. Cargill Foundation, The Ira W. DeCamp Foundation, Eisenberg Family Trust, The Jacob and Valeria Langeloth Foundation, Milbank Foundation for Rehabilitation, The New York Community Trust, and TD Charitable Foundation, as well as the United Hospital Fund.
Foreword

Engaging Family Caregivers as Partners in Transitions is both the title of this new United Hospital Fund Special Report and the organizing theme of the Fund's pioneering work with family caregivers since the mid-1990s. Our efforts have included primary research into who family caregivers are and what they do; analysis of and recommendations to improve the public policies and professional practices that constitute the context in which care is provided; and a series of Fund-grant-supported programs to stimulate and guide fundamental changes in how health care providers work with family caregivers. That work has yielded a rich and varied suite of products, all found on the Fund's websites, www.uhfny.org and www.nextstepincare.org.

This report focuses on a major three-year initiative, the Transitions in Care–Quality Improvement Collaborative. TC–QuIC, as it is known, brought together 45 teams from a variety of health care providers—hospitals, nursing home rehab centers, home care agencies, and hospices—to learn from an expert faculty, proven quality improvement tools and techniques, and their own colleagues and peers. The goal: to take on the challenge of examining how chronically ill patients are transitioned from one care setting to the next, and how that transition could be improved by systematically involving family caregivers and arming them with better information, training, and support.

Making change is difficult, especially in the frenetic pace of today's health care, and TC–QuIC was appropriately demanding. Participants had to critically examine individual and institutional processes and candidly assess how they related to both other providers and family caregivers. But by working in multi-disciplinary teams—with the support of each organization's senior leaders and TC–QuIC's faculty—team members made significant gains in identifying and assessing family caregiver strengths and needs, engaging them in critical processes such as medication reconciliation and discharge planning, and supporting them with essential training in complex caregiving tasks.

These activities and accomplishments are explored in this report, with numerous specific examples that should prove helpful to providers interested in making positive change. (Recognizing the length and depth of the full report we have also prepared a brief overview, available online at www.uhfny.org.) Those experiences—the real experiences of more than 200 health care professionals who participated in TC–QuIC—speak to the importance of forging effective partnerships with family caregivers, and show that with a great deal of hard work, punctuated by real gains as well as disappointing setbacks, much can be accomplished.

JAMES R. TALLON, JR.
President
United Hospital Fund
Executive Summary

What does it take to improve transitions in care for seriously or chronically ill persons? If there were a simple answer to that question, we would know it by now. Over the past two decades many different programs have been tested, with varying levels of success. What has been largely missing in all the efforts has been the active engagement and involvement of family caregivers, broadly defined, who are de facto care coordinators and are often responsible for performing complex medical/nursing tasks at home.

Building on 15 years of efforts to develop strong working partnerships between health care providers and family caregivers, the United Hospital Fund’s Transitions in Care–Quality Improvement Collaborative, or TC–QuIC, identified and tested ways to fill that gap.

Over nearly three years, more than 200 nurses, social workers, physicians, case managers, quality improvement specialists, and other health care professionals—from hospitals, home care agencies, nursing home rehab programs, and hospices—worked in 45 teams participating in one or both of two rounds of TC–QuIC (see page 5). Their experiences can guide other organizations embarking on a similar path. This summary provides a brief overview of TC–QuIC. A detailed look at what participants did, what they learned in the process, and the impact of their efforts is in the following pages’ full report.

The Basic Elements

TC–QuIC was not designed to create yet another transitional care model, but rather to move health care providers beyond a sole focus on the patient to look at family caregiver strengths, needs, and limitations in the transition process. What TC–QuIC ultimately demonstrated is that integrating family caregivers into the transition process is first and foremost a kind of paradigm shift—meaningful change that starts with recognition of the need, buy-in from all involved, and a concerted effort to transform both organizational attitudes and longstanding practices.

The collaborative adopted the Institute for Healthcare Improvement’s Model for Improvement—and its rapid-cycle Plan-Do-Study-Act process—as a framework for testing and measuring change. In this “ground up” approach, teams of front-line workers identify problems, develop small tests of change, analyze results, modify their tests, and try either a broader application or a new approach. The goal is to find the best ways to make sustainable improvements in real-world settings. Team members can be acutely sensitive to local circumstances, flexible in devising solutions, and able to introduce changes quickly. However, this model requires high levels of teamwork, creativity, and persistence.
Engaging Family Caregivers as Partners in Transitions

TC-QuIC’s overarching goal was to improve transition processes and outcomes by including family caregivers in decision making, and providing them with relevant information, preparation, and training. The foundation of that broad goal—and an essential basis for all further work—was early identification of family caregivers, allowing timely self-assessment of their needs for training and support.

Specific strategies to achieve that goal were:

- Inclusion of the family caregiver in medication reconciliation;
- Identification of post-discharge patient needs and discussion of patient discharge options with the family caregiver;
- Discharge preparedness (training, expectations of the day of discharge);
- A well-orchestrated day of discharge;
- Closing the loop, including post-discharge communication with the family caregiver and the receiving agency.

In addition, several Round Two teams focused on advance care planning.

A comprehensive set of materials and resources—the “change package”—began with the Fund’s Next Step in Care guides for family caregivers and providers, and added scripts and other resources, some from other transition programs. These materials are available at www.nextstepincare.org/Provider_Home/#Toolkit. Supplementing these materials were activities including webinars—33 in Round One and 16 in Round Two—and call-in sessions, faculty coaching calls, and site visits. Four all-day Learning Sessions in each round, each for roughly 100 team members, included team presentations, single-topic education, skill building on conveying teams’ stories and work to senior management, and—most highly rated by participants—“Voice of the Caregiver,” bringing the personal experiences of caregivers to team members (see box, p. 11). Teams were also expected to submit monthly data reports on measures chosen to monitor effects of the changes they made. All these activities reinforced TC-QuIC’s goal and provided support as teams moved forward.


Before a change in transition planning is introduced, it is important to step back and review the process already in place. This essential preparation was time well spent.

Teams examined current practices and policies, using techniques such as staff and caregiver surveys, transition mapping, and chart audits. This period of team building and data gathering allowed teams to understand what was actually happening in their institutions, before attempting to develop or implement any changes. It also improved communication within each team—before the teams began to change the way they communicated with family caregivers.
Through this prep work, teams uncovered many surprises and false assumptions about how their organization’s discharge process worked, who was responsible for training family caregivers, when discussions about discharge took place, and even what information was or should be communicated. They also learned that family caregivers did not hear or understand all instructions. Giving information is not the same as communicating, they discovered.

What Was Accomplished?
Success can be defined in many ways. TC–QuIC was not designed to reduce hospital readmissions, although several teams—usually working in tandem with other projects in their organizations—measured that outcome and reported improvements. Nor was it designed to reduce costs, although the more efficient practices and more productive use of staff time that new processes involved might well serve that goal. The primary measures of success focused on the level and quality of family caregiver involvement, and staff satisfaction with the new processes.

Over the course of TC–QuIC, more than 2,200 family caregivers were identified and engaged in tests of new processes, described in the full report. Some of the resulting “numbers”:

- Family caregivers whose needs were assessed: 897
- Family caregivers involved in medication reconciliation: 634
- Decrease in the average number of days from admission to medication reconciliation: down to 1.2 from 2.7
- Average number of discrepancies found when family caregivers were involved in medication reconciliation: 3.6
- Family caregivers given education and training prior to discharge: 335
- Satisfaction of family caregivers surveyed post-discharge following interventions, on a scale of 0 to 10: 9.5

Teams reported better communication with and involvement of family caregivers in all aspects of care transitions, including medication reconciliation and management, discharge planning, and post-discharge care. Participants also noted better teamwork and increased confidence among staff in identifying, educating, and working with family caregivers.

Beyond specific project outcomes, teams reported an expansion of organizational capacity to work with family caregivers, and a heightened awareness of caregivers’ potential role and impact in improving care transitions. Some teams described the effects of TC–QuIC as an organizational “culture shift.”
What Participants Learned

TC–QuIC was a process of learning as a group, more than the sum of individual participants’ experiences. Some of its lessons were broad, others very specific. Following is a sampling of what was learned.

Getting Started

• Prep work is essential—reviewing, mapping, and outlining how transitions actually happen currently will reveal misunderstandings, confusions, differences of opinion, and gaps in current processes.
• Both staff and family caregiver experience must be obtained and compared.
• Senior leadership must be engaged at the start.

Working with Family Caregivers

• Identify the appropriate family caregiver(s):
  >Before TC–QuIC, none of the participating organizations had a systematic way of finding out who was, for example, going to help the patient with medications or arrange for follow-up visits.
  >This information is vital and must be entered into the EMR or other patient record so that staff on different shifts or from different departments can access it.
• Talk to family caregivers about their own needs, capabilities, and limitations:
  >This is a caregiver self-assessment, not a professional judgment.
  >It is separate from the patient assessment.
• Use input from family caregivers to plan for discharge:
  >Provide information about options.
  >A realistic discharge plan is grounded in what caregivers report they can do.
• Provide training and education, especially related to medication management and follow-up care:
  >This will differ from patient education—direct it to the specific family caregiver’s needs and capacity.
  >Help family caregivers with follow-up appointments and information, connecting them to primary care and community resources, and find out from the receiving agency how the transition went from its perspective.
Making Institutional Change

- Improving transitions in care by involving family caregivers is a team effort that takes time, effort, and senior leadership support.
- Within the team there must be clear responsibility and accountability.
- Sustained quality improvement efforts require expertise in data collection and analysis.
- Partnerships between sending and receiving organizations need to be strengthened.
- Improving transitions requires an organizational culture that recognizes the value and needs of family caregivers and works with them as part of the care team.

The TC–QuIC Experience: Impressions and Impact

Qualitative evaluations of TC–QuIC after each round identified strengths and weaknesses. While Round One participants generally viewed the experience as positive, changes made in response to their evaluations contributed to even more favorable perceptions of Round Two.

What did team members take away from the experience?

Some participants noted a number of barriers, including getting physician buy-in and dealing with frequent house staff turnover, the need for additional training and support on data collection and analysis, sustaining the pace of efforts in the context of already hectic work days, and maintaining momentum after TC–QuIC ended.

But, beyond the specific accomplishments noted earlier, a sampling of enthusiastic comments is equally revealing:
- “Considering the results we were able to accomplish, the time and effort we devoted… was well worth it,” earning an average rating, on a scale of 0 to 10, of 9.4.
- “TC–QuIC was cutting-edge in the range of care transitions included, in its focus on the family caregiver and how to involve [them] as care team members.”
- “[The collaborative] gave us tools, a structure, and a framework for improvement”—including “…using data to see the impact of improvement….”
- “TC–QuIC helped us identify issues and barriers we faced in our discharge process and gave us credible tools so that we could address barriers and improve our process.”

And, perhaps the collaborative’s greatest lesson:
- “[This] gave us the voice of the caregiver” and ”gave us the family caregiver’s perspective for the first time.”
Looking Back before Moving Forward: A Prologue

On June 29, 2012, about 100 doctors, nurses, social workers, case managers, and other health professionals gathered for the final Learning Session of Round Two of the United Hospital Fund’s Transitions in Care—Quality Improvement Collaborative (TC–QuIC). Seated around team tables, participants listened to a panel of senior leaders talk about what they had learned from their organizations’ participation in TC–QuIC. Other items on the agenda were reports on project outcomes, “Team Talk” about key areas such as advance care planning and identifying and assessing family caregivers, and developing plans for sustaining and spreading improvements. After lunch, Alix Kates Shulman, a novelist and the author of the memoir To Love What Is, transfixed the group with her presentation about the realities of being a caregiver to a husband with dementia and traumatic brain injury.

As a concluding exercise, United Hospital Fund staff asked each person to reflect on his or her personal experiences during the collaborative and to fill in the blanks on two questions. Participants then read their responses aloud, their voices reflecting the emotional impact of thinking about TC–QuIC in this unexpected way.

Here are the questions and a sampling of the responses:

If I were a family caregiver, I would want health care professionals to:

- Keep me informed
- Tell me the truth about diagnosis and treatment options
- Be more patient and compassionate
- Listen to what I need, feel, want
- Respond to phone calls in a timely fashion
- Give me information in language I can understand
- Treat me with respect
- Understand my culture and family background

I did not realize that family caregivers:

- Have such a high level of responsibility
- Are fearful and anxious
- Are often left out of transitions
- Feel that they need more information
- Get so little acknowledgment from medical staff
- Have so few resources to call upon
- Might be intimidated by medical terminology
- Are taken for granted
- May displace their fear in anger and noncompliance or keeping silent

These heartfelt reflections are in their own way as important as run charts, outcome measures, and other indicators that will be described and discussed in the body of this report, for they speak to the human element that is an essential of practice change to improve care transitions for patients, families, and providers alike.
Introduction

In 1998 the United Hospital Fund (the Fund) published its first report on family caregiving. Its title, *Rough Crossings: Family Caregivers’ Odysseys through the Health Care System*, foreshadowed today’s emphasis on transitional care, although that term was still unfamiliar to most health care professionals and certainly to patients and families.\(^1\) Fifteen years later, transitions—often called handoffs or, in the European vernacular, handovers—are now the focus of significant policy and program initiatives. But the family caregiver’s role in improving quality and outcomes during transitions from one provider to another is still largely outside the primary focus of policymakers and practitioners.

Reducing preventable hospital readmissions and their associated financial penalties has simultaneously taken center stage. While this is only one aspect of the Fund’s concern about transitions, it, too, was a catalyst for developing and implementing the Transitions in Care–Quality Improvement Collaborative (TC–QuIC)—a unique effort to stimulate partnerships, across settings, among health care providers working with family caregivers of chronically ill or disabled persons, in order to improve transitions. TC–QuIC placed family caregivers at the center of transitions, as they are in reality.

Background

The statistics are well known and disturbing. Transitions in care for people with chronic illnesses, especially older adults, are frequent, costly, and risky. Nearly one in five Medicare patients admitted to a hospital is readmitted within 30 days of discharge. If the patient has heart failure, the chances are even higher—one in four—that he or she will be readmitted in that time frame. Jencks et al. estimate that in 2004 unplanned hospitalizations cost Medicare $17.4 billion.\(^2\) Hospital readmissions are expensive, often result in longer stays than the original admission, and lead to poor clinical and functional outcomes, not to mention additional stress on the patient and family.\(^3\)

Although some readmissions are planned and others are unavoidable, in 2007 the Medicare Payment Advisory Commission (MedPac) estimated that up to three-quarters of rehospitalizations may be preventable.\(^4\) Many rehospitalizations are the result of inadequate discharge planning, rushed communications resulting in medication and other errors, and failures to coordinate care with primary care providers or others responsible for the patient after hospital discharge. Even when inadequate hospital discharges do not result in 30-day readmissions, they may be missed opportunities for preventing problems with patient care and readmissions within a few months.
While improving safety and quality are certainly driving some of the current concern, the immediate impetus is financial: in October 2012 Medicare began to penalize hospitals that have high rates of readmission for three common conditions—heart attack, heart failure, and pneumonia. Other conditions will be added to the list. Hospitals with high rates of Medicare readmissions could eventually lose 3 percent of their regular Medicare payments, a severe blow to those already struggling financially.

There are positive incentives as well. The Affordable Care Act (ACA) encourages care coordination through bundled payments, the formation of accountable care organizations, and the $500 million Community-Based Care Transitions Program, which links community-based agencies and hospitals to improve transitions. The $500 million Partnership for Patients (PFP)—a public/private effort working at federal, state, and regional levels—focuses on reducing hospital-associated infections and improving care transitions to reduce hospital readmissions.

**Transition Strategies to Date**

The most widely used strategy to reduce preventable hospital readmissions has been some form of transitional care services. Naylor and colleagues reviewed 21 randomized controlled trials of transitional care interventions targeting chronically ill adults. While there were differences, most relied on a trained professional (typically a nurse, often an advanced practice nurse) to act as a navigator or coach to assist the patient through the hospital discharge to home, or less frequently to a skilled nursing facility rehab program. The navigator follows up at home, for periods of a few days or weeks to a month or more, helping the patient review medications, recognize warning signs, and make appointments for physician visits.5

Coaching the patient to manage his or her illness is the focus of all these efforts. However, as the Institute for Healthcare Improvement points out in its 2011 guide on improving transitions in care, one of the typical failures in transition education is “assuming that the patient is the key learner.”6 For patients with serious or chronic illnesses, particularly those who are elderly or have cognitive deficits, the key learner is likely to be the family caregiver—the relative, partner, friend, or neighbor who is responsible for providing or managing post-discharge care. Yet none of the interventions reviewed by Naylor and her colleagues specifically addresses the needs of the family caregiver during transitions. In fact, the authors note, “The most pressing needs [for future research] include standard, precisely specified measures that address patients’ and family caregivers’ experiences…. Because of the critical role of family members in the delivery of transitional care and the unique challenges faced in assuming this role, dedicated investments should be made to prepare and support informal
The United Hospital Fund was responsible for overall management of TC–QuIC. Three co-chairs participated in planning and implementation:

- David Cohen, MD, MSc, executive vice president for clinical and academic development, Maimonides Medical Center
- Audrey S. Weiner, DSW, MPH, president and chief executive officer, Jewish Home Lifecare System
- Carol Levine, director of the Fund’s Families and Health Care Project

The collaborative’s co-directors were Fund staff members Deborah Halper, vice president for education and program initiatives, and Jennifer Rutberg, senior project manager, Families and Health Care Project.

TC–QuIC faculty members and team coaches included Regina Neal, then with the Primary Care Development Corporation, New York City; Amanda Norton, data measurement expert; Ann Wyatt, nursing home specialist; and Carol Rodat, New York State director of PHI (Paraprofessional Healthcare Institute). Kristina Ramos-Callan, program associate with the Fund, also participated in TC–QuIC development, coached teams, and coordinated many TC–QuIC activities.

Lisa Payne Simon, a program evaluation consultant, conducted an overall assessment of both rounds of the collaborative.
PARTICIPATING TEAMS

After a six-month development phase that included teams from several organizations, two rounds of TC–QuIC took place, from March 2010 through June 2011, and from June 2011 through June 2012. All hospitals and most nursing home rehab programs and home care agencies in the New York City area were invited to submit applications, including a signoff by senior leadership. The Fund did not provide any financial support for team participation but, unlike some other collaboratives, did not charge a participation fee.

Round One of TC–QuIC included 26 organizations, or units within organizations, working in partnerships (cross-organizational teams) or on their own to improve the involvement, support, and training of family caregivers during care transitions. Round Two participants included 19 organizations or organizational units. Two partnerships—four teams—focused on expanding advance care planning, documentation, and use of advance directives; these were not part of the original design but were added at the teams’ requests.

At its conclusion, more than 200 team members—nurses, social workers, physicians, case managers, quality improvement specialists, and others—had directly participated in the collaborative, under the guidance of an expert faculty; other staff contributed to the work at participating organizations’ sites.

### Round One
March 2010-June 2011

**Hospitals**
- Beth Israel Medical Center (Continuum Health Partners)
- Coney Island Hospital (New York City Health and Hospitals Corporation [HHC])
- Franklin Hospital (North Shore-LIJ Health System)
- Lutheran Medical Center
- Maimonides Medical Center
- Metropolitan Hospital Center (HHC)
- Montefiore Medical Center
- New York Hospital Queens (NewYork-Presbyterian Healthcare System)
- The Allen Hospital of NewYork-Presbyterian
- NYU Langone Medical Center

**Nursing Homes/Rehabilitation Centers**
- Cobble Hill Health Center
- Isabella Geriatric Center
- Jewish Home Lifecare-Bronx Division
- Jewish Home Lifecare-Manhattan Division
- Lutheran-Augustana Skilled Nursing Facility
- Orzac Center for Extended Care
- Saints Joachim and Anne Nursing and Rehabilitation Center

**Home Care/Hospice Agencies**
- Extended Home Care
- First to Care
- HHHC Health & Home Care
- North Shore-LIJ Home Care Network
- North Shore-LIJ Hospice Network
- Visiting Nurse Service of New York (four teams)

### Round Two
June 2011-June 2012

**Hospitals**
- Beth Israel Medical Center (Continuum)
- St. Luke’s-Roosevelt Hospital Center (Continuum)
- Metropolitan Hospital (HHC)
- Kings County Hospital Center (HHC)
- New York Methodist Hospital (NewYork-Presbyterian)
- The Brooklyn Hospital Center (NewYork-Presbyterian)
- St. Barnabas Hospital Care Center

**Nursing Homes/Rehabilitation Centers**
- Casa Promesa Residential Health Care Facility
- Center for Nursing and Rehabilitation (CenterLight)
- Cobble Hill Health Center
- Isabella Geriatric Center
- Jewish Home Lifecare
- Dr. Susan Smith McKinney Care Center (HHC)
- St. Barnabas Rehabilitation and Continuing Care Center

**Home Care/Hospice Agencies**
- Dominican Sisters Family Health Service
- HHHC Health & Home Care
- The Brooklyn Hospital Center Certified Home Care Agency (NewYork-Presbyterian)
- Visiting Nurse Service of New York
- Visiting Nurse Service of New York Hospice
Creating Change: A New Approach to Care Transitions

TC–QuIC was not designed to create yet another transitional care model. Nor was it designed specifically to prevent hospital readmissions. TC–QuIC was intended to move health care providers beyond a sole focus on the patient to look at family caregiver strengths, needs, and limitations in the transition process. It addressed transitions beyond the typical hospital-to-home scenario, including those from hospital to nursing home rehab program or hospice; within nursing homes, from short-term rehab stays to long-term stays; and from formal home care to total family care.

The collaborative’s basic premise was that improving transitional care is every professional’s responsibility. While a specially hired or designated professional is an additional resource, many organizations do not have the personnel or funds to train and support such a person; realistically, more than one person is needed to cover shifts, vacations, and patient load. These positions are vulnerable to budget cuts if the program does not show significant savings once program costs are included. Even if available, a navigator or coordinator is likely to be more effective when family caregivers are part of routine care planning and have been prepared for the post-discharge phase by other professionals. TC–QuIC thus encouraged multidisciplinary teams of nurses, doctors, social workers, pharmacists, case managers, and others to work in partnership and with other organizations with which they regularly shared patients.

TC–QuIC was also designed so that the lessons learned from it and the materials it employed can be used independently or combined with other interventions. This has already been done successfully in upstate New York through the Fund’s participation in a quality improvement collaborative organized by the Health Foundation for Western and Central New York. This collaborative used Next Step in Care materials, the basic resource for TC–QuIC, in conjunction with Eric Coleman’s Care Transitions Intervention model.

Improvement Essentials

To achieve its goal, a learning collaborative needs commitment, structure, and processes. Senior leaders need to understand the level of commitment and resources required of staff, participants need to be able to work in teams, and the sponsor needs to articulate the methods for measuring and evaluating change.
Based on Fund experience in other collaboratives, the Model for Improvement developed by Associates in Process Improvement and used by the Institute for Healthcare Improvement was selected as the TC–QuIC framework for testing and measuring change. With its rapid-cycle Plan-Do-Study-Act (PDSA) process, this is a very different model from the strict research study. In the traditional model, trained researchers develop an intervention protocol based on a hypothesis or pilot data, implement it without change, and assess the results of the intervention by comparing the test group with a control group, with the goal of developing generalizable knowledge that can then be transferred to other settings. While this kind of research is the gold standard for evidence-based practice, it is seldom immediately applicable. It has been estimated that it takes 17 years for most research findings to make their way into practice.

If a research study is “top down,” the collaborative model is “ground up.” Participants—front-line workers, not trained researchers—work in teams to identify the problem they are trying to solve, develop small tests of change, analyze the results, adapt the test, and either try a broader application or try another approach (Figure 1).

The Model for Improvement is not designed to answer big questions but to find the best ways to apply research or other findings in the real world, a much messier environment than controlled research settings. In this model participants can be acutely sensitive to local circumstances, flexible in devising solutions, and able to introduce changes that work more quickly than in a research setting. However, the model requires high levels of teamwork and persistence. The tasks include data collection and analysis, which are not part of the training or skills of many front-line practitioners. In both rounds of TC–QuIC, only a minority of team participants had previously participated in a learning collaborative or quality improvement project beyond one addressing specific clinical techniques, such as infection control. Most teams needed frequent reviews of the model and coaching on how to use it. Data collection and analysis was a new and often difficult task for many.
Prep Work

One aspect of the model proved especially important—the preparation phase, or “prep work,” that made up the first two months of Round One and three months of Round Two. During this time teams examined current practices and policies, using techniques such as staff and caregiver surveys, transition mapping, and chart audits. This period of team building and data gathering allowed teams to understand what was actually happening in their institutions, before attempting to develop or implement any changes.

In the process teams uncovered many surprises and false assumptions. For example, even team members from the same discipline (nursing, for example) had different ideas about how their organization’s discharge process worked, who was responsible for training family caregivers, when discussions about discharge took place, and even what information was or should be communicated. Some nurses believed that a family caregiver whose relative was being transferred to a rehab program did not need medication information because nursing home staff would handle medications; others thought it was important to give family caregivers this information even if they would not be managing medications on their own for several weeks.

Staff surveys were an important source of information, especially when compared with family caregiver surveys asking the same questions. For some TC–QuIC participants, the different perceptions that were revealed—about what was communicated and how—were sobering. In Round One, a majority of staff (67 percent) from all types of institutions believed that they “always or usually” told family caregivers about the expected length of stay for their family member. An even higher percentage (83 percent) said that they “always or usually” assessed family caregiver needs. Yet only 39 percent and 35 percent, respectively, of family caregivers agreed with these statements (Table 1). Staff may have indeed given family caregivers some of this information, but not in a way that those family caregivers understood and could use.

| Table 1 | Differences Between Providers’ and Caregivers’ Perceptions of Communication |
|-----------------------------------------------|------------------|-------------------|------------------|
| Question                                      | Always/Usually  | Half the Time/Never | Always/Usually  | Half the Time/Never |
| Was family caregiver given an estimate of length of stay? | 67%             | 29%               | 39%             | 47%               |
| Were family caregiver needs assessed?         | 83%             | 17%               | 35%             | 53%               |
| Was family caregiver given explicit information on when to expect discharge? | 76%             | 21%               | 43%             | 47%               |

Note: Percentages may not total to 100 because of incomplete responses and/or rounding.
COMMUNICATION SKILLS

Improving communication between health care professionals and family caregivers was a recurrent theme throughout TC–QuIC. Prep work highlighted the gap between staff perceptions of what they had communicated and how well they had done it and family caregiver understanding of the same information (Table 1).

In Round One, developing communication skills was addressed directly through a Learning Session presentation by guest speaker Richard Frankel, PhD, professor of medicine and geriatrics and a senior research scientist at the Indiana University School of Medicine’s Regenstrief Institute. Dr. Frankel’s interests include the effects of face-to-face communication on health care processes and outcomes and the use of narrative to teach ethics and professionalism to medical professionals. For his TC–QuIC presentation, he adapted his “Four Habits Approach to Effective Clinical Communication” to include family caregivers as well as patients.

### Four Habits for Effective Communication

<table>
<thead>
<tr>
<th>Habit</th>
<th>Skills</th>
</tr>
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<tbody>
<tr>
<td>1. Invest in the Beginning</td>
<td>Create rapport quickly; elicit the patient’s concerns; let the patient know what to expect</td>
</tr>
<tr>
<td>2. Elicit the Patient’s Perspective</td>
<td>Ask for patient’s ideas; determine patient’s specific request or goal; explore the impact on patient’s life</td>
</tr>
<tr>
<td>3. Demonstrate Empathy</td>
<td>Be open to the patient’s emotions; make empathetic statements; convey empathy nonverbally (pause, touch, facial expression)</td>
</tr>
<tr>
<td>4. Invest in the End</td>
<td>Deliver diagnosis in terms of original concern; explain rationale for tests and treatments; summarize visit and review next steps</td>
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**Goal, Strategies, Aims, Activities: How TC–QuIC Worked**

The Model for Improvement calls for a clear overall goal and a statement of strategies to achieve it. For TC–QuIC, those would serve, in turn, as the basis for teams’ development of specific, narrower aims for their efforts.

Based on an evaluation of Round One, TC–QuIC’s initial goal and strategies were refined for Round Two. The final goal: To improve transition processes and outcomes by including family caregivers of seriously and chronically ill patients in decision making, and by providing focused information, preparation, and training.

In an important change, one of the Round One initial strategies was designated, instead, a foundation for all TC–QuIC activities: Early identification of family caregivers and self-assessment of needs for training and support.

This fundamental principal recognizes that every strategy for improving care transitions has to begin with identifying the family caregiver. Without this step, all other strategies will fail.
Strategic Framework

Five strategies were integral to participating teams’ efforts to achieve the broad TC–QuIC goal:

1. Inclusion of family caregivers in medication reconciliation and management;
2. Identification of post-discharge patient needs and discussion of discharge options with the family caregiver;
3. Discharge preparedness (training, expectations of the day of discharge);
4. Well-orchestrated day of discharge;
5. Closing the loop (post-discharge communication with the family caregiver and the receiving agency).

Within this framework, teams used the worksheet in Figure 2 to develop specific aims—often multiple aim statements over the course of the collaborative. The variety of activities they pursued, in both rounds, to achieve those aims speaks to both the complexity of the problems they identified and their resourcefulness in devising solutions. For a complete list of projects, see the Appendix.
Change Package

The Model for Improvement uses a “change package” as the basic resource. In clinical collaboratives the change package is literally a collection of implements, drugs, and instructions to be used in a defined and consistent manner—for example, to prevent infection when inserting a catheter. For TC–QuIC and other non-clinical collaboratives, the change package is a set of online or printed resources that guide but do not direct teams through the PDSA (Plan-Do-Study-Act) cycles.

TC–QuIC’s change package included not only basic teaching materials—highlighting the Next Step in Care guides—but also scripts, suggested questions to consider, and other resources. All the materials were available through a password-protected online community (and have since been made available online to all, at http://www.nextstepincare.org/Provider_Home/#Toolkit). A team working on the strategy of including family caregivers in medication reconciliation could, for example, click on that section of the change package and find the appropriate Next Step in Care tools for both providers and family caregivers, as well as related scripts and articles. One unexpected problem: some teams were unable to utilize the online community because they did not have access to a computer or their organization limited Internet access.

Collaborative-Wide Activities

Collaborative-wide activities organized by United Hospital Fund allowed teams to discuss and share their experiences with other teams, raise questions, and gain new knowledge. Four “Learning Sessions” were held for each round; roughly 100 team members participated in each of the daylong sessions. The agendas varied but included poster sessions or other opportunities for teams to present their work; “Walking with the CEO” sessions to build the skills needed to tell a team’s story succinctly to senior leadership; single-focus sessions, on topics such as pharmacy, communication skills, conducting a family meeting for advance care planning, and strategies for spreading changes; and “Voice of the Family Caregiver,” a personal narrative, video, or other method of bringing the personal experiences of caregivers to the group.

Between Learning Sessions, the Fund also organized a series of webinars—33 in Round One and 16 in Round Two—plus six unstructured call-in sessions. Each webinar featured a specific topic and opportunities for questions and discussion; all were recorded and made available to the online community. Call-in sessions with open phone lines provided participants with the opportunity to raise issues and ask questions on a variety of topics.
In addition to these collaborative-wide activities, TC–QuIC faculty held regular coaching calls with teams and were available to assist when questions came up. Site visits to 19 participating organizations, most in partnerships, were also arranged. This report’s section on evaluation presents feedback on these activities.

As the number and variety of these learning and coaching processes attest, TC–QuIC was a labor-intensive effort for all involved—teams, Fund staff, and faculty.

What were the results?

What Was Accomplished?

This section of the report summarizes the results of both Rounds One and Two, looking at these areas of concern:

- Family Caregiver Identification
- Family Caregiver Assessment
- Family Caregiver Engagement in Medication Reconciliation
- Discharge Options and Family Caregiver Preparation
- Advance Care Planning
- Reducing Hospital Readmissions
- Closing the Loop

We present collaborative-wide data when available, discuss the challenges and outline changes that led to improvement, and/or describe activity that supported team efforts; for each area, we also highlight a team’s experience.

A note on methodology: when possible, data have been combined to summarize the shared activities of both rounds (Table 2). It is important to understand, however, that data reporting from the 45 teams that participated in Round One or Two (a few participated in both) tended to be sporadic or limited, and did not represent the entirety of each organization’s efforts.

Qualitative findings support teams’ quantitative reporting, while also adding context and results that could not be supported numerically. Identified changes are those shown to have the most impact across organizations, and therefore considered highly likely to lead to improvement.
Family Caregiver Identification

Participating organizations identified 2,201 family caregivers—1,160 over the 15 months of Round One and 1,041 during the 12 months of Round Two. These numbers include only those reported to the Fund; the actual number is probably higher.

One of the earliest lessons learned by both Fund staff and team members was that it was often difficult for teams to determine who the family caregiver was. A number of common assumptions were soon proved wrong:

- **The person at the patient’s bedside in the hospital or nursing home is the caregiver.** The person at the bedside might have no ongoing role in the patient’s care. She might be a relative from out of state, an acquaintance, a coworker, or a church visitor.

- **The “emergency contact” or “next of kin” listed on the patient record, or the health care proxy, is the caregiver.** Proximity or family relationship or legal status does not necessarily translate into caregiving responsibility. The person listed in the medical record might be a neighbor who can do errands but is not responsible for care. The health care proxy may have decision-making power if the patient is incapable but may live in another state or have no ongoing caregiving role.

- **An alert patient can decide what care family members can and will provide.** Patients may not understand or accept the level of care that they will need, and may overestimate—or underestimate—the willingness or capability of family members to provide it.
The patient who says “I have no family caregiver” or even “I have no family” is being truthful. Some patients are reluctant to involve a family member because of fears of losing independence or imposing a burden.

There is always a “primary” family caregiver. Caregiving is often shared. Discussions with the patient about specific tasks often lead to identification of, for example, one person responsible for medications and another for taking the patient to the doctor.

Erroneous assumptions like these sometimes led to confusion and push-back from teams over the task of identifying the family caregiver. One team member reported that her organization would consider it a HIPAA privacy violation even to ask a patient about family members. Another felt that the majority of her facility’s chronically ill patients had no family caregivers, although many of these patients were so obviously impaired that they could not have managed on their own before their hospitalizations.

Changes Leading to Improvement

Improvement in identification of the family caregiver was achieved through a variety of changes. Among the most successful:

- Modification of an organization’s paper and/or electronic medical record (EMR) to:
  - Include and in some cases require a more specific field for the identification of the family caregiver, the caregiver’s relationship to the patient, and the appropriate contact information;
  - Identify more than one family caregiver;
  - Identify the purpose/role in caregiving performed by the identified caregiver;
  - Eliminate automatic carry-over of family caregiver information, requiring staff to ask—each time a patient returned to a facility—who the family caregiver was, to ensure that changes in caregiver status were documented;

**TEAM HIGHLIGHT**

**FAMILY CAREGIVER IDENTIFICATION**

New York Methodist Hospital

**Problem:** New York Methodist Hospital’s prep work showed that the hospital was not consistently identifying the appropriate family caregivers of cardiac patients, which reduced the effectiveness of both education and care planning.

**Cause:** Role confusion. Clarification was needed on who holds responsibility for identifying the family caregiver. Was it the nurse? The case manager?

**Change:** Methodist altered its EMR to include caregiver identification in the initial nursing assessment, and to have it doubled-checked by the case manager with an EMR field for “Family Caregiver Validation” as part of the Discharge Planning Assessment.

**Outcome:** By the end of the collaborative, 90 percent of all initial nurse assessments identified a family caregiver, and 89 percent of those initially identified caregivers were validated by the case manager.

**Keys to Success:** Strong prep work identifying the problem; team consensus on an approach to test; ability of staff to add/change fields within the EMR on demand.

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Strong prep work identifying the problem; team consensus on an approach to test; ability of staff to add/change fields within the EMR on demand.
• Process improvements so that family caregivers were identified earlier in a care episode, during the initial nursing assessment or during the initial case management/social work assessment;
• Altering staff protocol so that all adult patients, regardless of diagnosis or age, were asked if they had a family caregiver.

Key Qualitative Findings
Once organizations realized that they were misidentifying or failing to identify family caregivers, they learned that identification based on a specific role was most effective. As they began asking patients more precise questions—“Who is the person who helps you with your medications at home?” “Who is the person who helps you get to your medical appointments?”—“invisible” family caregivers came clearly into focus. This was an important change. As one participant later reported, “Identifying the family caregiver is now a major factor in all our patient-centered initiatives.”

Round Two organizations were much more successful at establishing systems for caregiver identification than those in Round One, because this was now a foundation piece that had to be accomplished, during prep work, before participants could move on. Often the greatest barrier to making improvement was the need to implement system-level change. Although many organizations could test small changes, prove their impact, and create solid plans for integrating the change into standard practice, changes to EMRs or organizational policy require that organizations invest both time and resources. This kind of move from testing to implementation was, at times, quite difficult for organizations. But this step is, of course, essential for sustaining and spreading improvements.

Family Caregiver Assessment
The number of family caregivers whose needs were assessed increased markedly as TC–QuIC progressed, from 356 during the 15 months of Round One to 541 in just the 12 months of Round Two—an increase of some 21 percentage points (Table 2). Despite this improvement, however, many of the family caregivers who were identified in Round Two still did not have their needs assessed. Just why that was the case is explored below.

Redefining the Assessment
Although widely used in community-based and publicly funded social service settings to establish eligibility and make referrals to support services, formal caregiver needs assessments are new to most health care settings. Where they are done they tend to be infrequent, informal, and incomplete. They are often focused solely on caregiver burden or psychosocial issues, rather than on the need for training and support to manage complex tasks. Asking families to complete a self-assessment raised concerns and red flags that became barriers to improvement.
Assessments are also typically based on the professional’s—not the caregiver’s—perspective. And the results may not be shared with others involved in the case. In Round One, for example, the team from Orzac Center for Nursing and Rehabilitation learned that, when family caregivers were included in physical therapy sessions, staff were facilitating caregivers’ self-assessment of needs related to availability, feasibility of providing physical care, education, and overall concerns about caregiving over the long term. But that information was not being shared with other departments. Once nursing and social work staff became aware of it, they were able to integrate it into their own caregiver needs assessments.

To address these problems, the change package and Learning Sessions defined the purpose of the family caregiver assessment as giving family caregivers an opportunity to identify their own caregiving needs. This nuanced approach to assessment became the foundation of all of TC-QuIC’s work, directly challenging providers to reconsider the way in which family caregivers were engaged in the provision of care.

This subtly different approach also clarified what the family caregiver assessment may disclose, and the limitations of information-gathering without a careful assessment process. The self-assessment may, for example, reveal problems in the home setting, or issues such as health conditions that limit the caregiver’s availability or capability, any of which will complicate a planned discharge. Information from patients about the help they receive at home, and who provides it, often understates their needs because they do not want to appear dependent. And both patients and family caregivers may assume that, once home, life can go back to normal without additional help. As a result, caregivers are unprepared for the tasks expected of them. Without a discussion of specific tasks, caregivers are likely to respond in general terms, rather than identifying particular needs.
Grappling with Barriers
The primary instrument for caregiver self-assessment was the Next Step in Care guide *What Do I Need as a Family Caregiver?* (http://www.nextstepincare.org/Caregiver_Home/What_Do_I_Need/). This practical, task-oriented tool focuses on the caregiver’s immediate needs in the transition process, as well as future needs.

Participating organizations’ testing and implementation of this instrument was affected by factors including its length, existing caregiver assessments, and team members’ concerns that self-assessment, rather than professional assessment, was inappropriate.

Sometimes nurses and social workers were reluctant to ask family caregivers what they needed because they knew that they could not meet all these needs. They underestimated the importance of or did not have information about community referrals to services such as transportation, day care, and caregiver support groups.

Another, little-recognized barrier to engaging family caregivers is distrust of the health care system and other authorities: in some cases, caregivers themselves declined to do the self-assessment, citing privacy or other concerns. Despite explanations that their answers would not be used to deny services to the patient or to start an investigation of the home environment or immigration status, some caregivers were wary of answering even basic questions, such as employment status. Some comments during TC–QuIC webinars suggested that the manner in which the assessment tool was presented to caregivers (as yet another task to accomplish, for example) may have influenced the responses.

While the guide is online for family caregivers as a single tool, TC–QuIC providers in Round One suggested that it would be more useful to them if divided, so that different staff—nurses or social workers, for example—could use whichever section was most appropriate for their area of concern. This change was made for Round Two, with revised guides—dividing the self-assessment into three sections—added to the provider section of the Next Step in Care website:

- Availability and other responsibilities
  (http://www.nextstepincare.org/uploads/File/Guides/Provider/What_Do_You_Need-Availability.pdf)
- Training needs
  (http://www.nextstepincare.org/uploads/File/Guides/Provider/What_Do_You_Need-Training.pdf)
- Other worries
  (http://www.nextstepincare.org/uploads/File/Guides/Provider/What_Do_You_Need-Worries.pdf)
The improvement in the use of caregiver assessments in Round Two may have been related to this easier-to-use version of the assessment instrument, to participants’ greater familiarity with the concept of self-assessment, or to process changes after Round One that gave Round Two participants more flexibility in defining how they would assess family caregivers, even as the emphasis remained on self-assessment. Very few organizations chose to utilize *What Do I Need as a Family Caregiver*? in its entirety; many chose to adapt it or to use different forms of assessment. Staff often felt more comfortable creating their own tools than using existing tools, because they felt that their population was “different.”

**Changes Leading to Improvement**

Improvement in assessing the family caregiver was achieved through a variety of changes, the most successful of which included:

- Shifts in organizational process allowing for two family caregiver assessments, one completed by professionals and another completed by the family caregiver;
- Creation of scripts to be used by staff to introduce the family caregiver self-assessment;
- Introduction of the assessment by the social work rather than clinical staff;
- Modifications to make the assessment
  - Shorter;
  - Divided into sections that could be completed at different points in the care episode;
  - Focused on one specific component of care, such as medication management or discharge planning.

**Key Qualitative Findings**

Organizations working to improve family caregiver self-assessment required much more than process improvements focusing on which assessment form to use. Participants quickly learned that improvement was heavily tied to staff willingness to shift their perceptions and approach while working with family caregivers. At the most basic level, staff had to move away from a task-completion approach to recognize that family caregivers may conduct their self-assessments at various intervals during the care episode, and may not complete the entire assessment. Sometimes the assessment best served as a way to start a conversation about planning transitional care.

During Round One it took a median time of three days from admission to complete this assessment, time that the fast-paced health care arena often does not afford. Round Two teams did not report the time from admission until family caregiver assessment was completed.

Teams also encountered administrative obstacles to making assessment improvements. Some organizations, or their accrediting bodies, required a specific assessment of the family caregivers, generally limited to a few questions in the patient assessment. TC–QuIC teams often struggled to change organizational policy so that different forms of assessment could be approved for standard use.
Family Caregiver Engagement in Medication Reconciliation

Medication reconciliation, according to the Centers for Medicare and Medicaid Services (CMS), is the "process of identifying the most accurate list of all medications that the patient is taking, including name, dosage, frequency, and route, by comparing the medical record to an external list of medications obtained from a patient, hospital, or other provider."\(^1\)

Since medication errors are one of the most common causes of preventable hospital readmission, getting medications right before discharge is critical.\(^2\) Family caregivers of seriously and chronically ill patients are often more knowledgeable about medication history and current use than the patients themselves, particularly when patients have cognitive deficits or delirium. Family caregivers can often provide information about prior side effects, interactions, and use of over-the-counter supplements and herbals. Engaging family caregivers in the medication reconciliation process was thus a core improvement strategy for both rounds of TC–QuIC.

A Pharmacist’s Perspective

Based on family caregiver responses during Round One prep work, and on research showing the impact of medication issues on transitions and overall health, TC–QuIC leaders brought in pharmacist Anne Myrka, BS Pharm, MAT, to reinforce the critical nature of medication reconciliation and provide participants with additional tools. A certified geriatric pharmacist with board certification in pharmacotherapy specialty, Ms. Myrka works with IPRO, New York State’s Medicare quality improvement organization, and has taught in Vermont and New York. Her presentation at Round One's second Learning Session, on “Medication Management: Providers and Family Caregivers Working Together,” was so well-received by participants that she was invited back for a webinar in Round Two, and for a panel on dealing with dementia at the first TC–QuIC Booster Session in December 2012 (see p. 45).

Ms. Myrka stressed the importance for clinicians and family caregivers of understanding the different responses of geriatric patients to medications, and the red flags that might indicate a drug-related adverse event. This pharmacy perspective provided invaluable information on up-to-the-minute medication guidelines, tools such as the updated Beer's List, and strategies for safe medication use. Equally important, Ms. Myrka brought an understanding, both personal and professional, of the role of family caregivers in medication reconciliation, management, and adherence.

Reconciliation vs. Management

Organizations participating in Round One could focus on medication reconciliation, medication management, or both. Medication management is the day-to-day implementation of a medication list, revising as required, and observing and reporting expected outcomes (less pain) and unexpected ones (confusion). This is largely a patient and family caregiver responsibility.
As the collaborative process unfolded, it became clear that most organizations were strongly focused on the reconciliation process, while fewer were able to improve medication management. Although participants continued to support family caregivers in developing confidence to manage medications, the impact of these efforts proved difficult to measure. For Round Two, this collaborative strategy was defined more simply as medication reconciliation; this might, in part, explain why Round One organizations reported engaging 240 families in the medication reconciliation process, while 394 were reported to be engaged in the shorter time period of Round Two.

**Time to Medication Reconciliation**
Round One organizations working to improve medication reconciliation and/or medication management considered the time from admission for each care episode until reconciliation a key process measure, tracking it on a monthly basis (the day of admission was considered Day 1). The baseline average for all organizations reporting these data was slightly over two days. By the end of the collaborative, the average was one day, with a median of 1.2 days.

Although there were too few data points for a strict statistical interpretation, the trend was toward improvement. Notably, hospitals showed the greatest decrease in average days until medication reconciliation—placing great value on receiving a reconciled list early in the care episode so that the highest quality care could be provided during the typically short patient stay.

In Round Two, two organizations—a nursing home rehab program and a home care agency—tracked time to medication reconciliation prior to starting the collaborative and at its end, rather than as a monthly process measure. For both, there was no change in length of time: reconciliation was completed with the family caregiver at 3.5 days both pre- and post-collaborative. It is likely that in these settings, where patient stays last weeks instead of days, reducing the length of time from admission until completion of reconciliation could be considered less crucial.

**Medication Discrepancies**
For TC–QuIC, a medication discrepancy was defined as any identified difference between what the family caregiver reported the patient was taking and what was currently recorded in the patient’s medical record. These discrepancies could relate to administration and dosage or to medications or supplements missing from the patient’s current medication list.

Teams in both Round One and Round Two were asked to track medication discrepancies that were identified after discussing the medication list with the family caregiver. Round One organizations found 248 discrepancies in five months, with an average of 3.6 discrepancies per patient. These teams also found that during the medication reconciliation process, family caregivers were very likely to ask questions or identify concerns. On average, 97 percent of family caregivers surveyed by Round One
teams had questions about the dosage, purpose, side effects, and administration of medications, or about allergies related to them. This experience was echoed by a report from the AARP Public Policy Institute and the United Hospital Fund on results of a national survey of family caregivers, which found that most caregivers did not receive professional training on medication management.13

In Round Two, only one organization reported a total number of discrepancies—20—identified through the reconciliation process. Nor did participants track whether patients had questions about medications, since the earlier experience indicated that almost all caregivers did, in fact, have questions. Instead, teams worked on strategies to address the questions that came up.

The Teach Back Method

Even with a concerted focus on identifying and involving family caregivers, how to teach them the volume of information and skills they need to grasp remains problematic. One increasingly used approach—the Teach Back method—was introduced to participants in a collaborative-wide Round Two webinar.

As illustrated in Figure 3, Teach Back speaks to some of the most common issues related to clinical communications: 40 to 80 percent of medical information is immediately forgotten, almost half of information is remembered incorrectly, and the more information that is conveyed the more that is forgotten. The method’s repeated cycles of assessment, clarification, and demonstration of mastery

![Figure 3: The Teach Back Method](image-url)

have proved valuable, explained Jeffrey Greenwald, MD, associate professor of medicine at Boston University School of Medicine and Boston Medical Center, and co-investigator on Project BOOST and discharge intervention director for Project RED, two major care transitions initiatives.

Reinforcing that introduction, Teach Back was spotlighted at the next Learning Session, when Patrick Luib, MS, GNP-BC, manager of geriatric services for VNSNY CHOICE, facilitated a workshop giving participants an opportunity to practice the method.

Changes Leading to Improvement
Improvement in family caregiver engagement in medication reconciliation was achieved through a variety of changes. Among the most successful:

• Process improvements so that initial nursing assessments ask family caregivers for up-to-date medication lists;
• Scheduled meetings with family caregivers, upon admission, specifically to review medications;
• Improvements to paper and electronic records to allow entry of family caregivers’ lists of medications into the medical record;
• Changes in protocols so that non-clinical staff, such as social workers and case managers, asked or reminded family caregivers to bring up-to-date medication lists;
• Utilization of Teach Back as a way to both reconcile medications and respond to family caregivers’ medication questions.

Key Qualitative Findings
In general, improving the time from admission to medication reconciliation seemed most important to hospital teams, primarily because care episodes are often very short and acute care patients benefit quickly when providers have appropriate medication information. Skilled nursing facilities and home health care agencies often found that, although it is important to have this information soon after admission, the need was not as immediate. They also assumed that the process would have taken place in the hospital. For them, the medication reconciliation process was focused on both ensuring that
organizations had accurate accounts of what patients were previously taking and what might have been discontinued in the hospital, and that family caregivers had the opportunity to identify questions and concerns.

Teams found that, for newly trained staff, the idea of asking family caregivers essentially to review staff members’ communication skills was novel and often unsettling. At the outset they often received feedback, for example, indicating that caregivers felt “quizzed” or tested, which was not the intent. Scripting the intervention helped build staff confidence and a more interactive style, and this type of feedback diminished.

Staff implementing the Teach Back method or other approaches also found that prioritizing medications was an effective strategy. If staff attempted to use Teach Back on all medications, they found that many caregivers grew tired of the process or were overwhelmed with the quantity of information. Strategically choosing those medications that either posed high risks or were especially important because of the patient’s condition alleviated these concerns. This also allowed home care agencies to review medications at several points in the care episode.

**Discharge Options and Family Caregiver Preparation**

The pressure to reduce length of stay is a fact of health care life. Hospital staff members understand that options for transitions are limited by a patient's condition, the availability of rehab beds, the patient's insurance status, and other factors. They can often estimate reasonably well who can go home quickly and who will need a longer stay, and whether a particular patient can be sent home safely or not. But family caregivers are often totally confused by having to make last-minute choices, or feel they have no choices at all. Decisions have been made, and they are expected to agree. At best, patients and family caregivers adjust to the decision, but anger and frustration linger on. At worst, families may refuse to take the patient home—rejecting home care services or not understanding that this option exists—or allow a transfer to a nursing home rehab program. No one benefits from these crises. Most can be avoided with better communication.

The need for exploring discharge options with family caregivers is not limited to the hospital setting. Rehab staff recognize when patients will not be able to transition home safely and may need to be admitted to a long-stay unit, or when they will no longer be eligible for insurance coverage. Home care staff can evaluate patients’ and family caregivers’ needs for continued support and care after their services end. In some cases, a transition to hospice may be appropriate. But even the most careful estimates of discharge status and needs can be wrong, leading to too-quick transitions, hurried care planning, and opportunities for essential information, limitations, or needs to be missed.
Improving communication—between staff and family caregivers or patients, and even among staff within a facility—is central to clarifying discharge options. Although the date of discharge may be known in advance, staff may fail to communicate it effectively to the family caregiver. A nurse may tell the patient, who cannot remember or fails to understand. A social worker may pass the information on to a colleague who is not on duty when the family caregiver is present. Arrangements may be made to transfer a patient to a nursing home rehab program, without clarifying for the family caregiver that this is a short-term measure, not “putting Mom in a nursing home.” Discharge from the hospital may take place at night, with no one informing the family caregiver, who arrives the next day to find the bed occupied by someone else, or empty. The result is often confusion, dismay, or alarm.
Because discharge decisions can happen quickly, involving family caregivers early in discussions about the options is important. A caregiver may be unaware that a discharge is imminent, or may have unrealistic expectations about the patient's recovery or his or her own ability to provide needed care. Organizational change can facilitate timely, realistic discussion about discharge.

Changes Leading to Improvement in Planning
While both Round One and Round Two participants worked to improve family caregiver understanding of discharge options, the exact number of family caregivers engaged in education about discharge options was only tracked in the later phase. Round Two organizations reported engaging 186 family caregivers in discharge option conversations. In a post-discharge survey of 236 family caregivers—some of whom had been engaged in other improvement efforts, such as assessment and medication reconciliation—that experience was explored. On a scale of 0 (“not at all”) to 10 (“completely”), the average rating on the survey question “How well did you feel your needs were taken into account during discharge planning?” was 9.5.

During Round Two—as a result of TC–QuIC discussions about this aspect of transition planning, and participant requests—Fund staff developed a Next Step in Care provider guide, Hospital Discharge Planning—First Steps with Family Caregivers, outlining the key elements to discuss (http://www.nextstepincare.org/Provider_Home/Hospital_to_Home/).

TEAM HIGHLIGHT
DISCHARGE EDUCATION
Metropolitan Hospital Center and HHC Health & Home Care

**Problem:** The New York City Health and Hospitals Corporation, the city’s public health care system, had extensively documented high readmission rates among its patients with heart failure. To address this problem, Metropolitan Hospital Center, one of 11 acute care hospitals in the system, worked in partnership with the HHC Health & Home Care agency to decrease readmission rates for discharged heart failure patients referred to home care services.

**Cause:** During prep work, the hospital team found discrepancies between how well prepared family caregivers felt at and after discharge. They found that at the time of discharge caregivers often reported understanding patients’ medications and what to expect at discharge. At follow-up by home care staff, however, families reported not feeling confident, and had questions about care.

**Change:** The teams implemented a comprehensive multidisciplinary program, focused on supporting heart failure patients and their family caregivers across the care continuum. With input from all disciplines and review by selected patients, they created a short manual to standardize patient and caregiver education for improved management of this chronic condition. All staff started using the patient manual at every educational encounter, including home care, creating consistency and encouraging patient “ownership” of the material.

**Outcome:** This partnership participated in both TC–QuIC rounds. Metropolitan Hospital reported that its 30-day readmission rate for all heart failure patients dropped from 30 percent in July 2011 to 18 percent in May 2012. Among patients who accepted home care, the improvement was even greater, with readmission rates dropping to 13 percent.

**Keys to Success:** The team’s effort was marked by strong physician leadership, especially in ensuring that colleagues provided timely follow-up appointments; team leaders’ accomplishments were also recognized by senior leaders and coworkers. At the same time, HHC’s Medicare Advantage program provided scales to members who needed them; this shared cost allowed the hospital to provide scales to non-member patients as well. While the success of this effort cannot be attributed solely to family caregiver involvement, it was a crucial element.
Improving Family Caregiver Preparation for Discharge

Preparing for the discharge process involves attention to both short- and long-term issues. Patients and family caregivers need to understand what will happen on the day of discharge—including the final medication review, transportation, timing, and arrival at the next care setting—but also need to be educated and trained to manage ongoing care needs, including medications, appointments, and physical care. Even for patients going to rehab facilities or into long-term care, the success of the discharge process often depends on family caregivers having a thorough understanding of what is to come, and plans for ongoing care.

TC–QuIC participants reported engaging 156 family caregivers in pre-discharge education and training during Round One of the collaborative; 179 family caregivers were engaged in Round Two.

Organizations working to improve discharge planning found that they needed flexibility in their approaches, to allow them to respond to family caregivers’ differing needs for understanding, education, and training, and to their desired level of engagement in the planning process. Some common threads were identified, however, as participants developed new processes:

• Timely engagement of family caregivers in discharge planning is essential. If such engagement is left until just before a transition, the organization is unable to successfully affect the caregiver’s discharge experience;

• Effective communication about anticipated discharge dates helps reduce caregiver stress. Even when discharge dates had to be changed, teams found, bringing caregivers in earlier as integral parts of the conversation seemed to have a positive effect on them (whether this was related to concurrent communication about diagnosis, treatment, and prognosis was not determined, however);

• As far as possible, primary education of the family caregiver should not occur on the day of discharge. Round One team Orzac Center for Nursing and Rehabilitation tested integration of the family caregiver into nursing care (including wound care, personal care, and medication management) and physical and occupational therapies shortly after admission, allowing a few days first for the patient and family caregiver to adjust to the new setting. This process incorporated elements identified in the specific family caregiver’s assessment—training to give injections, for example, or post-stroke care—into this process. Introducing this cross-disciplinary approach reduced average discharge time from over 120 minutes to 30 minutes, because with earlier training and mastery the process only involved a final check of medications and other needs. The team attributed subsequent improvements in Press Ganey patient satisfaction scores to both this earlier integration of family caregivers with the provider team and to the smoother days of discharge that resulted.
Advance Care Planning

Advance care planning is intended to allow individuals to think about treatment preferences in advance and then communicate them, verbally and in writing, in the event they are unable to speak for themselves. For individuals with chronic conditions, timely and adequate advance care planning is an essential element of managing care transitions, because it ensures that their documented preferences accompany them from setting to setting. Advance care planning may involve naming a health care proxy (a substitute decision maker), creating a living will or other document, or completing a Physician Order for Life-Sustaining Treatment (POLST), called a Medical Order for Life-Sustaining Treatment (MOLST) in New York State.

Although improving family caregiver engagement in advance care planning was not an original TC–QuIC strategy, several Round Two organizations identified it as an important opportunity for improvement, especially in reducing preventable hospital readmissions. Recent legislative changes in New York State requiring discussions about palliative care may have contributed to this increased interest.

Round Two organizations engaged 202 family caregivers in discussions of advance care planning.

Changes Leading to Improvement

Improvement in family caregiver engagement in advance care planning was achieved through a variety of changes, the most successful of which included:

- Training hospital staff and residents on the use of the MOLST form and how to have discussions with families about treatment options;
- Altering organizational processes so that all patients have advance directives reviewed upon admission or at the start of care, and prior to any transition;
- Staff training to improve comfort with end-of-life discussions;
- Identifying patients in need of advance care planning earlier in the care trajectory;
- Scheduling family meetings to review or establish advance directives.

Key Qualitative Findings

Conversations with patients and families about end-of-life care are both difficult and time-consuming. Organizations working to improve advance care planning quickly learned that improvement relied heavily upon better staff education and increased comfort with such discussions. Engaging staff in training to improve their competence and comfort level was a necessary task before improvement efforts could move forward. Organizations also learned that not all staff will be a good fit for this role—but selecting specific staff members based on their demonstrated comfort with this type of conversation makes implementation across an organization especially difficult.
ADVANCE CARE PLANNING: TRAINING AND PRACTICE

Team members’ concerns about communicating with patients and family caregivers on advance care planning prompted a Round Two Learning Session on this difficult subject. Myra Glajchen, DSW, director of the Institute for Education and Research in Pain and Palliative Care at Beth Israel Medical Center in New York City, gave a presentation on “The Family Meeting,” guiding participants through the process of opening discussions with family members in a collaborative way, and pointing out the ways these discussions can be sabotaged or helped.

Common pitfalls, she noted, include:
- Medical staff sticking to “safe” topics;
- Meetings being rushed, or the team pushing for a quick decision;
- Distractions, like cell phones and beepers;
- A focus on one family member while ignoring the others.

She also listed common “bloopers,” words or phrases that upset family members and do not advance the discussion: “Do you want us to do everything possible?” “There is nothing more we can do.” “What do you want us to do if he stops breathing?” Alternatively, she suggested positive wording: “Your father’s comfort and dignity will be our top priority.” “Let’s discuss what we can do to fulfill your mother’s wish to die at home.” “We want to help him live meaningfully in the time that is left.”

Partnership Initiatives

Two Round Two hospital and nursing home partnerships—St. Luke’s-Roosevelt Hospital Center and Jewish Home Lifecare, and St. Barnabas Hospital Care Center and St. Barnabas Rehabilitation and Continuing Care Center—used the MOLST form to expedite advance care planning and ensure that patients did or did not receive interventions, consistent with their wishes, as they were transferred from one setting to another. Hospitals quickly learned that although the acute care setting might seem to be an appropriate place to introduce the form, rapid staff and resident turnover created a need for constant retraining. Short lengths of stay in acute care also made conversations about life-sustaining treatment difficult, since families were still in the process of understanding and accepting the patient’s condition and prognosis. These conversations proved to be better suited to the rehab, home care, or long-term care setting, where patients and families could have more time to absorb the information.

Another two participants tried different approaches. Isabella Geriatric Center, a skilled nursing facility, began work on advance care planning near the end of Round Two. Physicians experienced in talking to family caregivers gave presentations about advance directives during family council meetings and a health fair, and offered individual or family follow up. Families and patients, staff discovered, wanted details regarding research on outcomes of specific clinical treatments, such as resuscitation, artificial respiration, and artificial feeding, as well as the implications of patients’ physical status and disease course. As one team member described it, “Conversations need to include the pros and cons of different interventions as well as real-life success rates, to provide contrast to what people think they know from television or other experiences.” Although Isabella only had preliminary findings at the end of Round Two, it appeared that patients and families who participated in these conversations more often agreed on courses of treatment and appropriate times or conditions for hospitalization, making inappropriate or unwanted hospital admissions less likely.
The Visiting Nurse Service of New York Hospice partnered with VNSNY’s certified home health agency to improve the flow of patients from home health to hospice services. For patients nearing the end of life, the decision to use or not use hospice benefits can be critical—and can reflect how the patient and family both view end of life and understand the patient’s prognosis. During prep work, team members found that as an episode of home care came to a close, patients and family caregivers were not being educated, even if appropriate, about the hospice option. In line with VNSNY’s “right care at the right time” philosophy, the hospice and home health agency worked together to improve internal referral processes and to provide home health nurses with effective “learning experiences” to improve their understanding of hospice and how it might benefit patients and their families.

As the project continued, the teams addressed family comfort with care-in-place versus hospitalization, and the home health nurses’ comfort with discussing end-of-life issues; they also improved the accuracy of the field nurses’ identification of hospice-eligible patients. An important component was building skill in recognizing verbal and non-verbal cues about family caregiver or patient openness to discussing end-of-life issues.

**Problem:**
Frequent readmissions and emergency department visits of patients transferred from St. Luke’s-Roosevelt to skilled nursing facilities (SNFs), for symptoms attributed to typical disease courses.

**Cause:**
The partnership found that advance care planning was routinely underdocumented because of concerns about the negative impact it might have on SNF admissions, and a resulting increased likelihood of an extended hospital stay. Participants found that patients with documented rehab needs are given priority in access to SNF beds because rehab services are reimbursed at higher rates than long-term or end-of-life care. Without discussion of end-of-life care, however, family caregivers often thought that patients with advanced illness were going to be restored to wellness after rehab. They did not understand that the goal was only improved function and comfort as illness progressed. Moreover, clinicians did not feel they had the skills needed to have the necessary conversations with families. Rapid turnover (every two weeks) of hospital medical residents, who might be expected to initiate the conversations, was another challenge.

**Change:**
Jewish Home Lifecare System—which is committed to accepting patients regardless of the level of care they need—shared the St. Luke’s staff’s concerns. Already skilled at addressing the issue of prognosis with patients and families, Jewish Lifecare System staff provided training for St. Luke’s-Roosevelt geriatric team members, particularly residents, about family conversations and meetings and use of the MOLST. Hospital rounds were also altered to incorporate identification of patients for end-of-life conversations.

**Outcome:**
The end of the partnership’s work found an increase in the proportion of patients going from hospital to Jewish Home Lifecare with a MOLST in place. In addition, family caregivers first arriving at the long-term care facility demonstrated better understanding of the course of patients’ disease, permitting a more careful consideration of caring-in-place versus hospitalization. Jewish Home Lifecare has experienced increases in utilization of both hospice and palliative care services by patients from St. Luke’s-Roosevelt.

**Keys to Success:**
Lead geriatricians at the hospital have become advance care planning champions and have incorporated MOLST training into resident orientation; MOLST completion with a trained clinician has been reduced to a sustainable time period of 20-25 minutes; a strong partnership between team leaders has enabled sharing of talent and open communication.
Reducing Hospital Readmissions

In Round One, TC–QuIC did not specifically set a goal of reducing hospital readmissions, a task that involves many systemic changes. The Fund felt that goal would distract teams from the more fundamental challenge of changing deeply entrenched attitudes and practices that limited the involvement of family caregivers in transitions. Nevertheless, TC–QuIC did address one of the most frequently overlooked elements of readmissions—the role of the family caregiver in providing and coordinating follow-up care. Several teams were also working on readmissions issues in projects other than TC–QuIC. Despite this not being a major focus of the collaborative, several teams did find positive results related to their efforts (see box, p. 31, for an additional team highlight):

- Brooklyn Hospital Center reported a drop in its 30-day hospital readmission rate for patients with heart failure, from 19 percent to zero;
- First to Care Home Care reported a 30-day hospital readmission rate 6 percent lower than the New York City average;
- Center for Nursing and Rehabilitation reported that its 30-day hospital readmission rate declined from 36 percent to 22 percent; 85 percent of patients whose medications were reconciled with family caregivers prior to discharge did not have a hospital readmission post-discharge;
- New York Methodist Hospital reported that its 30-day all-hospital readmission rate dropped from 17.2 percent to 12.9 percent; the 30-day hospital readmission rate for all skilled nursing facility patients dropped from 41.8 percent to 31.6 percent.

Closing the Loop

The final strategy, “closing the loop,” involved follow-up communication between sending and receiving organizations and family caregivers to determine what went well during a transition and what could have been improved. This strategy was the least reported activity in TC–QuIC and the one most in need of further study and improvements. A collaborative of longer duration might have created more opportunities for teams to address this important evaluative step. Given the time frame, however, teams prioritized understanding and improving internal processes.

Changes Leading to Improvement

Even given those limitations, some partnerships and organizations made positive strides toward closing the loop. Among these successful efforts:

- New York Methodist Hospital and the Center for Nursing and Rehabilitation initiated regularly scheduled video conferencing between physicians (via FaceTime on their personal iPhones), which led to improvements in continuity of shared patient care and common treatment protocols;
Problem: Isabella, a comprehensive skilled nursing facility (SNF) and health care center, joined TC–QuIC as a way to enhance its use of INTERACT 2 (Interventions to Reduce Acute Care Transfers) through engagement of family caregivers. During prep work, participants realized that most SNF patients were sent to the hospital emergency department in response to family demand. Many of these patients were not admitted to the hospital, but were sent back to Isabella for care in place. Prep work chart audits reflected negative patient outcomes, possibly due to the stress of transportation and waits in the emergency department, and frustration for both families and staff.

Cause: The team determined that families often visited their loved ones in the evenings and on weekends and frequently did not have strong ties to the clinical staff on duty at those times. Discussions with family caregivers revealed that they often noticed changes in their loved ones, and had questions about their status, but were unsure about what to do with this information. As a result, families felt the facility was not adequately addressing the patient’s needs, and they insisted on hospitalization.

Change: Isabella was preparing to implement the INTERACT Stop and Watch protocol house-wide to improve staff responsiveness to changes in patient status and to prevent unnecessary hospitalization. The team decided to broaden the use of Stop and Watch to include family caregivers as well. Stop and Watch would provide a positive pathway for families to convey concerns to clinical staff and understand the staff response, and for staff to communicate with families regarding observation and treatment. The team adapted the Stop and Watch tool for family use in English and Spanish, sent mailings to all family contacts on record, presented the program at family council meetings, and included the tool in family meetings.

Outcome: After implementing the Stop and Watch family form, a staff evaluation found that 85 percent of concerns identified by family caregivers were addressed and documented in the medical record. The Isabella team reported that implementation of this tool on two pilot units led to a 57 percent reduction in rates of preventable hospitalizations, compared to the previous year. The team also reported a 25 percent reduction in transfers to the emergency department that did not result in hospitalization. Furthermore, the use of this tool encouraged at least half of the families on the pilot units to develop strong relationships with their unit’s charge nurses. In turn, this supported improved communication and a spontaneous move from use of the paper tool to spoken communication of concerns with staff.

These concerns were handled in the same manner as written concerns. In recognition of Advance Directives Day, in April 2012 the facility hosted an event, open to the entire community, featuring a physician, nurse, and attorney discussing issues and considerations in making advance care planning decisions. The event was so successful that staff repeated it at both resident and family council meetings.

Keys to Success: Application of the family caregiver “lens” for further improvement on an existing project; willingness of evening, night, and weekend staff to build relationships with families; comprehensive examination of how staff responded to family use of Stop and Watch—rather than just evaluating rates of hospitalization—provided opportunity for recognition of good staff work and in-depth understanding of communication between staff and families.

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**TEAM HIGHLIGHT**

**REDUCING READMISSIONS**

_Isabella Geriatric Center_

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**Preventable Hospitalizations with Use of Stop and Watch**

![Graph showing reduction in preventable hospitalizations](image_url)

These numbers reflect the impact of the Stop and Watch approach with both staff and family members on two units.
Many of the partnerships, notably NYU Langone Medical Center’s heart failure staff and their partnering Visiting Nurse Service of New York acute care team, forged professional relationships—including, ultimately, cross-agency team meetings—that improved clinical exchanges as well; Franklin Hospital and Home Care created a shared, secure computer network drive to enable both communication of referral information and ongoing exchange of patient and family caregiver information, including dialogue between social workers and community services on follow up and the success or failure of referrals to those services; Dr. Susan Smith McKinney Nursing and Rehabilitation Center adjusted and enhanced its post-discharge phone calls, targeting family caregivers and using the information gained in those conversations to improve internal processes; Metropolitan Hospital Center and HHC Health & Home Care’s work led to significantly improved communication between clinic doctors and home care nurses, which the partners feel has prevented rehospitalizations.

**TC–QuIC Evaluation**

United Hospital Fund commissioned qualitative evaluations of Rounds One and Two to identify TC–QuIC’s strengths, assess its impact and participants’ experiences, and find insights on ways in which the collaborative might be improved. A particular interest was helping Fund staff and TC–QuIC faculty determine which collaborative components and strategies were most effective in supporting participant learning and results.

Round One’s evaluation—including a follow-up assessment nine months after the round’s conclusion, focusing on the project’s spread and sustainability—was used to make changes in the collaborative process and materials for Round Two. It was also seen as laying the groundwork for a larger discussion about strategies for effective engagement of family caregivers in care transitions—carried on as one of the purposes of this report.

The results reported here rely more heavily on feedback about Round Two than Round One. For Round Two, evaluation findings were derived from final team reports and from semi-structured qualitative interviews with four faculty members and 19 participants and senior leaders, representing all teams. Interviews were conducted from May to July 2012.
The TC–QuIC Experience: Accomplishment and Culture Change

Overall, participants in Round Two of TC–QuIC thought the experience extremely positive. Asked about their agreement with the statement “Considering the results we were able to accomplish, the time and effort we devoted to TC–QuIC was well worth it,” the average rating on a scale of 0 (“strongly disagree”) to 10 (“strongly agree”) was 9.4. That was a marked increase from the 6.9 average of Round One, one that may reflect the modifications growing out of that earlier experience.

The results that factored into that judgment were of two distinct types. Asked, in evaluation interviews, to identify the most significant outcomes of their work in Round Two, many participants described measurable, specific project results. These included reduced 30-day hospital readmission rates (achieved by five teams); high rates of family caregiver identification; assessment of caregiver needs soon after admission; increased caregiver education, leading to greater caregiver knowledge and confidence; safer discharges achieved through more comprehensive discharge planning and education; increased prior notification of discharge; caregiver involvement in medication reconciliation and management; and (in two teams) an increase in advance care planning, use of advance directives, and MOLST documentation for patients and families.

But many participants also pointed to a broader, perhaps more far-reaching effect: increased capacity for organizational change and quality improvement, and a host of lessons learned, among participating teams and their organizations.

Most notable, as reported by all teams, was heightened awareness among staff of the potential role and impact of family caregivers in improving care transitions. Some teams described this improvement as an organizational “culture shift” toward greater recognition and appreciation of the role and potential value of family caregivers in care transitions. Teams reported better communication with and involvement of family caregivers in all aspects of care transitions, including medication reconciliation and management, discharge planning, and post-discharge care.

Participants also highlighted better teamwork and increased confidence among staff in identifying, educating, and working with family caregivers.

These outcomes were particularly significant because—as many participants put it—before TC–QuIC, the family caregiver was “ignored,” simply not involved in patient care or care transitions. “TC–QuIC Two was cutting-edge in the range of care transitions included, in its focus on the family caregiver and how to involve family caregivers as care team members. This focus on the family caregiver is missing in most work on improving care transitions,” commented one interviewee.
Another important, frequently identified outcome was an enhanced capacity for quality improvement work and a new ability to use data to demonstrate improvement. Although many teams struggled with this aspect of the collaborative, they learned how to effect and measure change, and to implement improvements based on the Model for Improvement. As one team member stated, “[We learned] the importance of ongoing monitoring and reporting for performance improvement. TQ–QuIC helped us set up for continuity.”

That dual perspective—a focus on family caregivers partnered with a focus on process—contributed to the success of Round Two. While Round One participants appreciated the value of Next Step in Care materials, a number of participants (particularly senior leaders) noted that a focus on family caregivers alone was not enough for sustainability: “It is only one important piece of the puzzle,” said one. Another offered this recommendation: “Include a broader focus on improving care transition processes in the next Round of TC–QuIC and the projects will be more successful and more sustainable.”

Round Two sought to do just that. Teams better integrated their use of Next Step in Care materials and their involvement of family caregivers with important organizational efforts aimed at specific goals within the areas of improving care transitions, reducing hospital readmissions, or increasing the use of advance directives. This greater alignment made TC–QuIC Round Two more compelling for participating organizations.

That may also have influenced participants’ ratings of their team accomplishments on a scale of 0 ("not at all successful") to 10 ("highly successful"). For Round Two, the average rating was a very successful 8.4, a notable increase from the Round One average rating of 6.6.

What did teams consider their most significant accomplishments? Ten teams highlighted identifying and effectively involving family caregivers in patient care and care transitions. “Our greatest achievement was reaching families—identifying the caregiver, getting to know their needs and recognizing their role in supporting patients and the care team,” said one participant. Others identified as key achievements reducing hospital readmissions through family caregiver involvement, and using what they learned from TC–QuIC, such as tools for safer discharge, care planning strategies that include the family caregiver, and caregiver involvement in medication reconciliation and management. Still others pointed to greater partnering and communication, both within and across organizations, for improved continuity of care. And several noted that staff and clinicians now see the value of integrating advance care planning into discussions with patients and families.
For many, these achievements reflected the new perspectives and skills that TC–QuIC provided. Most participants said that they hadn’t previously identified and worked with family caregivers. Some reported that use of the PDSA cycle, small tests of change, and other quality improvement strategies were new activities, as were data collection and management. One interviewee said, “Seeing how data can help us... using data to see the impact of improvement... was new.” Some cited the process of learning among participants and their organizations as an important contribution in itself.

Barriers—and Support
Asked about barriers to improvement that teams faced in TC–QuIC Round Two, several participants reported none or “…at least none that were insurmountable.” Most frequently cited, however, was the need to educate and re-educate physicians and staff about the benefits and processes of family caregiver identification and engagement. “In our hospital, the medical team changes every two weeks so we need to re-educate all over again,” reported one interviewee. Another suggested, “It might be helpful if there could be less change of medical floor staff to allow for consistency in carrying out protocols and to minimize repetitive teaching to accomplish these goals.”

Another commonly reported barrier was getting physicians on board with an expanded discharge planning effort and early notification, to allow time for patient and caregiver education prior to the day of discharge: “It’s hard to engage family caregivers if we cannot know or plan the time of discharge.” Also commonly cited: the rapid pace of patient discharges.

Other barriers included:
- Finding the caregiver, caregiver availability, or the absence of a family caregiver;
- Poor documentation systems, including electronic medical records (EMRs) without fields for family caregiver documentation (several teams added this functionality during the collaborative);
- Partner organizations using different EMRs;
- Regulatory and process differences across care settings that affect care transitions;
- Clinician discomfort with discussions of end-of-life care and the option of hospice;
- Insufficient staffing or staff time for TC–QuIC activities such as caregiver and staff training—time that, in the case of staff training, is necessary for TC–QuIC tools and improvements to take hold;
- The time and work involved in the data collection process;
- Getting teams together: “We all come from settings with a high volume of patients, and finding the time to meet was challenging”;
- Changes of team leaders;
- “Determining next steps for our project and what to focus on next—it was hard to pick one thing and stick with it.”
Yet many Round Two participants saw TC–QuIC as helping them overcome these challenges:

- “TC–QuIC gave us tools, a structure, and a framework for improvement.”
- “The PDSA process taught us to focus on one piece of the problem at a time.”
- “TC–QuIC helped us identify issues and barriers we faced in our discharge process and gave us credible tools so that we could address barriers and improve our process. For example, we identified documentation as a barrier and were able to get IT support to add a field in the hospital EMR for documenting identification of the family caregiver.”
- “TC–QuIC reinforced for us the importance and value of what we were already doing.”
- “The support was incredible! [TC–QuIC] gave us the voice of the caregiver. It gave us knowledge about the Model for Improvement, how to collect and use data for improvement, and how to implement effective Teach Back with patients and caregivers. This was all valuable learning, and the faculty was so helpful and so available!”

Rating TC–QuIC’s Components

Participants gave high marks to most of the component tools and activities of TC–QuIC (Table 3), beginning with its important three-month preparatory phase.

This structured introduction was one of the real strengths of the collaborative. Through its highest-rated element, the chart audit, they “discovered what our issues were and how little we were capturing in the chart that could support continuity of care,” one participant noted. The staff survey “helped guide our aims statement,” said another. Other teams found that the transition mapping exercise illustrated how complex and ineffective their care transition processes were. As one participant said, “[It] showed us what a spaghetti mess our transition process was before we started

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Rating TC–QuIC’s Components</th>
<th>Average Rating*</th>
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<tbody>
<tr>
<td><strong>Prep Work</strong></td>
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<tr>
<td>Chart audit</td>
<td></td>
<td>9.1</td>
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<tr>
<td>Family caregiver survey</td>
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<td>8.7</td>
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<tr>
<td>Staff survey</td>
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<td>8.6</td>
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<tr>
<td>Transition mapping exercise</td>
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<tr>
<td><strong>Online Community</strong></td>
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<tr>
<td>Tools and resources</td>
<td></td>
<td>8.9</td>
</tr>
<tr>
<td>Measures and data collection</td>
<td></td>
<td>8.9</td>
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<tr>
<td>Sharing information</td>
<td></td>
<td>7.1</td>
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<tr>
<td><strong>Other Components</strong></td>
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<tr>
<td>Next Step in Care family caregiver guides</td>
<td></td>
<td>9.2</td>
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<tr>
<td>Learning Sessions</td>
<td></td>
<td>8.9</td>
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<tr>
<td>Other online change package tools and resources</td>
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<td>8.8</td>
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<tr>
<td>Training in a structured approach to quality improvement</td>
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<td>8.8</td>
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<tr>
<td>Faculty coaching</td>
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<td>8.7</td>
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<tr>
<td>Webinars</td>
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<td>7.4</td>
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</tbody>
</table>

*Based on a scale of 0 (“not at all beneficial”) to 10 (“highly beneficial”)
this project.” This team used the mapping prep work to simplify its transition process, and will continue to use it as a guide to further improvement.

Teams used this time and the findings from it to determine their project focus and plan their intervention. The planning period enabled teams to “hit the ground running” with a clear sense of what processes to address and with baseline data to guide their improvement activities. One participant observed, “We used all of the data from the pre-work as a benchmark throughout TC–QuIC.”

Another evaluated component was the online community. Participants gave it high marks as a repository for tools and resources, and as a source of information to support measurement and improvement activity. Fewer participants found the online community as useful for peer exchange or problem solving. Several commented that they did not use the online community, that it took too much time to use, or that they did not have time to benefit from it. A few teams used the online community to share data with their own members. One participant noted, “Our team [had] members from multiple sites within the organization. The online community provided a good construct for a virtual team.” Another suggested that teams might benefit more from the online community if they were instructed to allow more team members access to it at the beginning of the collaborative.

Participants also weighed in on the benefits of other Round Two components. Again, all were rated highly, with one exception. Participants identified the collaborative change package, Learning Sessions, support on quality improvement methods, general faculty support, and Next Step in Care guides as among TC–QuIC’s greatest strengths, along with the preparatory phase. One interviewee did note that “half-day Learning Sessions would work better. There is too much information provided in a full day—too much to take in. Split the sessions into two half days.” Overall, these Round Two ratings were much higher than the comparable ones for Round One, likely because of changes introduced as a result of the Round One evaluation.

The one Round Two element that, for some, was less successful than the others was the webinar feature, which drew mixed reviews. A number of participants said the webinars “were all good,” but one observed, “The webinar information was less useful and keeping people engaged in the webinars was hard. I do see the value of keeping the project in the forefront through monthly contact but the webinars weren’t great.” Most participants found the webinars at least moderately beneficial; interestingly, when asked which type was most beneficial—content-focused, an expert speaker, or peer presentations and exchange—interviewees divided their votes evenly. Webinars focused on the Teach Back method and on community resources were cited as particularly beneficial, while some
participants identified peer exchange webinars as least beneficial because they felt their project didn’t have enough in common with other TC–QuIC projects. A number of participants requested that webinar materials be sent in advance to allow time for preparation.

Other Feedback: Structure and Process
Feedback on the TC–QuIC Round Two structure and process was extremely positive overall, in contrast to the feedback—constructive but somewhat critical—on a few areas of TC–QuIC Round One. For example, many Round One participants thought the collaborative process as a whole was “too cumbersome.” One senior leader had observed in an interview, “There was too much focus on process and not enough on the project.” Many Round One participants were also new to the collaborative process, and felt at times that they would have benefitted from more orientation and guidance about what to expect and from greater clarity about participant responsibilities, team roles, and the role of partnerships. A number of participants identified the need for clearer illustration of why and how to apply quality improvement methods to support implementation of improvements. Interestingly, none of these themes continued in Round Two interviews.

Round Two teams were given greater flexibility in selecting their aims. According to faculty interviews, this approach worked well because Round Two projects were more tailored to each participating organization’s needs and better aligned strategically with organizational priorities (such as reducing hospital readmissions). This approach also benefited from the earlier completion of the prep work, which helped teams fine-tune their aims and develop plans for implementation.

A couple of themes, touched on earlier, continued to arise as issues in Round Two, however. These related to the data component of the projects and to staffing resources. “The team collaboration was great,” one participant noted, “but we were challenged by the data collection and by the logistics of setting up team meetings.” Said another, “Project staffing was an issue. Additional funding for project staffing or data entry support would have helped us.”

Partnership Ups and Downs
For most participants, partnerships were a central part of Round Two, whether across units or care settings within the same organization or across organizations. On a 0 to 10 scale, interviewees rated the overall success of their partnerships an average of 8.4, a large rating increase over the 5.9 average of Round One.
All participants working in partnerships reported that they had a positive impact on their ability to accomplish TC–QuIC goals. One participant noted, “We would have scored a ‘4’ in this project without our partners.” Several reported working differently with their partner organizations as a result of what they learned in TC–QuIC, and that the closer, more solid working relationships that resulted will continue to support better care transitions between partner organizations. A few partnerships had worked together previously, including in Round One.

In contrast to Round One, where five teams reported that their partnerships had not worked well, there were no reports of partnership failure in Round Two. (One partnership ended early in the collaborative, not as a result of inability to work together but because of one partner’s decision to focus first on internal improvement. This team reports that it is now ready to partner externally on care transitions.)

Several teams reported that their Round Two partnerships were good overall but experienced a few challenges. For some, differences in the pace of work or the pace of change within partner organizations were problematic; one participant noted that the partner organization was “…slow getting going and entirely new at identifying the family caregiver.... We were ahead of them.” Another said, “The exchange of information and perspectives was good, but the system change work at both sites was done independently. We did our own thing for that part.”

Other issues that were noted included time constraints and difficulty freeing up time for partners to meet and accomplish the work of the collaborative; different documentation systems and EMRs that made it hard to share data across organizations; and poor communication among some partners.

While several participants said no change in the TC–QuIC partnership approach was necessary, others called for:

- A longer collaborative period, allowing for time to focus on partnership building;
- More guidance on how to develop a shared goal as a partnership, supported by coaching;
- Rapid replacement of team members as needed;
- Hands-on participation by all team members, with no one just observing or commenting;
- Partnership accountability for participation.

“Teams need to create structure, including a calendar…to achieve project goals and milestones,” one participant noted, “with an established meeting schedule and… meeting agendas.” Another suggested, “After the collaborative ends, teams should continue to meet face to face to keep up momentum and sustain the changes.”
The Quality Improvement Learning Experience

How effective was Round Two as a mechanism for learning about quality improvement (QI)? The average participant rating, on a scale of 0 to 10, was 9.5—the highest rating received by any element of Round Two. This was a significant improvement over the average Round One rating of 7.3, probably reflecting a number of changes in approach and procedure. In Round Two, faculty started training participants and integrating QI into team activities earlier in the collaborative. Teams also had access to a broader change package of tools and resources expanding content knowledge and supporting improvement activity. Many participants reported that the training and capacity building, integration into collaborative projects, and demonstrated impact of QI were among Round Two strengths.

All interviewees gave positive feedback about the applied QI training and support in Round Two, and most said it was “very helpful.” About a third reported that they already knew about QI or had used it prior to TC-QuIC, and a few said the training was therefore “too basic for our team, but still a good refresher.” Many teams that were new to the Model for Improvement reported that they benefited from this training by learning how to effect change, measure change, and implement improvements using the model.

In evaluation interviews, participants demonstrated their new or enhanced understanding of the value of data analysis. They noted its utility to demonstrate impact and show improvement trends and change over time, and the overall benefit of “…collecting data and letting it guide you,” as one interviewee commented. Faculty, too, noted Round Two improvements. In Round One, several observed, many participants didn’t complete the monthly QI requirements; as one faculty member put it, “They didn’t know the QI methodology and couldn’t use it.” In Round Two, faculty said it was still hard to get the monthly reports, but “…when the data did come it was so much better! It showed a much deeper use and understanding of QI methods among participants.”

Still, all but two participants said they encountered challenges collecting and reporting data. Several reported difficulty collecting data on family caregivers or their interactions with caregivers due to poor documentation systems and EMR limitations. Others noted that reporting and submitting data on time was a challenge. A few identified poor response rates to family caregiver follow-up surveys as negatively affecting data collection.
Additional Support Requested

About half of Round Two participants felt they didn’t require additional support to help them succeed with this aspect of the collaborative. One noted, “There was great preparation and instruction. The faculty was very responsive and knowledgeable.” Others suggested changes largely dealing with timing:

- “Give us the data collection tool earlier in the project. That would have helped us stay on track and understand earlier on what’s expected of us in the collaborative.”
- “Early intervention for the data collection and reporting piece would have been helpful. We would have done a better job and made better decisions if we had more coaching in this area early on.”
- “The data reporting timeline was tough and United Hospital Fund did not always appreciate how challenging it was. More flexibility and support with data collection and reporting would have helped.”

Impact on Family Caregivers

A focus on involving family caregivers in care transitions is at the heart of the TC–QuIC initiative. How life changed for these caregivers and patients—and for the providers interacting with them—is, then, crucial to evaluating the entire endeavor.

Asking to rate the effectiveness of Round Two as a mechanism for improving the involvement of family caregivers in care transitions, participants provided an average rating of 9.3, up from an average of 8.1 in Round One. “TC–QuIC gave us the family caregiver’s perspective for the first time,” many noted—along with tools to effect change based on that recognition.

All but one team focused their TC–QuIC interventions on involvement of family caregivers to support care transitions or advance care planning. (That team focused instead on establishing relationships in its organizational network and in the community that would support continuity of care and care transitions for patients without any family caregivers.) Through their activities, participants observed a range of significant impacts on family caregivers.

Many reported that family caregivers were more involved, informed, and prepared for their role, with Next Step in Care guides, the TC–QuIC change package, and other TC–QuIC tools helping them become better prepared and more realistic about what they can and cannot do as caregivers. Some participants observed greater caregiver confidence and reduced anxiety about their caregiving role. Other interviewees observed that caregivers “found a voice” and that they became “empowered as part of the patient care team and process,” “better advocates for their loved ones,” and “better decision makers regarding patient care.” One participant also noted that there was better communication among nurses and other staff and family caregivers, and greater appreciation on the part of caregivers for clinicians’ efforts to provide care and support.
For participants, recognizing caregivers as individuals and improving communication between them and the care team was an important leap, and among the rewards of participation. Most gratifying, interviewees found: identifying caregivers, assessing their needs, and knowing that they were better prepared to support their loved ones.

**Barriers to Change**

As in Round One, a few participants—particularly those from safety net providers—found it hard to reach or communicate with family caregivers from diverse backgrounds, particularly those with limited English language capability. Others noted that some patient populations—such as the homeless—are less likely to have family caregivers. These groups continued to present a challenge for teams.

In terms of tasks, Round Two participants identified planning for discharge and the day of discharge as the most challenging areas of work with family caregivers. One participant commented: “It is hard to plan for discharge with reliability. There are many variables and a lot of communication is required.”

Other significant barriers that participants identified included:

- Implementing medication reconciliation and management processes, which requires engaging caregivers in understanding and implementing these processes;
- Assessing caregiver needs and comprehension of patient care requirements. One participant observed, “Families often do not have a clear understanding of a patient’s care or what next steps to anticipate. There are very big gaps in communication and understanding when it comes to patient care requirements, necessary medications, and follow up”;
- Working with clinicians to plan care transitions, often because of mixed messages or other kinds of poor communication from different clinicians involved in a patient’s care, or because of clinician reluctance to have difficult end-of-life conversations with patients and families.

**Long-Term Impact**

Whether change is sustainable beyond the life of an initiative like TC–QuIC is always a key question. Interviewees rated the overall effectiveness of Round Two in fostering sustainable improvement in care transitions an average of 8.8, up from the Round One average of 7.1. Participants’ expectations for sustainable improvement and spread of improvements made in their own projects were also highly encouraging. All participants said that their organizations would sustain processes developed in Round Two for improving family caregiving and care transitions. All but one team reported that improvements developed in Round Two had already spread to new areas of their organizations or beyond, or that such expanded activities were currently underway.
More than half of responding participants reported ongoing efforts to support sustainability and spread of new processes developed in TC–QuIC. These included staff training and in-service practice, re-education, and improved communications. Several teams reported that their TC–QuIC projects had been selected as unit- or organization-wide performance improvement projects for the next year. Most teams plan to continue monitoring the results of their interventions—for example, hospital readmission rates or follow-up appointment rates post-discharge—to demonstrate impact and foster program sustainability. Many teams continue to meet, working to spread institution-wide TC–QuIC improvements beyond their initial implementation. In one organization’s case, “We are moving the process to other regions of [our organization], with the goal of city-wide expansion. We meet at least once a month to advance this goal and keep the team engaged.”

Several hospitals reported sustaining and expanding family caregiver involvement in care transitions by forging new partnerships with other organizations to which patients often transition following discharge. “We are using the EMR to communicate to other providers who the patient’s family caregiver is,” one team said. “We are also sending electronic reminders to caregivers and other providers involved in the patient’s care.” Participants also noted that regulatory agency and payer policies are reinforcing the importance of TC–QuIC efforts to improve care transitions and reduce avoidable readmissions.

All teams reported that senior leaders in their organizations are supportive of spreading and sustaining family caregiver involvement in care transitions, but, as one team member commented, “Communicating to senior leaders the success and impact of this program was key in its agency-wide adoption.” As noted above, nearly all participants reported that TC–QuIC improvements had spread (or were spreading) beyond the initial implementation. “We are bringing the [Round Two] family caregiver approach into the New York State Gold Stamp Initiative [an improvement collaborative focused on preventing pressure ulcers].” Another team, the Dominican Sisters Family Health Service, incorporated TC–QuIC lessons into ongoing work with the “transition coach” model. These examples notwithstanding, there were relatively few efforts to systematize and coordinate all the transitional care programs so that they could share information and experiences.

**Barriers to Sustainability**

Although seven teams anticipated no particular barriers to sustaining or spreading TC–QuIC interventions, others identified a number of potential impediments:

- Having sufficient time to train additional staff and include caregiver assessment and support in daily operations;
- The need for clinician buy-in, training, time, and behavior change, both for use of Next Step in Care materials and advance care planning and for agency-wide spread of these and other tools and processes;
• Insufficient resources to sustain TC–QuIC activities, given the number of projects and the pace of work in health care organizations;
• The challenge of maintaining momentum after the collaborative ends. “Another round of TC–QuIC would help foster sustainability,” one team noted.

Supportive Factors
Participants suggested a number of factors likely to help spread and sustain the achievements of their TC–QuIC projects, the majority related to their organizational environments. Among them:
• Emerging unit- or organization-wide performance improvement projects, such as the Six Sigma set of tools, focused on family caregiver involvement in patient care transitions and spread of improvements from TC–QuIC;
• “Our organizational focus on care planning, discharge planning, and reducing rehospitalization” and “Our service line structure and use of Lean Process Improvement methodology”;
• Continued staff education and “[Reinforcing] the changes we made to the discharge process in TC–QuIC”;
• Institutionalization of changes: “Planning for a safe and orderly discharge based on the Next Step in Care best practice is now a required activity and part of our process”;
• Updating electronic medical/health records: “Our EHR update will help institutionalize family caregiver identification and will communicate to other providers who the patient’s caregiver is”;
• Senior leadership support: “The CMO and Senior VP of the hospital are supportive of TC–QuIC [and] will retain the family caregiver component [developed in Round Two] in any redesign of transitional care programs designed to reduce readmissions”;
• Recognition of impact: “Senior leaders have seen the results of TC–QuIC (lower readmission rates) and they like it. This will reinforce our efforts.”

Six teams also identified factors in the health care environment that they believe could support TC–QuIC improvements. Among these:
• New York State’s new regulations on education about and provision of palliative care;
• An industry standard for time of day of patient discharges;
• The current emphasis among hospitals and policymakers on improving care transitions and reducing avoidable readmissions.

But perhaps the major factor supporting sustainability will be one of sheer numbers. As one faculty member observed, “Many health care providers are working on care transitions, but few are working to partner with the largest health care workforce involved in care transitions: the family caregiver. Organizations involving the family caregiver in improving care transitions now have an edge on this issue where others do not.”
What Comes Next?

While United Hospital Fund has no plans for a Round Three of TC-QuIC, a number of activities are building on the TC-QuIC experience:

- **Transitions in Care 2.0: An Action Agenda.** This Fund policy document (available at www.uhnyc.org) outlines ten steps to improve the next generation of transitional care programs by including family caregivers in the process. Included in those steps are actions on relevant legal, payment, and accreditation issues.

- **Day of Transition Initiative.** In this new Fund-supported grant project, three New York City hospitals—Mount Sinai Medical Center, New York Methodist Hospital, and Metropolitan Hospital Center—have embarked, as lead agencies, on a year-long program designed to ensure that communication between hospital and partner home care agency is timely, accurate, and complete. Mount Sinai and Methodist are working with Visiting Nurse Service of New York, and Metropolitan is partnering with its Health and Hospitals Corporation home care agency. The initiative’s emphasis that the family caregiver has to be included in the transition plan and follow up derives from TC-QuIC findings that partnerships among health care providers are often fragile, putting the patient and family at risk of errors or miscommunications. The hospitals and their partners will work together to develop better processes for sharing information, understanding each other’s needs, and following through with family caregivers to determine whether transitions went as planned or, if not, what barriers or surprises were encountered. A special feature of this initiative is the requirement for family caregiver and patient participation at all stages of planning and implementation.

- **Change Package updates.** The Round Two online change package (http://www.nextstepincare.org/Provider/_Home/#Toolkit) is being refined and expanded with additional material—including video presentations on such issues as working with family caregivers of patients with Alzheimer’s disease—so that organizations not previously involved in TC-QuIC can use the tools and scripts as they make process improvements.

- **TC-QuIC “Booster” sessions.** The Fund is holding a series of in-depth sessions on topics of particular interest that were not fully explored during the regular Learning Sessions, including working with patients with dementia, and hospice and palliative care.
Conclusions

TC–QuIC was a process of learning as a group, more than the sum of individual participants’ experiences. Some of its lessons were broad, others very specific. Following is a sampling of what was learned.

Getting Started

• Prep work is essential—reviewing, mapping, and outlining how transitions actually happen currently will reveal misunderstandings, confusions, differences of opinion, and gaps in current processes.
• Both staff and family caregiver experience must be obtained and compared.
• Senior leadership must be engaged at the start.

Working with Family Caregivers

• Identify the appropriate family caregiver(s):
  > Before TC–QuIC, none of the participating organizations had a systematic way of finding out who was, for example, going to help the patient with medications or arrange for follow-up visits.
  > This information is vital and must be entered into the EMR or other patient record so that staff on different shifts or from different departments can access it.
• Talk to family caregivers about their own needs, capabilities, and limitations:
  > This is a caregiver self-assessment, not a professional judgment.
  > It is separate from the patient assessment.
• Use input from family caregivers to plan for discharge:
  > Provide information about options.
  > A realistic discharge plan is grounded in what caregivers report they can do.
• Provide training and education, especially related to medication management and follow-up care:
  > This will differ from patient education—direct it to the specific family caregiver’s needs and capacity.
  > Help family caregivers with follow-up appointments and information, connecting them to primary care and community resources, and find out from the receiving agency how the transition went from its perspective.

Making Institutional Change

• Improving transitions in care by involving family caregivers is a team effort that takes time, effort, and senior leadership support.
• Within the team there must be clear responsibility and accountability.
• Sustained quality improvement efforts require expertise in data collection and analysis.
• Partnerships between sending and receiving organizations need to be strengthened.
• Improving transitions requires an organizational culture that recognizes the value and needs of family caregivers and works with them as part of the care team.
# Appendix: Team Projects

## Round One

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<tr>
<th>Organization/Partnership</th>
<th>Goals</th>
<th>Highlights</th>
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<tbody>
<tr>
<td>Beth Israel Medical Center</td>
<td>To improve transitions, from hospital to home, of Chinese patients with a diagnosis of heart failure, primarily using Chinese-language versions of Next Step in Care materials</td>
<td>• Beth Israel identified follow-up appointments as an opportunity for improvement. Staff developed a Chinese-language “Phone Angel” volunteer program to conduct post-discharge phone calls with family caregivers and assist in scheduling/rescheduling appointments with the heart failure clinic and other physicians.</td>
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<td>Visiting Nurse Service of New York (VNSNY)</td>
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<td>• Discharge disposition is now a part of routine quality assurance monitoring and analysis in the hospital’s test unit.  • Both partners focused on caregiver worries. VNSNY used this focus as a means of bonding with family caregivers.</td>
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<tr>
<td>New York Hospital Queens</td>
<td>To improve transitions between hospital and home care settings, concentrating on the sickest patients who are supported by family caregivers</td>
<td>• Family caregivers present with very different needs in the home than in the hospital, the team found, and with a strong expectation that the patient will be “as good” or “better” than prior to the hospitalization.  • To improve family caregiver confidence in medication management, education about medications was being tested closer to the time of discharge from the hospital.  • Coleman’s discharge preparedness checklist was used to see if family caregivers felt prepared for discharge.  • The partners tested methods of identifying patients who were at high risk of rehospitalization, using the modified Rankin Scale.  • The partners worked to improve medication reconciliation when patients go from home to hospital. Results indicate success with coaching family caregivers to bring a list of the patient’s medications with them to the emergency department and to all doctor visits.</td>
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<tr>
<td>VNSNY</td>
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<td>Cobble Hill Health Center</td>
<td>To improve transitions between sub-acute rehabilitative services and home care by integrating more effective assessment of collaboration with family caregivers</td>
<td>• Extended Home Care nurses found that they gained more specific information about the home situation, in less time, using the Next Step in Care self-assessment tool What Do I Need as a Family Caregiver? than with their existing assessment tool, which has since been replaced with the Next Step assessment.  • Cobble Hill worked to reduce tension for both staff and family caregivers near the time of discharge. One simple but effective change was increasing the size of the line spaces nurses had for writing out the patient’s medications on the discharge instructions; the increased legibility and readability this provided reduced confusion and stress.  • Cobble Hill tested the effectiveness of new teaching materials for diabetics, and continues to use the post-discharge survey of family caregivers to monitor their success.</td>
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<tr>
<td>Extended Home Care</td>
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<tr>
<td>Organization/Partnership</td>
<td>Goals</td>
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| Coney Island Hospital                   | To reduce readmissions from the nursing home to the hospital resulting from medication reconciliation problems; the partners are targeting family caregivers of patients using anticoagulant and insulin therapies that may contribute to transition problems or poor outcomes | • Dealing with both long-term care residents and short-term rehabilitation patients, this partnership has been surprised by the knowledge base of family caregivers regarding patients’ current and past medications.  
• Partnership physicians are working to standardize their handling of medication-related issues to reduce rehospitalization.  
• Coney Island used four metrics: identification of the family caregiver, involvement of the family caregiver in medication reconciliation and later in medication management education, and identification of the family caregiver’s learning needs.  
• Learning from the example of other participating organizations, Coney Island successfully tested the use of a Heart Failure Zone Tool for disease education and management. For continuity, the hospital is now extending use of the tool to its outpatient clinic. |
| Saints Joachim and Anne Center for Rehabilitation |                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Metropolitan Hospital Center            | To improve family caregiver awareness, education, and preparation for ongoing medication management in the home | • Metropolitan found that most family caregivers were caring for more than one person.  
• Caregiver assessment gave Metropolitan the opportunity to target caregiver support and training. Based on needs assessments completed in the hospital, home care nurses, too, were able to tailor caregiver education based on disclosed needs.  
• Medication discrepancies were resolved with patients’ physicians within 24 hours.  
• Metropolitan saw a reduction in readmissions with the aid of medication reconciliation with family caregivers and HHC Health & Home Care follow up on needs and medications in the home. |
| HHC Health & Home Care                  |                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Maimonides Medical Center               | To educate family caregivers on the differences between acute and transitional care settings, with a goal of improving transitions between them | • Use of the Next Step in Care caregiver needs assessment has helped identify potentially unsafe discharges to home care. Hospital partners moved the needs assessment closer to the time of discharge to increase family caregivers’ preparedness.  
• The partnership identified illegible medication lists from the hospitals as barriers to successful transitions to home care. Lutheran instituted EMRs with printed med lists, and Maimonides altered its form to increase legibility.  
• Both home care agencies reconciled hospital and home medications with family caregivers. VNSNY created a three-question screening tool for medication issues.  
• VNSNY used the Next Step in Care guide When Home Care Ends to aid with preparation for discharge.  
• First to Care found that family caregivers who evidenced adequate in-hospital preparation for medication management had more success after discharge and higher feelings of competence, with fewer rehospitalizations for patients. |
<p>| Lutheran Medical Center (Medical/Surgery Unit and Acute Inpatient Rehabilitation Unit) |                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| First to Care Home Care                 |                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| Lutheran Augustana Center for Skilled Nursing |                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |
| VNSNY                                   |                                                                 |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                     |</p>
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| **North Shore-LIJ Health System:**  | To improve transitions for heart failure patients through more effective communication between acute and home care settings, hospital and rehabilitation settings, and home- and hospital-based hospice | • Franklin and Home Care worked closely to make best use of clinical pharmacy staff to improve education and engagement of family caregivers. Nurse educators now work with family caregivers in consultation with the clinical pharmacist, who directly handles cases with unusually complex medications or repeated hospitalizations.  
• Social workers at Franklin screened for family caregiver needs using a modified caregiver assessment and shared this information with nurse educators in the hospital and with home care social workers, for follow up and continuity.  
• Home Care Network used a pre-test at the beginning of services and a post-test after home care ended to test changes in family caregiver confidence in medication management.  
• Orzac focused on discharge preparation from the time of admission, with targeted integration of the family caregiver in ongoing medication and therapy/mobility education, so less would have to be covered on the day of discharge. Satisfaction scores subsequently improved significantly.  
• Hospice Network’s focus on the transition from an inpatient hospice unit to hospice at home or in a skilled nursing facility reduced the number of 911 calls and increased appropriate use of palliative medications. The Network found skilled nursing facilities to present the largest challenge, and is seeking new methods of engagement and education of staff and family caregivers in those settings. |
| **Jewish Home Lifecare (Manhattan)** | To improve the resident and family caregiver experience in moving between sub-acute rehabilitation and long-term care settings | • By testing a range of interventions—from new user-friendly reference sheets listing staff members, to welcome parties, to a family support group—sub-acute and long-term care teams increased patient and family caregiver satisfaction with transitions between their units. |
| **Montefiore Medical Center**     | To increase medication adherence, improve caregiver satisfaction, and reduce readmissions | • Montefiore focused on identification of the family caregiver, the needs assessment, and medication reconciliation. Early results showed family caregiver satisfaction with the engagement of social workers and nurses, and greater comfort in handling medications in the home.  
• Montefiore found success with post-discharge telephone follow up by nurses, who answered family caregivers’ questions, checked on follow-up appointments, and reconciled medications. |
<p>| <strong>Jewish Home Lifecare (Bronx)</strong>   |                                                                 |                                                                                                                                                                                                                                                                            |</p>
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| NYU Langone Medical Center    | To develop shared protocols for transferring information about family caregivers between providers at the time of transition to home care | • Partners created a “Patient and Caregiver Dyad Assessment Tool” to standardize information gathered about patients and family caregivers, which guided referrals and education efforts. The tool proved to be a timesaver, and opened targeted, constructive communication among nurses, patients, and family caregivers.  
• Based on common needs identified through use of the dyad tool, NYU’s nursing students planned education such as cooking classes for caregivers of patients with heart failure.  
• VNSNY helped family caregivers participate in the daily weighing of patients, and master actions to be taken based on the results.  
• Shared protocols established a better flow of information for readmitted patients.  
• Post-collaborative, improved interorganization communication led to regular cross-agency team meetings. |
| VNSNY                         |                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |

| Allen Hospital at New York-Presbyterian | To improve transitions between acute care and short-term rehabilitation through increased communication with and preparation of family caregivers | • While proper referrals for education and training have been made internally, Isabella found that follow up and evaluation of that training has become an essential piece of “closing the loop.”  
• Isabella found that family caregivers of patients in the short-term rehabilitation unit benefited from a combination of increased concrete services, such as adult day care or transportation, and individual counseling.  
• Allen Hospital found that early identification of family caregivers, as well as early discussions of discharge options, lessened caregivers’ feelings of being overwhelmed and made for smoother, possibly swifter discharges. |
| Isabella Geriatric Center      |                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |

| Round Two                     |                                                                      |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                   |
| Beth Israel                   | To reduce readmissions of heart failure patients                    | • Beth Israel added identification and needs assessment of family caregivers to existing Project RED and CTI efforts with heart failure patients.                                                                                                                                                                                                                                                                                                                                                                         |

| Casa Promesa                  | To create a network of caregivers for patients who were ready to return to the community but had no family caregivers | • Casa Promesa integrated community resources into the entire discharge planning process, ensuring a smooth and rapid start of services in the home, with people familiar to and trusted by patients.  
• 100 percent of the patients in the target group went to follow-up appointments within 30 days after discharge. |
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| **Center for Nursing and Rehabilitation**       | To reduce avoidable readmissions for patients in sub-acute care units | • Staff increased and improved related skills, with:  
  > Adoption of Teach Back method for medication education;  
  > New hypoglycemia protocol;  
  > New in-house treatment of heart failure exacerbations;  
  > Increased use of PICC lines for IV fluid/antibiotic therapies.  
• The Center adopted a multi-layered approach to reconciling medications with family caregivers, with each staff member involved throughout the admission process requesting a list/bag of home medications. Readmissions of patients whose family caregivers were involved in medication reconciliation fell to 15 percent, versus 22 percent institution-wide.  
• Staff increased clarity of medication lists for family caregivers by working with pharmacy providers to revamp the list format.  
• Monthly video conferencing with doctors at New York Methodist Hospital resulted in shared clinical protocols for diabetes and heart failure. |
| **Cobble Hill Health Center**                   | To improve communication regarding post-discharge needs with family caregivers of sub-acute care residents with diagnoses of acute myocardial infarction, heart failure, pneumonia, chronic obstructive pulmonary disease, diabetes, or end-stage renal disease | The team:  
• Restructured rounds on the sub-acute unit to create discharge dates agreed upon by all disciplines;  
• Reduced feelings of abandonment reported by family caregivers by renaming discharge planning meetings “after-care planning meetings”;  
• Moved after-care planning meetings closer to the day of admission, exceeding MDS (Minimum Data Set) requirements, to provide more time for preparation of home and services. |
| **Dominican Sisters Family Health Service**     | To improve medication adherence among patients with heart failure or pneumonia | • Staff learned to identify the family caregiver involved in medication management, and the type and mastery of that involvement, and modified the EMR to record this information.  
• The EMR was also modified to reflect and record staff integration of family caregivers into medication reconciliation. Teaching and reinforcing the use of the Teach Back method improved staff skill levels. |
| **Kings County Hospital**                       | To identify family caregivers (Kings County), and to prepare family caregivers to manage medications at home (McKinney) | • Kings County worked on improved, consistent documentation of family caregiver identification.  
• McKinney staff developed good processes for early identification of family caregivers, increasing the amount of time staff had in which to engage them on medication management and follow-up appointments.  
• A Portable Medical Profile developed by the McKinney team is helping with patient and family caregiver education, and is being used after discharge with providers.  
• The number of post-discharge calls to family caregivers was increased, with calls now being placed after 7 and 30 days. |

**Dr. Susan Smith McKinney Nursing and Rehabilitation Center**
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| Metropolitan Hospital            | To continue earlier work to reduce readmissions of partners’ shared heart failure patients | • Social workers at Metropolitan now make needs assessment of family caregivers part of their “Standard Work.” Caregiver information between partners now flows effectively.  
• Metropolitan’s cardiac medicine department facilitates five-day-post-discharge appointments with community cardiologists and outpatient clinics by working with them to ensure that room is made in their schedules.  
• Physicians have a new focus on rapid response to calls from HHC Health & Home Care nurses.  
• Standardized, consistent heart failure education is now in place across the continuum of hospital, home health agency, and clinic care. |
| HHC Health & Home Care           | To reduce hospital readmissions through inclusion of family caregivers in INTERACT 2 Stop and Watch protocols (see page 31), and through increased engagement of family caregivers in advance care planning | • Use of Stop and Watch protocols led to 57 percent fewer rehospitalizations than in the prior year.  
• New educational programming on best practices for stabilizing resident conditions (e.g., management of J-tubes, fever, change in mental status) raised staff skill levels and contributed to reduced rehospitalizations.  
• Testing for the most effective methods for engaging family caregivers in advance care planning found that multiple conversations with very specific, common-language information on outcomes and expectations are essential. |
| Isabella Geriatric Center        | To use the Medical Order for Life-Sustaining Treatment (MOLST) across settings to ensure patient- and family-centered care and reduce unnecessary readmissions | • The partnership achieved a 95 percent success rate on MOLST completions, at least in part because anticipated resistance to MOLST from families was not found.  
• Despite cross-setting education on MOLST for residents, sustainability was compromised as trained residents left and new groups needed to be trained.  
• Palliative care and hospice were discussed openly for referred patients going from the hospital to rehab or long-term care, with Jewish Home Lifecare providing a “bridge” nurse to St. Luke’s to facilitate transitions and MOLST. |
| St. Luke’s-Roosevelt Hospital Center | To reduce readmissions and improve transitional care for heart failure patients | • Social workers at Metropolitan now make needs assessment of family caregivers part of their “Standard Work.” Caregiver information between partners now flows effectively.  
• Metropolitan’s cardiac medicine department facilitates five-day-post-discharge appointments with community cardiologists and outpatient clinics by working with them to ensure that room is made in their schedules.  
• Physicians have a new focus on rapid response to calls from HHC Health & Home Care nurses.  
• Standardized, consistent heart failure education is now in place across the continuum of hospital, home health agency, and clinic care. |
| Jewish Home Lifecare             | To use the Medical Order for Life-Sustaining Treatment (MOLST) across settings to ensure patient- and family-centered care and reduce unnecessary readmissions | • The partnership achieved a 95 percent success rate on MOLST completions, at least in part because anticipated resistance to MOLST from families was not found.  
• Despite cross-setting education on MOLST for residents, sustainability was compromised as trained residents left and new groups needed to be trained.  
• Palliative care and hospice were discussed openly for referred patients going from the hospital to rehab or long-term care, with Jewish Home Lifecare providing a “bridge” nurse to St. Luke’s to facilitate transitions and MOLST. |
| New York Methodist Hospital      | To reduce readmissions and improve transitional care for heart failure patients | • Nursing staff focused on early identification of family caregivers, and early education on disease management for both caregivers and patients.  
• A new discharge medication document was developed and implemented.  
• Streamlined, targeted documentation improved coordination with skilled nursing facilities on transitions, reducing readmissions.  
• Identification of family caregivers is being extended for all patients. |

*This partnership began this work in Round One.*
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| St. Barnabas Hospital    | To reduce readmissions by increasing the number of advance directives for patients with heart failure, cancer, AIDS, or end-stage renal disease who are moving between the partners | The partnership:  
• Tested ways to identify family caregivers who would be involved in advance care planning;  
• Created a positive flow of advance directive/MOLST information;  
• Developed and began to test a training and coaching program, for staff at multiple levels in both facilities, to prepare them for detailed advance care planning conversations with patients and families. |
| St. Barnabas Rehabilitation and Continuing Care Center | To reduce readmissions for heart failure patients living at home | • Communication was found to be a core issue: among hospital staff, among staff and community doctors, and among other staff, doctors, patients, and family caregivers.  
• A number of standard procedures were reevaluated and revamped: rounds were initiated on every floor, and changes were made in the process for assigning doctors to patients. The EMR was changed to include family caregiver information, and staff were trained on who family caregivers can be and how to identify them.  
• Clinical pharmacy staff were integrated into family caregiver and patient education on heart failure.  
• Follow-up appointments with community doctors are now scheduled prior to discharge.  
• Communication between case managers and doctors on discharge dates and post-discharge care needs have been increased, along with referrals of high-risk patients to home care services.  
• The number of social workers has been increased. |
| The Brooklyn Hospital Center | To reduce readmissions for heart failure patients living at home | • Communication was found to be a core issue: among hospital staff, among staff and community doctors, and among other staff, doctors, patients, and family caregivers.  
• A number of standard procedures were reevaluated and revamped: rounds were initiated on every floor, and changes were made in the process for assigning doctors to patients. The EMR was changed to include family caregiver information, and staff were trained on who family caregivers can be and how to identify them.  
• Clinical pharmacy staff were integrated into family caregiver and patient education on heart failure.  
• Follow-up appointments with community doctors are now scheduled prior to discharge.  
• Communication between case managers and doctors on discharge dates and post-discharge care needs have been increased, along with referrals of high-risk patients to home care services.  
• The number of social workers has been increased. |
| Visiting Nurse Service of New York Hospice | To increase communication with family caregivers of CHHA patients regarding care needs and options for hospice and palliative care | • A newly created pocket card prompts staff to identify family caregivers.  
• Coaching increased CHHA nurses’ knowledge of and comfort with hospice and ability to discuss it with family caregivers, and hospice brochures gave them an additional resource for those discussions.  
• Using the Teach Back method allowed assessment of the effectiveness of family caregiver education on hospice and palliative care.  
• The partnership initiated contact with reluctant community doctors to discuss continuing care for patients receiving hospice services. |
References


10 For a description of the Model for Improvement, see http://www.ihi.org/knowledge/Pages/HowtoImprove/default.aspx


14 See http://interact2.net

15 The tool has since been updated. For further information, see http://interact2.net/docs/INTERACT%20Version%203.0%20Tools/Communication%20Tools/Communication%20Within%20The%20Nursing%20Home/INTERAC%20Stop%20and%20Watch%20Early%20Warning%20Tool%20Dec%202012.pdf

16 http://www.nextstepincare.org/Provider_Home/#Toolkit