# CONTENTS

Executive Summary ................................................................. 1  
Introduction And Project Goals .................................................. 2  
Landscape Of Serious Illness ....................................................... 3  
Methods And Project Steps ....................................................... 4  
  Environmental Scan And Literature Review ................................ 4  
  Expert Input ........................................................................... 5  
Framework Components ......................................................... 6  
  Population ............................................................................. 7  
  Structure And Services .......................................................... 12  
  Outcomes ............................................................................. 17  
  Implementation Considerations .............................................. 23  
  Business Model ................................................................. 26  
  The Serious Illness Framework .............................................. 34  
Conclusions And Next Steps ..................................................... 36  
Appendix A: Case Studies .......................................................... 38  
Appendix B: Complete Review Of The Literature ......................... 74  
Appendix C: Works Cited ............................................................ 86  
Appendix D: Feedback From Convening Sessions ............................ 89
ACKNOWLEDGEMENTS

C-TAC and Healthsperien thank our project partners for their contributions to the development of the Framework: Gordon & Betty Moore Foundation, The Betty Irene Moore School of Nursing at UC Davis, The Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School, and The Center to Advance Palliative Care (CAPC). Additionally, we would like to thank all of those who engaged with the convening sessions and webinars for their additions to the conversation.

Project Team

Lead Authors

Khue Nguyen (Project Lead)* PharmD, Chief Operating Officer, C-TAC Innovations
Theresa Schmidt* MA, PMP, Vice President of Strategy, Healthsperien; Director of Data and Quality, National Partnership for Hospice Innovation
Robin Whitney* PhD, Assistant Professor, University of California San Francisco School of Medicine
Gary Bacher (Project Lead)* JD, MPA, Founding Member of Healthsperien, Co-Director, Smarter Healthcare Coalition, Adjunct Assistant Professor, Georgetown University
Janice Bell* PhD, MPH, MN, Associate Professor at the Betty Irene Moore School of Nursing, University of California, Davis
Sibel Ozcelik ML, MS, Research and Implementation Associate, C-TAC Innovations

Contributors and Reviewers

Tom Koutsoumpas,* Co-Founder and Co-Chair, Coalition to Transform Advanced Care (C-TAC)
Mark Sterling* JD, MPP, Senior Fellow, Project on Advanced Care and Health Policy, Petrie-Flom Center at Harvard Law School; Chief Strategy Officer, C-TAC & C-TAC Innovations
Jill G. Joseph* MD, PhD, Professor at the Betty Irene Moore School of Nursing, University of California, Davis
Brad Stuart* MD, Chief Medical Officer, C-TAC & C-TAC Innovations
David Longnecker* MD, Chief Clinical Innovations Officer, C-TAC
Jon Broyles MS, Executive Director, C-TAC

Project Advisor

Kathleen Kerr* Healthcare Consultant, Kerr Healthcare Analytics

*Convening Session Panelist
Expert Stakeholders Consulted

Convening Session Panelists

Namita Ahuja (case study) MD, Sr. Medical Director, Medicare, UPMC Health Plan; Clinical Assistant Professor of Medicine, University of Pittsburgh
John E. Barkley MD, FCCP, Chief Medical Officer, Continuing Care Services, Carolinas HealthCare System
K. Eric De Jonge MD, Director of Geriatrics at MedStar Washington Hospital Center; Associate Professor of Medicine, Georgetown University School of Medicine
Timothy Ferris MD, MPH, Senior Vice President of Population Health Management, Partners HealthCare and Mass General Hospital
Diana Franchitto MBA, President & CEO, HopeHealth/Hope Hospice & Palliative Care
Muriel Gillick MD, Director, Program in Aging, Harvard Pilgrim Health Care Institute and Professor of Population Medicine, Harvard Medical School
Anna Gosline SM, Senior Director of Health Policy and Strategic Initiatives, Blue Cross Blue Shield of Massachusetts
Lauran Hardin MSN, RN-BC, CNL, Senior Director Cross Continuum Transformation, National Center for Complex Health and Social Needs, Camden Coalition of Healthcare Providers
Emma Hoo, Director, Pacific Business Group on Health
Russell Portenoy MD, Chief Medical Officer, MJHS Hospice and Palliative Care; Executive Director, MJHS Institute for Innovation in Palliative Care; Professor of Neurology and Family and Social Medicine, Albert Einstein College of Medicine
David Posch MS, Executive Vice President, Population Health, Vanderbilt University Medical Center
Jay Rajda MD, MBA, FACP, Chief Clinical Transformation Officer, Aetna
Monique Reese DNP, ARNP, FNP-C, ACHPN, Chief Clinical Officer, Sutter Care at Home
Allison Silvers* MBA, Vice President, Payment and Policy, Center to Advance Palliative Care (CAPC)
Robert Sowislo MBA, Government Affairs Officer, U.S. Medical Management
Gwynn B. Sullivan MSN, Project Director, National Consensus Project, National Coalition for Hospice and Palliative Care
Jennifer Valenzuela MSW, MPH, Principal of Program Department, HealthLeads
Victoria Walker MD, CMD, Chief Medical & Quality Officer, The Evangelical Lutheran Good Samaritan Society

Additional Interviewees

Erin R. Kime (case study), Program Director, Medicare Products, UPMC Health Plan
Suzanne Kinsky (case study) PhD, MPH, Senior Program Administrator, UPMC, Adjunct Assistant Professor, Behavioral and Community Health Sciences, Pitt Public Health, University of Pittsburgh
Sonia Sarkar (case study) MPH, Chief Policy and Engagement Officer, Baltimore City Health Department
Sally Okun RN, MMHS, Vice President, Advocacy, Policy, and Patient Safety, PatientsLikeMe
Harriet S. Warshaw, Executive Director, The Conversation Project, Institute for Healthcare Improvement
EXECUTIVE SUMMARY

The American health care system’s approach to the treatment of serious chronic illness is fragmented, and this exacts a heavy toll on some of its sickest and most vulnerable patients and their families. Wide regional variations in quality, utilization, and cost of care for patients with serious chronic diseases have been reported for decades. The challenge is amplified by the aging of the US population and the diversity of those living with serious illness, creating a tremendous burden on our health care system at large.

Promising care-delivery programs for serious illness have emerged in recent years and are gaining momentum due to the introduction of alternative payment models. Despite growing national interest in innovative care models for serious illness that improve quality and reduce costs, limited information is available to guide health care organizations from program innovation to implementation.

This white paper proposes a Serious Illness Program Design and Implementation Framework (SIP Framework) to inform program development, replication, and scaling across a broad range of serious illness populations and settings. The SIP Framework process begins with setting a vision and completing a local needs assessment and walks through a range of evidence-based options for each facet of care model design and implementation, including possible business models, target populations, services, and outcomes to guide health care organizations in adapting serious illness programs to their local contexts. Key implementation considerations for encouraging program success include leveraging existing programs and resources, recruiting strong program leaders, engaging staff, assembling experienced multidisciplinary care teams, building strong relationships among team members and with patients/caregivers, and establishing processes for program evaluation and continuous quality improvement.

The SIP Framework reflects a growing landscape of care models for serious illness, distilling existing evidence from a wide range of existing programs to offer a variety of promising approaches to program implementation. Next steps in this work include framework impact assessment, piloting the framework for use with future programs, monitoring and reporting program implementation, creating a simulator for serious illness program payment models, and identifying and implementing research and policies aimed at promoting the implementation of a serious illness program.

1 The Coalition to Transform Advanced Care. The Advanced Care Project. http://www.thectac.org/key-initiatives/advanced-care-project/
INTRODUCTION AND PROJECT GOALS

C-TAC has collaborated with Healthsperien, the Betty Irene Moore School of Nursing at UC Davis, and the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School to develop a flexible Serious Illness Program Design and Implementation Framework (SIP Framework) consisting of foundational elements of program design and components that contribute to program success.

The SIP Framework is a flexible tool for health care systems and providers, designed to inform the development, implementation, and evaluation of serious illness care programs built upon available evidence for successful care models. The model highlights the characteristics to consider when identifying the structure and services most appropriate for an individual. These include the characteristics of each health care provider, the population, and the organizational context. The SIP Framework is also designed to encourage the use of outcomes data to measure success and better inform future program development.

The SIP Framework is designed to:
- Inform serious illness program development, replication, and scaling
- Integrate with care model payment design
- Inform care model proforma simulator development
- Inform other aspects of design and development such as policy, standardized measurements, and regulatory analysis

Panelist Perspective:

The SIP Framework provides a roadmap to build compassionate and holistic teams that serve ill people from early in serious illness until the end of life if needed. Consider a patient of mine, Ms. S., who has had multiple strokes and suffers from diabetes, advanced dementia and the inability to walk. She and her daughter need 24/7 access to good primary care and daily social services. Her providers need a payment system that both rewards coordination of all her care and supports services that help her stay at home.

Too often, however, the usual care has many gaps: there is no primary care team, information is scattered, daily support services are hard to find, or no one is available after usual office hours. People with serious illness then face tough decisions like calling 911 for unneeded hospitalizations, seeking fragmented care from a variety of specialists, and placing high burdens on family caregivers.

By applying this new framework when developing programs, health systems and others can learn to better serve people like Ms. S. and her family and create more sustainable practices at the same time. Public and private payers can reference this framework to ensure that emerging payment systems support the range of structures and services that will meet the needs of providers, caregivers, and people like Ms. S.

K. Eric De Jonge, M.D.
Director Geriatrics
MedStar Washington Hospital Center
LANDSCAPE OF SERIOUS ILLNESS

Care for serious illness is a national issue with broad personal, economic, and political ramifications. The population is aging rapidly today – the number of older Americans will double by 2060 – and needs specialized, person-centered care that, under present conditions, will either be unavailable or too costly for many people. Researchers estimate that 45 million Americans have “one or more chronic conditions that limit personal function” and are expected to lead to further declines. People with serious illness make up 14% of the population but 56% of health care expenditures, costing nearly one trillion dollars. Patients with serious illness use hospital services at more than twice the rates of patients with multiple chronic conditions only.

While serious illness has been defined as “a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments or caregiver stress,” the National Academy of Medicine emphasizes the diversity of those living with serious illness in its definition of that population:

People with serious illness is defined as those with complex and pressing care needs due to a particular disease, e.g., persons with metastatic lung cancer or amyotrophic lateral sclerosis who have breathing difficulty. The definition also includes people who have some years of self-care disability, often at the ends of their lives, from conditions such as cognitive or neuromuscular impairment, strokes, organ system failures, frailty of old age, or other conditions.

The needs of people with serious illness extend beyond the medical model of health care to include social supports, symptom relief, care coordination, communication, and decision support. However, patients often have limited access to services that transcend the medical model to help support their quality of life. Innovative serious illness programs across the United States seek to meet these needs and improve patient and population health.

3 Commonwealth: High-Need, High-Cost Patients, 2016 Issue Brief
5 Miller and Wang (2017)
6 Commonwealth: High-Need, High-Cost Patients, 2016 Issue Brief
8 Miller and Wang (2017) p.1
9 Miller and Wang (2017)
METHODS AND PROJECT STEPS

The SIP Framework was developed in phases designed to combine empirical evidence from reviews of serious illness or related programs with the expertise and experience of stakeholders in advanced illness, serious illness, and end of life care.

The following is a summary of the project steps that are elaborated below:

• Reviewed white papers and existing literature
• Developed draft SIP Framework, continued literature review
• Hosted first convening session at the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School with 10 expert panelists, 11 project partner panelists, and 46 registrants
• Conducted nine follow-up interviews with expert stakeholders
• Hosted webinar with 89 attendees, predominantly members of C-TAC
• Refined and enhanced Framework; added details and definitions, analyzed reviews
• Hosted second convening session at the Petrie-Flom Center with nine expert panelists, seven project partner panelists, and 40 registrants
• Finalized SIP Framework, completed evaluation of evidence from literature, and presented final webinar
• Completed case studies and white paper

The resulting SIP Framework showcases core considerations for designing and implementing a new serious illness program or enhancing an existing program.

ENVIRONMENTAL SCAN AND LITERATURE REVIEW

We identified reviews of serious illness programs by first conducting a preliminary scan of “white papers” — defined as technical or other reports published on websites of known health policy, advocacy, and government organizations (e.g., National Academy of Sciences, Robert Wood Johnson Foundation, Center to Advance Palliative Care) — to efficiently identify current approaches to providing serious illness care and describe the range of terminology, populations, and programs that fit under the umbrella of “serious illness.” In addition, we solicited recommendations for sources to include in the synthesis from experts in the field of serious illness care, including members of our project team and other expert stakeholders who attended our convening sessions and first webinar. Finally, we identified additional resources from the reference lists of all identified papers. From this process, it quickly
became evident that a multitude of leading health care organizations — including many representative of the hospital industry, government agencies, insurers, and health care policy or advocacy groups — have been deeply engaged in a national conversation about the state of serious illness care, with a proliferation of research on interventions for individuals with serious illness over the last decade.

Our search identified a large number of systematic reviews and/or meta-analyses focused on the outcomes of programs that were created to serve populations that fall under the definition of a “serious illness population” but used alternative labels or population definitions. Importantly, despite the range of population definitions and programs, these reviews share common elements and areas of overlap relevant to serious illness care. Accordingly, we conducted a synthesis of reviews rather than of individual studies in an effort to collate high quality existing evidence gathered from a range of populations under the broader concept of serious illness care. To our knowledge, this large body of evidence has not been synthesized to date.

Key questions that we set out to answer with the synthesis included:

1. What serious illness care populations are included in the programs reviewed?
2. What outcomes are improved by serious illness care programs? What is the strength or quality of existing evidence for serious illness care programs?
3. What specific program structures and services are associated with success?
4. What implementation considerations are described in the literature?

Collectively, the reviews assessed outcomes of 869 studies or programs, including 426 randomized controlled trials. However, these are not 869 unique programs, as some studies were included in multiple reviews. See Appendix B for a full discussion of the review methodology and literature selected, including inclusion and exclusion criteria, along with the data collection strategy.

**EXPERT INPUT**

As we created the SIP Framework, informed by the evidence identified in our literature review, we also sought input from distinguished stakeholders to refine and focus the developing framework (See Acknowledgements for a list of contributors). We presented our initial SIP Framework at a March 10, 2017, convening session at the Petrie-Flom Center for Health Law Policy, Biotechnology, and Bioethics at Harvard Law School. During this session, we invited 10 external panelists to participate in a round-table discussion with project partners, provide feedback on the draft SIP Framework, and offer insight into the development and implementation of serious illness programs. The first convening session was followed by nine interviews with these panelists and other experts in the field. On May 17, we presented our updated draft of the SIP Framework to 89 attendees of a C-TAC webinar and
solicited feedback on the SIP Framework components specifically and program implementation more broadly. Finally, we brought together nine external panelists (including two from the first convening) to discuss the revised framework and share their experiences with and recommendations for implementing serious illness programs.

**FRAMEWORK COMPONENTS**

The SIP Framework incorporates evidence from the review of literature and expert feedback. Through the SIP Framework, we introduce an iterative process (Figure 1), wherein a business model is developed, population chosen, structures and services identified to meet core outcomes, and an implementation plan created. This section describes these framework components in detail. Because the components are interrelated, each may be revisited during the phases of design and implementation.

*Figure 1: Developing a Serious Illness Program*

1. **ASSESS AND PLAN**
   Set the vision for the program, perform an organizational and environmental assessment, and develop the appropriate business model to address context and meet program goals.

2. **DESIGN PROGRAM**
   - Refine population parameters for people you will serve and understand the needs.
   - Develop program structure that will allow you to provide the services needed to achieve optimal care outcomes.

3. **IMPLEMENT PROGRAM**
   Create an implementation plan and guide your organization through program roll-out, evaluation, and continuous improvement.

To assess how these components align with existing programs, we applied the SIP Framework to eight serious illness programs. Appendix A includes six case studies of models chosen because of their diversity, inclusion in the literary review and previous academic peer reviewed papers, and availability of outcomes data. This appendix also includes two “deep-dive” case studies, which summarize our interviews with stakeholders involved in innovative models of care.
Population

Across our review of existing program literature, the terminology used to describe individuals with serious illness varied widely, as did the population foci reported for serious illness care programs. We organized serious illness populations into five categories stemming from the primary motivations for program development: 1) high need/high cost; 2) illness or condition; 3) insurance; 4) age; and 5) services (e.g., palliative care, primary care). The categories are not mutually exclusive, and many of the reviews included population definitions that touched on multiple categories (see Appendix B, Table 3). By far, the most reviews focused on programs that defined their populations by condition—typically multiple or advanced chronic conditions—populations that might arguably fall under the high need/high cost category as well. See Appendix B for a complete discussion of the populations covered in our review of existing program literature.

In the SIP Framework, patient care needs were characterized in the population by incorporating applicable population elements from the literature review. The population health care needs can be characterized by three primary factors: health status, functional status, and psychosocial status. While the factors are interdependent, each can serve as a primary criterion to target a population, and any combination of the three factors can result in more specific serious illness population targeting (e.g., advanced cancer or advanced cancer with functional limitations and low caregiver support).

The goal of the SIP Population Framework is to elucidate the broad and diverse range of patient care needs within the serious illness populations. This is important as programs seek to determine patient eligibility criteria to identify target populations and design services to match population needs. Multiple factors influence how a program designs patient eligibility criteria. Given this variability, the SIP Population Framework displayed in Figure 2 provides a common “map” that can clarify the population needs of any given program.
To validate the usefulness of the SIP Population Framework as a generalizable serious illness population needs map, we charted the population definitions from representative care models to the SIP Framework. Figure 3 displays this crosswalk, which reveals similarities and differences in populations between care models.
The similarities between the models illustrated in Figure 3 suggest that the SIP Population Framework represents a generalizable way to map the wide-ranging needs of the serious illness population. However, programs must utilize more specific descriptors and standardized patient assessment scales to operationalize patient identification and selection. Figure 4 describes the features and sub-components of health, functional, and psychosocial status. Based on stakeholder input, we have emphasized disease progression, social determinants, and existential/spiritual concerns as important patient needs to address in program design.
Figure 4: Population Characteristics

**HEALTH STATUS**
- **Disease Severity**
  - Hospitalization risk
  - Number/type of chronic conditions and comorbidities (advanced cancer, dementia)
  - Severity of illness
  - Condition requires disease management
  - Prior utilization patterns, “high-cost/high-need”
  - Risk score
- **Disease Progression**
  - Chronic illness/disability
  - Terminal or life-limiting illness
  - Expected rapidity of decline

**FUNCTIONAL STATUS**
- **Physical Status/ADLs**
  - The level of assistance needed for activities and instrument activities of daily living and/or caregiver burden
- **Disease Progression**
  - Cognitive impairment
  - Dementia/Alzheimer’s
  - Mental Illness
  - Addiction
  - Trauma/other psychological needs

**PSYCHOSOCIAL STATUS**
- **Environment/Access**
  - Provider availability and linguistic and cultural competency
  - Transportation
  - Access to food that meets dietary needs
  - Insurance coverage or payment ability
  - Physical features or residence
  - Caregiver status and support at home
- **Coping/Resiliency**
  - Cognitive ability and mental illness as it relates to patient’s ability to care for self
  - Motivation and self-management skills
  - Social networks or isolation
- **Other Social Determinants**
  - Socioeconomic status and economic stability
  - Demographics
  - Education and health literacy

Figure 5 lists the identification criteria employed by existing programs, which may be applied alone or in some combination. Any set of criteria will convey a certain level of sensitivity (true positive identification rate) and specificity (true negative rate) in identifying patients for the desired target population. Patient needs often remain variable at some level in terms of health, functional, and/or psychosocial status. Therefore, it is important to identify the underlying needs of the population selected by a set of eligibility criteria rather than relying solely on the eligibility criteria themselves to describe population needs.
Multiple factors influence how programs select a target population for improvement, including existing capabilities and expertise, level of influence over the care of the population, cost, available payments, and return on investment. As discussed in the Business Model section below, many of these factors are predefined for a given program, which leads to a certain level of predictability for design and implementation. Alternative payment models (APMs) may offer some opportunities for flexibility by providing payment incentives for improving care for certain patient populations where the care gap and opportunities are significant. Many value-based payment models target specific populations, often focusing on the concept of high-risk / high needs which corresponds to the serious illness population characteristics. Figure 6 lists the broadly-defined populations served by CMS APMs.
A stated goal in many of the reviews discussed in existing literature was identifying features of serious illness programs that are associated with successful outcomes. However, identifying specific structures and services that contribute to success is challenging for several reasons. First, most serious illness programs are multifaceted and most studies are not designed to assess the independent or relative contribution of individual program features. Second, comparisons between programs are complicated by the heterogeneity of program features and their descriptions. For example, commonly mentioned program features such as “care coordination” or “comprehensive assessment” were often not further defined in the literature, contributing to a lack of clarity about the exact interventions that might be included in those terms. Due to these challenges, many of the reviews included in our synthesis did not yield data sufficient to identify specific program features associated with success.

Of the 28 final reviews, 17 attempted to identify program features associated with success, despite methodological challenges. Most did so either by: 1) tabulating program features and identifying those that were more common among successful programs than among unsuccessful programs, or 2) including qualitative assessments of what contributed to program success. The most common features identified were:

1. Appropriate targeting and selection of high-risk individuals
2. Care coordination or patient navigation
3. Transition management
4. Face-to-face contact between coordinators and patients and providers
Our conversations with stakeholders similarly emphasized the importance of care continuity, transitions management, and communication. For example, panelists in both convening sessions stressed that continuous contact and strong relationships between and within teams and providers and with the patient and family are key factors in program efficacy. Stakeholders also provided feedback on key care management services during interviews.

Two prominent themes in stakeholder conversations that were less pronounced in the review of existing program literature were the need for social support services and existential/spiritual support services. Many of these services tie directly to the Psychosocial Status category of the SIP Population Framework. None of the program reviews specifically considered spiritual support services or features, and only two examined existential or spiritual concerns as an outcome. This gap points to the need for future studies of this important serious illness care program domain.

The SIP Services and Structure Framework (see Figure 7) lists the key program services and structural elements that can be considered during program design to ensure the program meets population needs. Elements identified in the review of existing program literature as associated with program success are indicated with a ✓ symbol. In designing services, programs may choose to fill a specific service gap such as care coordination or a range of comprehensive services such as community-based palliative care or advanced illness care.

Figure 7: Program Services and Structure
Figure 8 and Figure 9 offer descriptions of each of the services and structural components listed in the SIP Framework along with the range of designs observed in the literature and through stakeholder discussions. Not all listed services emerged in the review of existing program literature, suggesting important areas for future research. The complete review of existing program literature related to structure and services is featured in Appendix B. Like the population, the services and structure of a program will be informed by the business model, including existing capabilities and expertise, regulatory and licensure issues, geography, and available payment models.

**Figure 8: Care Management Services**

<table>
<thead>
<tr>
<th>Service/Intervention</th>
<th>Description</th>
<th>Range of Designs</th>
</tr>
</thead>
</table>
| Care Coordination & Transitional Care                    | Identify, coordinate, and facilitate follow-up services                                                                                                                                                      | • Clinical and social services  
• Patient coaching vs. coordination with providers vs. direct set-up of services  
• Transitional care focuses on coordination between care settings/services (e.g. hospital to home)                                                                                                                                                                                                                                                                        |
| Multidimensional Assessment                              | Person-centered assessment: physical, emotional, psychological, spiritual, and social status; future risks                                                                                                                                                              | • Disease-focused vs. person-centered  
• Hands-on assessment e.g. physical exam vs. question-based assessment                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Goal-setting & Advance Care Planning                    | Facilitate identification of values, beliefs, and preferences over time. Elevate the patient’s voice. Promote shared decision-making                                                                                                                                  | • Frequencies of planning: once vs. occasional vs. ongoing during advanced illness to end-of-life  
• Aspects of planning: advanced directive, link personal values/preferences with end-of-life treatment modalities                                                                                                                                                                                                                                                                                                                                                       |
| Proactive Clinical/ Symptom Management                  | Facilitate proactive management of clinical issues (includes ADL support, cognitive support, psychological support, behavioral health, medication management, etc.)  
                                                                                                                                                                                                                                                       | • Monitor and anticipate clinical status and coordinate with treating providers  
• Provide clinical expertise and manage clinical issues along with treating providers                                                                                                                                                                                                                                                                                                                                                          |
| Spiritual Services                                       | Operational processes to identify and enroll eligible patients                                                                                                                                              | • Strict vs. informal eligibility determination, linked to exclusion and discharge process  
• Organized vs. informal identification process  
• Access to EHR for clinical information or automated reports                                                                                                                                                                                                                                                                                                                                                                             |
### Figure 8 (cont.): Care Management Services

<table>
<thead>
<tr>
<th>Service/Intervention</th>
<th>Description</th>
<th>Range of Designs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Coaching / Care Training</td>
<td>Utilize patient engagement techniques to coach patient on self-management</td>
<td>• Patient’s self-management skills and motivation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Social, emotional, and clinical aspects of health literacy</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Disease-focused management</td>
</tr>
<tr>
<td>Caregiver Support</td>
<td>Provide technical guidance and emotional support to caregivers; conduct caregiver assessment</td>
<td>• Caregiving skills and confidence</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Caregiver’s well-being assessment &amp; additional support such as respite services</td>
</tr>
<tr>
<td>Transportation</td>
<td>Facilitate transportation to patient appointments or other locations</td>
<td>• Program vans/cars</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Rideshare services</td>
</tr>
<tr>
<td>Home Safety / Access Adaptations</td>
<td>Assess and modify the patient’s residence to improve ability to function safely</td>
<td>• Access ramps and through floor lifts</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• internal widening for wheelchair access, grab bars</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Bathroom and Kitchen adaptation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Security alarms and motion alarms</td>
</tr>
<tr>
<td>Homemaker Services</td>
<td>Assist with daily household tasks</td>
<td>• Housekeeping Services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Shopping and errands</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Meal Planning and preparation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Laundry, Dishes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Pet care, plant care</td>
</tr>
<tr>
<td>“Upstream” Community Programming</td>
<td>Provide services to the community to support population health.</td>
<td>• Education and health-literacy programs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Community bereavement program</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Community outreach around key topics (ex. advance directives)</td>
</tr>
</tbody>
</table>
### Figure 9: Program Structural Components

<table>
<thead>
<tr>
<th>Structural Component</th>
<th>Description</th>
<th>Range of Designs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multidisciplinary Care Team Composition</td>
<td>Clinical and non-clinical resources involved in care delivery</td>
<td>• Composition of team members involved in care management services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Informal vs. formal division of responsibilities and coordination between team members</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Scope and richness of care management interventions is dependent on team composition</td>
</tr>
<tr>
<td>Patient Targeting</td>
<td>Operational processes to identify and enroll eligible patients</td>
<td>• Strict vs. informal eligibility, exclusion and discharge criteria</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Organized vs. informal identification process</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Access to EHR for clinical information or automated reports</td>
</tr>
<tr>
<td>Relationship Building and Caregiver Consistency</td>
<td>Staffing structure to support relationship-building with patients, family and usual care providers</td>
<td>• Patient and provider experience of various team member encounters</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Clarity of main point of contract and team coordination</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Staffing plan must balance efficiency with caregiver consistency</td>
</tr>
<tr>
<td>Robust Communication</td>
<td>Communication between coordinators, patients, and providers via multiple channels</td>
<td>• Face-to-face contact on a regular basis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Telephone outreach (regular/daily)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 24/7 support line</td>
</tr>
<tr>
<td>Days of Operation</td>
<td>Care access and clinical response approach based on days of operations</td>
<td>• Prevention and anticipatory management can be accomplished during business hours</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Time-sensitive interventions require 7-day or 24/7 coverage (e.g. transitional care, high-acuity co-management services)</td>
</tr>
<tr>
<td>Care Delivery Settings</td>
<td>Direct &amp; virtual patient care encounters in various care settings</td>
<td>• Care management strategy and scope is dependent on delivery settings: nature of advanced care planning varies if delivered in office or hospital vs. home setting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Virtual delivery/ telemedicine is effective and efficient but limits hands-on care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Physician coordination is facilitated by office/clinical presence</td>
</tr>
</tbody>
</table>
### Outcomes

Designing a system to measure outcomes is critical for assessing the impact of a program on a population and individual patients. To incorporate both quality and sustainability into the SIP Framework, we build on the Quadruple Aim for optimizing health system performance, “enhancing patient experience, improving population health...reducing costs...[and] improving the work life of health care providers.”

The SIP Outcomes Framework translates the Quadruple Aim into the categories of Experience (Patient, Family/Caregiver, Staff), Health Outcomes, Care Processes, and Utilization / Cost, and adds another category to include Operational Outcomes. The collective evidence for serious illness care programs in the existing program literature evaluated more than 50 outcomes, which tend to fall in the first four categories. See Figure 10 for a crosswalk between the SIP Framework categories and the Quadruple Aim.

---

**Outcomes: Health Service Utilization and Costs**

The most commonly studied outcomes of serious illness care programs were broadly categorized as health service use and costs (Appendix B, Table 9), with all reviews including at least one measure in this category and all but four reviews showing a reduction in at least one measure.

Reduced hospital admissions was the most commonly demonstrated health service outcome, with strong evidence for reduced admissions associated with serious illness programs across a range of population definitions. Of the eighteen reviews that studied hospital admissions, 13 demonstrated a reduction with five showing inconsistent or no effects. Some reviews also demonstrated reduced hospital readmissions and reduced hospital bed days.

A similar body of evidence, albeit with mixed results, suggests a decrease in total health care costs—presumably driven by reduced hospital admissions, which are known to comprise the greatest share of health care costs.11 Seventeen reviews addressed total costs with 10 reviews demonstrating reduced costs, 10 showing inconsistent or no effects and two reviews demonstrating an increase in total health care costs with serious illness programs. These findings are also consistent with the mixed evidence for reduction in overall health care use associated with serious illness care programs, with nine reviews including this outcome, five reviews showing a reduction, and four showing no effects or inconsistent effects. Other outcomes in this category with mixed results include Emergency Department (ED) use, Intensive Care Unit (ICU) days, specialty visit use, home-based intervention costs, long-term care or nursing home admissions, hospice use, use of chemotherapy among advanced cancer patients, and cost effectiveness of serious illness care programs.

---

Outcomes: Experience

The patient reported outcomes most consistently included in the reviews were experience and satisfaction, with both patients and caregivers consistently reporting improved satisfaction with serious illness care programs.

Outcomes: Health

Patient symptoms and symptom burden were also commonly studied with many reviews reporting improvement and a few reporting no effect. Likewise, most reviews that measured quality of life reported improvements with a minority finding inconclusive or no effects. Of five reviews reporting physical health status outcomes, patients reported improvements in three reviews and inconsistent or no effects in two reviews. Psychosocial health status (five reviews), functional health status (three reviews), functional autonomy (one review), and positive health behavior change (one review) improved in all reviews that reported these outcomes.

Only one review included existential or spiritual concerns, reporting improvement. Of three reviews that considered caregiver burden, two reported decreases and one reported inconsistent or no effects. Finally, two reviews found lower mortality rates and two reviews reported increased rates of death at home with serious illness care programs.

Outcomes: Care Process

Limited evidence (10 reviews) was available to describe care process outcomes associated with serious illness care programs (Appendix B, Table 9). The most commonly studied outcomes in this category were: quality of care; care planning, broadly defined; and more specifically, advance care planning (e.g., advance directive completion). Quality of care improved in three of three reviews, advance care planning improved in two of two reviews; however, of the three reviews that considered care planning broadly, improvements were noted in only one. Physician-patient communication improved in one review; however, inconsistent or no effects were reported for clinician adherence to guidelines and process quality measures. Evidence for physician experiences with advanced illness care programs was mixed, with one review finding improvement and one review finding no effects. One review found improvements in quality of primary care and hospital to home care but no improvements in home-based care quality.

Outcomes: Operational

Only one review examined operational outcomes, specifically referrals, finding no effect. While there was little evidence on operational outcomes studied, we included this as a distinct category to capture outcomes that could be assessed to determine the business success of a program, which is important to program sustainability and the ongoing ability to achieve outcomes in the other categories.
Summary of Evidence for Outcomes

On the whole, the evidence for serious illness care programs is promising, with positive outcomes reported related to health service use and costs, experience, health, and care processes. Given the heterogeneity in program components, it is not possible to disentangle the effects of specific serious illness program intervention components on specific outcomes. By far, the evidence is most robust for health service utilization outcomes—specifically for reductions in hospital admissions. This suggests that aligning payment structures to support these programs might benefit payers, providers, patients, and caregivers alike. Further research is warranted to focus on other outcomes including outpatient service use and advanced illness care outcomes (hospice, advance care planning). Studies of cost effectiveness of serious illness care programs should also be prioritized.

Although less frequently studied than health service use, the evidence for improvements in experience and health outcomes is quite consistent, with most reviews that addressed these outcome categories finding improvements—including in the realms of physical health, psychosocial health, symptom burden, and quality of life. Of note, the evidence for reduced mortality was similarly consistent and positive, albeit addressed in only a few reviews.

By far, the most limited evidence was for care process and operational outcomes. While the results in the reviews of these outcomes were quite promising, further study is clearly needed to better understand these outcomes, ideally, in studies designed to contribute evidence for future dissemination and implementation. See Appendix B for a complete discussion of the outcomes identified in our review of existing program literature.

SIP Outcomes Framework

Although there was mixed evidence for the effects of serious illness programs on various outcomes and well-documented challenges measuring quality for these populations,12 several organizations have begun work on creating guidelines and measure concepts that can be useful in evaluating serious illness programs. Some examples include the National Quality Partners’ Advanced Illness Care Initiative,13 American Academy of Hospice and Palliative Medicine’s (AAHPM) Measuring What Matters project,14 the Center to Advance Palliative Care’s Palliative Care in the Home,15

---

12 For example, see Joan M. Teno, Rebecca Anhang Price, and Lena K. Makaroun. Challenges Of Measuring Quality Of Community-Based Programs For Seriously Ill Individuals And Their Families. Health Aff July 2017 36:1227-1233
and the National Consensus Project for Quality Palliative Care’s *Guidelines for Quality Palliative Care*. Measures and concepts from these programs were used to inform the outcomes categories shown below.

Experts interviewed during the course of this project also stressed the importance of developing a quality measurement system that supports both accountability and continuous quality improvement. Additionally, the need for program sustainability emerged as a theme. Thus, the SIP Framework includes the category of “Operational Outcomes” to capture business measures of program success as noted above.

Figure 11 presents the SIP Outcomes Framework. Although these categories represent outcomes that may be qualitatively different from one another, experts stressed the relationships between these outcomes, especially cost and quality (i.e., health and process outcome). As noted during the second convening session, “Cost and quality go hand in hand; lead with quality, and financial savings will follow.” Outcomes with a strong evidence base are indicated with a \( \uparrow \) or \( \downarrow \) to indicate whether programs were found to increase or decrease the outcome. In all of the indicated outcomes, \( \downarrow \) is favorable.

**Figure 11: Outcomes: Person-centered & Value-based to Define Program Success**

While these general categories cover a broad landscape of outcomes, there are various ways of measuring these outcomes (see Figure 12). Rather than trying to capture every possible measure, program designers should select measure concepts

---

that align with program goals and payment or regulatory needs. Process, outcomes, and structure measures all have a place in measuring experience, health outcomes, care processes, and operational efficacy; program designers can identify both broad measures of program success and specific measures for quality and performance improvement. Finally, program designers should consider the feasibility of collecting data and the measurement burden when designing the measurement system.

Figure 12: Sample measure concepts

<table>
<thead>
<tr>
<th>EXPERIENCE</th>
<th>HEALTH</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Experience</strong></td>
<td>• Functionality (physical, mental)</td>
</tr>
<tr>
<td>• Patient feels services reflect goals and preferences</td>
<td>• Symptom / clinical performance</td>
</tr>
<tr>
<td>• Satisfaction with and confidence in care</td>
<td>• Patient safety: falls, medication errors, etc.</td>
</tr>
<tr>
<td>• Patient feels social, emotional and spiritual needs are met</td>
<td>• Care concordance with goals and preferences</td>
</tr>
<tr>
<td><strong>Caregiver Experience</strong></td>
<td>• Self-efficacy</td>
</tr>
<tr>
<td>• Caregiver burden</td>
<td>• Mortality / survival</td>
</tr>
<tr>
<td>• Confidence in care provided</td>
<td></td>
</tr>
<tr>
<td>• Satisfaction in care</td>
<td></td>
</tr>
<tr>
<td>• Caregiver health status: physical/mental/emotional</td>
<td></td>
</tr>
<tr>
<td><strong>Clinician/Staff Experience</strong></td>
<td></td>
</tr>
<tr>
<td>• Turnover and retention</td>
<td></td>
</tr>
<tr>
<td>• Employee engagement</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>UTILITY AND COST</th>
<th>OPERATIONAL</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inpatient &amp; Other Utilization</strong></td>
<td><strong>Market Penetration</strong></td>
</tr>
<tr>
<td>• LOS at each care setting</td>
<td>• Number of Patients Served</td>
</tr>
<tr>
<td>• Hospitalizations, readmissions</td>
<td>• Geographic footprint</td>
</tr>
<tr>
<td>• ER Use, ICU Use</td>
<td></td>
</tr>
<tr>
<td>• Unnecessary visits, tests, and medications</td>
<td><strong>Financial Sustainability</strong></td>
</tr>
<tr>
<td><strong>Out-of-pocket Costs</strong></td>
<td>• Net revenue or loss</td>
</tr>
<tr>
<td>• Cost to patient and family</td>
<td>• Donations or investments</td>
</tr>
<tr>
<td><strong>Total Health Care Expenditure</strong></td>
<td><strong>Staffing Levels</strong></td>
</tr>
<tr>
<td>• Provider sector (e.g. hospital) and health system</td>
<td>• Caseload</td>
</tr>
<tr>
<td>• Health plan</td>
<td><strong>Partner/Provider Relationships</strong></td>
</tr>
<tr>
<td>• Total system: payers &amp; provider</td>
<td>• Number of contracts</td>
</tr>
<tr>
<td></td>
<td>• Referral patterns</td>
</tr>
</tbody>
</table>

A useful construct for selecting measures is the National Quality Forum’s hierarchical measure framework.17 NQF prioritizes measures that are outcome-focused, improviable and actionable, meaningful to patients and caregivers, and that support systemic and integrated view of care. These criteria overlay a measures hierarchy under which measures have different importance at different levels in the health care

17 Content from: Burstin, Bernot, and Tilly. “Strategic Plan: Prioritization of Measures and Gaps”. NQF Annual Conference Presentation, April 4, 2017
system, from “improvement measures” that help drive performance improvement up to “high impact outcomes” that can be used to assess national progress in a given area of health care (See Figure 13). By choosing measures at several levels in the hierarchy, program designers can measure the impact of the program on individual patients to drive improvement as well as assessing the overall success of the program.

Figure 13: NQF Hierarchical Framework

**Implementation Considerations**

One of the critical tasks of our review was to identify implementation considerations that would be informative for organizations undertaking the design or modification of a serious illness program. However, relatively few of the included reviews (10 of 28) discussed implementation. Reviews that discussed implementation based their findings on qualitative program synthesis or interviews with stakeholders involved in successful and unsuccessful programs. The most commonly identified implementation consideration was the need to build strong relationships between program staff and patients and caregivers as well as key medical care providers (e.g., primary care providers), and the need to leverage health technology for decision support and continuous quality improvement. Other considerations included tailoring program design to the local context, changing organizational culture to support program success, hiring appropriately trained and experienced staff, finding ways to pool resources, and implementing in organizations with better infrastructure to support these programs (e.g., accountable care organizations). Appendix B includes a complete review of implementation considerations discussed in existing literature.

Several of these considerations were echoed by expert stakeholders, who noted that continuous contact and strong relationships between and within providers and with the patient and family are key factors in program efficacy. Other important factors
mentioned included creating an implementation plan that matches organizational culture, engaging senior leaders to ensure the program is prioritized and sufficiently resourced, assessing staff and providing ongoing educational opportunities, and establishing processes for iterative learning and adapting program components to incorporate feedback. Across all of these components, effective and ongoing communication is essential to success. Figure 14 illustrates the SIP Implementation Framework, which reflects considerations identified by stakeholders and in the existing literature.

**Figure 14: Implementation Considerations**

![Diagram of Implementation Considerations]

---

Informed by stakeholder conversations, we identified several barriers to program success that should be noted during implementation and also discuss techniques for overcoming these barriers:

1. **Lack of buy-in:** The common barrier to program implementation is insufficient or variable staff buy-in and participation. Staff are challenged by multiple competing priorities and demands on their time. Implementation can address this through creating clearer protocols and definitions of care processes and staff roles and responsibilities.18

---

2. **Regulatory challenges:** Different markets will have different regulatory challenges that may be anticipated in the design of the business model, but may need to be addressed before and during implementation. These include licensure or related complications, delays related to potential approvals required, regulatory ambiguity that may slow implementation, and the potential need to make structural changes to address issues.

3. **Unexpected delays:** Operational delays, hiring delays, protracted development of key program tools, and lengthy approvals by IRBs can all create challenges in implementation that may need to be mitigated.

4. **Unanticipated complexity:** Programs should be prepared to address participants’ needs and life characteristics, including changing social needs and circumstances.

5. **Resources:** A program may have limited resources to provide the range of needed services to the populations that require them the most or lack resources to fund start-up costs. A program may also compete for resources with other programs and initiatives in the same organization. Aligning resource needs to the business case and value proposition is a good strategy. In addition, program developers can think creatively about how to meet resource needs such as capitalizing on existing capabilities and creating alignment with other services or initiatives.

6. **Care breaks down at the “synapses”:** Because care often occurs in silos, program design and implementation may include the integration of various components of serious illness care. This would target transitions between settings, providers, and payers.

7. **Challenges of multiple programs and funding mechanisms:** Financial incentives may be misaligned when multiple programs collaborate. The willingness of plans and providers to enter value-based or risk-based payment models may help align these incentives. In addition, organizational leadership can create a coherent internal financial model despite multiple external payment models. Patient “churn” – switching insurance coverage – can also disrupt care.

8. **Outreach, referral, and enrollment challenges:** Programs struggle to appropriately define the patient populations and then identify and contact potential patients, creating barriers to access. Patients often do not understand their own prognoses and options, creating barriers to effective decision making. Patients and families often do not know about the availability of quality care because of confusing terminology, misinformation in the marketplace, and misperceptions of what is involved in various types of care. Community-based health care organizations can play an important role in shaping these perceptions through their actions at a local level (e.g., through patient education).

9. **Interoperability and technical barriers:** Limits on the ability to transfer information between providers erode care transitions. When establishing a program, consider addressing technical barriers to exchanging the most
essential information first; for example, determine how to track where a patient is receiving care or know in near real time when a patient is having an acute episode.

One technique for mitigating barriers and incorporating a process of continuous learning is to begin with a pilot program prior to large-scale program implementation. For example, by first implementing a narrow set of services or selecting a subset of the possible population, an organization can test the effectiveness of the program for achieving desired outcomes, learn what works and what does not, and create a business case for implementation of a larger program. This technique can be particularly helpful if an organization is considering different program options or has limited resources to invest.

**Business Model**

During the first convening session, stakeholders emphasized the importance of context and structure for program design. Population needs can be impacted by contextual variables such as geography and availability of other providers, and the services a program is able to provide can also be impacted by factors like the available payment mechanisms, current capabilities, and local regulations. Because addressing these considerations and identifying others is so important to program success, we include a business model component in the SIP Framework.

The existing program literature generally lacks discussion of the relationship of program business models to outcomes, but individual reviews did reference internal capabilities, local context, and organizational leadership (See Appendix B). Though the evidence is limited, we suggest the following:

- Payment structures should encourage value, scalability, and sustainability
- Program leaders should be financially invested in success
- Payment must align incentives to support the care model, such as moving to a population health model
- Program designers should examine what reimbursement options exist in current fee-for-service (FFS) for key roles (e.g., case managers)

Designing a business model that both articulates the goals of the program and addresses the context in which the program will exist prompts program designers to structure the program in the way that best meets these goals. Thus, the business model becomes the foundation for the services a program offers to meet the needs of the selected population and achieve desired outcomes. Because the process of design is iterative, some of the considerations outlined in the business model will need to be revisited as the program’s population, structure and services, and outcomes become better defined. See Figure 15 for an illustration of how the business model relates to the other components of the SIP Framework within the program’s context.
Figure 15: Interrelated SIP Framework Components

![Diagram of the Serious Illness Program Framework](image)

Figure 16 illustrates the organizational, leadership, payment, and regulatory elements to consider during program design. Some of these elements represent decision points. For example, an organization may decide to operate all of the parts of the program services itself or partner with other organizations. Other elements of the business model represent contextual factors that a program may not be able to impact but program leaders can mitigate, like state licensure requirements. Still, other elements may offer opportunities to make decisions related to contextual factors. There may not be a payment model that currently exists in the local market to fully cover desired program services, but an organization could partner with a health plan to implement an APM to meet population needs. A good place to start when developing a business model is by conducting organizational and environmental assessments to help identify the internal and external factors that comprise the biggest barriers and opportunities for program success.
**Business Model: Organization**

The organizational aspects of the business model can be divided into organizational structure, legal structure, internal capabilities and infrastructure, and local context, with the following organizational considerations:

1. Organizational Structure
   a. What are the vision and goals of the program? How far upstream and downstream do you want to have an impact on care?
   b. Where do the program’s goals align with organizational goals and strategies?
   c. In what kind of organization are you operating (e.g., physician practice, home health agency, hospital, hospice, health plan)?
   d. How is the program structured? This will impact the resources and program governance:
i. Independent
ii. Part of a larger program
iii. Partnership between multiple providers / programs / network

2. Legal Structure
   a. Is the organization commonly owned by provider participants, or is it a convener/contractual model?

3. Local Context
   a. What are the needs of the community? How will you engage and incorporate the “community voice” to learn this?
   b. What is the size of the potential population? Is there much variation in the types of conditions represented? What are the unique population needs?
   c. What is the extent of population health programs and risks in the market?
   d. What providers are in your area? What relationships currently exist among these providers?
   e. What are your primary potential referral sources?
   f. What is the extent of your footprint?
      i. Will you serve a large/small geographic area?
      ii. Urban/rural area?

4. Internal Capabilities and Infrastructure
   a. What care delivery services already exist, and can they be leveraged? How?
   b. What assets are already in place, and what will you need to buy, develop, or outsource?
      i. Staff
      ii. Expertise and prior experience
      iii. Technology
      iv. Equipment and facilities
   v. What potential partners might be needed to fill any gaps?

A program’s business model should also consider the program’s relationship to other providers and programs in the health care system; an organization can choose to operate the program in its entirety, but its reach can also extend throughout a local health care environment. As illustrated in Figure 17, a provider can focus on improvement within the program (intra-impact). Alternatively, a program could improve its services as well as impact the care transitions between or connections to other programs (inter-impact). Finally, a program could be designed to impact services and processes throughout a network of interrelated programs (extra-impact).
**Business Model: Leadership**

We included leadership as a category separate from organizational characteristics because convening panelists asserted the paramount importance of program and organizational leadership in program success. Having buy-in from senior management, executive sponsorship, and programmatic champions is critical to program success because the philosophy, ideologies, and priorities of leaders influence resource availability and other forms of organizational support. Leaders can also play a critical role in promoting or facilitating change management. One way to engage senior leaders is to create and promote a “burning platform” that expresses the need for the program and its potential impact on key performance indicators like readmissions, length of stay, mortality, and cost. Senior leaders often do not have expertise in program implementation or quality improvement, so the industry could more broadly could offer education for leaders on how to be effective sponsors or champions in launching a program within an organization and measuring success.

Experts attest that program leaders should build a culture and structure that is sustainable beyond individual people or leaders. Succession planning is necessary to create a sustainable program, and programs should cultivate future leaders with 1) broad understanding of the program and environment and 2) alignment with the mission of the organization. In addition, a program should devise both an early and a long-term strategy for workforce development. The Baldrige Performance Excellence Program offers one framework for creating a high-performing organizational management system.¹⁹ Figure 18 lists some of the key considerations related to program leadership.

Figure 18: Leadership Considerations

<table>
<thead>
<tr>
<th>Governance</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• How is program accountability structured?</td>
<td></td>
</tr>
<tr>
<td>• Who is involved in strategic decisions?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Senior leadership</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• How is senior leadership deployed?</td>
<td></td>
</tr>
<tr>
<td>• Having buy-in from senior management, executive sponsorship, and programmatic champions is critical to program success because the philosophy, ideologies, and priorities of leaders influence resource availability and other forms of organizational support.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Program leadership</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Choose program leaders aligned with mission/vision/values of organization</td>
<td></td>
</tr>
<tr>
<td>• Develop future leaders as a part of succession planning to ensure sustainability</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Assess stakeholder interest and influence</td>
<td></td>
</tr>
<tr>
<td>• How does the program engage stakeholders – consumers, providers, community organizations?</td>
<td></td>
</tr>
</tbody>
</table>

Business Model: Payment Sources

Panelists in the first convening session noted that payment necessarily impacts the structure and sustainability of programs, so identifying the potential sources for funding is a key part of the business-planning process. Figure 19 reveals several financial considerations for serious illness programs that relate to the program infrastructure, features, and future strategy.
Figure 19: Financial Considerations

Current Risk & Value-based Payment Participation (VBP) → Organizational Strategic Plan for Future Risks/VBP → Federal & State Policies → Population Health Investments → Infrastructure (e.g., provider network development, analytics, new organizational structure) → Existing Service Improvement (e.g., primary care improvement and overall population health strategy) → Serious Illness Programs • Population targeting • Services • Infrastructure

Figure 20 lists several payment models that cover programs in the general serious illness landscape. Current providers that commonly participate in the program are indicated with an X, while providers that could potentially participate in the future are noted with an *.
### Business Model: Regulatory Considerations

The payment model for a program and the services it is able to offer may be constrained by the federal and state regulatory environment. Regulatory questions to consider in program design include 1) What are the licensure and compliance requirements to deliver new serious illness program services? and 2) Under current regulations, what services can your organization deliver and who can you partner with to fill gaps? As noted above, failing to recognize the regulatory environment and address these considerations can lead to delays in implementation. Figure 21 lists common regulatory topics to consider.

**Figure 20: Payment Model Examples**

<table>
<thead>
<tr>
<th>Payment Model Examples</th>
<th>Provider Sector</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Health System</td>
</tr>
<tr>
<td>Risk Contracts with Private Health Plans (e.g. MA, Managed Medicaid, Commercial)</td>
<td>x</td>
</tr>
<tr>
<td>ACOs (MSSP &amp; Private Insurer Program)</td>
<td>x</td>
</tr>
<tr>
<td>Hospital Value-based Purchasing</td>
<td>x</td>
</tr>
<tr>
<td>Bunded Payment for Care Improvement</td>
<td>x</td>
</tr>
<tr>
<td>CMMI Primary Care &amp; Specialty Models (e.g. CPC+, IAH, Oncology, DM, ESRD)</td>
<td>x</td>
</tr>
<tr>
<td>Home Health Valued-based Purchasing</td>
<td>*</td>
</tr>
<tr>
<td>SNF Value-based Purchasing</td>
<td>*</td>
</tr>
<tr>
<td>Medicare Care Choices Model</td>
<td>*</td>
</tr>
</tbody>
</table>

X: common participant; *: potential participant
Figure 21: Common Regulatory Considerations

**Federal regulations**
- Home Health Medicare Conditions of Participation: requirements for services delivered by home health agencies
- Hospice Medicare Conditions of Participation: requirements for services delivered by a Hospice

**State licensure**
- Home-based services
- State by state licensure requirements limit services across state lines

**Restrictions related to referrals and inducements**
- Anti-kickback, Stark

**Antitrust**

The Serious Illness Framework

Figure 22 depicts the high-level components of the SIP Framework. The SIP Framework, as a whole, is intended to guide program design, but working through it is an iterative process:

- The Business Model, including organization assessment, serves as the foundation on which the Structure and Services of a program may be built.
- Structure and Services should be designed to identify and address the needs of a selected population and achieve desired patient, program, and community Outcomes. As the needs of the population increase, the scope and intensity of the services must also increase to meet those needs.
- The available or target Population and pre-existing Structures and Services will also inform both aspects of the Business Model,
such as the payment mechanisms, and the structure and services of the new or expanded program.

- Likewise, the Implementation process must incorporate evaluation and learning, and other components may need to be redesigned as unanticipated opportunities and barriers are identified.

Figure 22: The Serious Illness Program Design and Implementation Framework

The SIP Framework in its entirety offers so many considerations that panelists in the second convening session expressed the concern that organizations seeking to develop a new program might not know where to start. Figure 23 illustrates the steps an organization might take in the cycle of designing and implementing a serious illness program. Program designers can use these steps and the associated SIP Framework components as a compass to help guide program development, while adapting the concepts to their organizational characteristics and local context.
Conclusions and Next Steps

The primary goal of this project was to create a framework to support the design and implementation of serious illness programs. Through our review of the evidence surrounding program effectiveness, we identified both common program elements as well as the outcomes that are commonly measured. We found strong evidence of the effectiveness of programs as a whole for improving experience and health outcomes and reducing unnecessary utilization. However, further research is needed to understand how individual structures and services affect outcomes. Likewise, additional work could reveal the business models, payment structures, and implementation techniques that contribute to the success of serious illness programs.

We combined our evaluation of the evidence with the perspectives of health care experts with experience implementing, operating, researching, and funding programs related to the broad spectrum of serious illness. Through these conversations and feedback on initial versions of our framework, we identified additional factors critical to program success. The resulting SIP Framework outlines five
categories of considerations an organization may use to guide program design and implementation: Business Model, Population, Structure and Services, Outcomes, and Implementation. While the considerations described above are intended to reveal the range of design and implementation considerations, the list is by no means exhaustive. By working through these categories with the knowledge that each organization is unique and operates within its own distinct local context, organizations can begin the process of effectively planning new programs or expanding existing programs.

Our work to develop the SIP Framework establishes a foundation for future initiatives in the area of serious illness. An immediate next step for C-TAC and Healthsperien is the creation of an expert network to continue to exchange ideas and experiences related to serious illness program implementation and operation. We also hope to use the SIP Framework elements as inputs in the development of a Payment Model Simulator: a calculation and modeling tool that will allow provider and payer organizations to project the impact of different program and payment implementation options on the cost and quality of care. This project will also fuel potential peer-review publications and potential future research to develop additional evidence. In addition, our findings will inform the C-TAC policy and regulatory agenda as we support policies and payment structures that enable increased patient access to serious illness programs. Finally, we aim to pilot the use of the SIP Framework in program development and assess its real-world utility for supporting the design and implementation of serious illness programs.
Appendix A: Case Studies

PROGRAM: MERIDIAN CARE JOURNEY
Organization: Meridian Health System
Organizational Type: Integrated Health System
Location: New Jersey

Program Overview

Meridian Care Journey is a program delivered by the Meridian Health System (MHS), an integrated health system. Meridian Care Journey uses a system-wide approach to deliver palliative care in skilled nursing facilities (SNFs), acute care hospitals, inpatient homes, and outpatient practices. Interdisciplinary teams work across the network, serving people with chronic illness and focus on engaging patients early within the disease course, and assuring continuity across settings and over time. An electronic health record (EHR) supports services and is accessible to affiliated physicians across all system sites. The EHR alerts case managers and the care team at any point of an enrolled patient’s engagement with MHS.

Key Features

- Strong systems for identifying and recording patient goals & preferences
- EHR notification to the care team if an enrolled patient arrives at the Emergency Department or has a hospital admission
- Robust transitional care

Business Model

Most of the program revenues (65%) come from per-member-per-month (PMPM) payments, initially from the Centers for Medicare and Medicaid Services (CMS) as part of a Medicare Health Care Quality (MHCQ) demonstration project. The program is currently transitioning to receiving revenue from commercial payers. The remaining financial support comes from Medicare fee-for-service (FFS) professional billing (-14%) and the Meridian Health System (its parent organization (-21%)).

Population

Although the specific population is different by care setting, all members in this program have chronic diseases. In nursing home-based programs, patients most often have cancer or heart failure (17% and 23% respectively). In home-based programs, patients most often have COPD or heart failure (25% and 38% respectively). In clinical settings, cancer and heart failure are most common (40% and 22% respectively).

Structure and Services

Team Composition: Clinical teams are comprised of advanced practice nurses (NP) or physician assistants (PA), physicians (MD), registered nurses (RN) (placed only for home-based programs), chaplains/spiritual care professionals and social workers (SW).

Core Services: Regardless of care setting, the palliative care teams address the eight domains of palliative care within the National Consensus Project for Quality Palliative Care. On the other hand, disease-specific treatments and primary care stay the primary or specialty care provider’s responsibility. The palliative care team addresses the following: medication management and reconciliation, pain and symptom management, goals of care conversations and documentation (advance care planning), psycho-emotional support for patients and family caregivers, discussing medical information and providing prognostication support, case management and care coordination, spiritual care, transitional support, community resource referrals for social and practical need assistance, and bereavement support.

Outcomes

Outcomes measured include:

- Documentation of advance care planning in EHR occurred for > 91% of enrolled patients who receive home-based services
- Patient and family satisfaction levels of > 90%
- For patients enrolled in the home-based program (vs. historical data)
  - 35% ↓ reduction in hospital admissions
  - 22% ↓ reduction in emergency department visits
  - 46% ↓ reduction in ICU days
- Percent of enrolled home-based patients re-hospitalized ↓ decreased from 23% in Year 1 to 16% in Year 2 of the program

Quality monitoring metrics tracked monthly include:

- Proportion of patients with advance care planning discussion documented and an advance care planning document on file
• Proportion of patients with shortness of breath, pain, and nausea assessed and with shortness of breath, pain and nausea addressed
• Number of MD, NP, RN, SW, and chaplain visits and phone touches
• Patient and family satisfaction, measured through interviews and focus groups conducted with demonstration patients, and their caregivers and family members

Implementation

Champions: Program leaders believe in the model and understand its value and strength in managing transitions across the care continuum. They strongly believe in making information (e.g., assessments and care plans) accessible to all providers via the EHR and value the program’s focus on family support and care. Organizational leadership saw the importance of palliative care in the organization’s future in value-based care and palliative care, a factor of their success.

Experience and expertise: By participating in the Medicare demonstration project, the home-based program grew and enabled the collection of metrics to demonstrate cost and quality impacts.

Provider engagement: Engaging community-based private physicians to obtain referrals early in the disease process was a challenging process as was finding qualified providers.

Measures: MHS set internal quality measures but did not base these on external benchmarks. Because the results did not have matched comparison groups, it was difficult to determine whether those quality measure results could have occurred in the absence of the Meridian Care Journey. On the other hand, MHS had positive qualitative results from the patient, caregiver, and family interviews, and the focus groups. MHS attributed success to the following: the integration of spiritual and social services, diversity of provider teams, continuity of personnel, frequency of visits, involvement of family members, longevity of services, and their ability to meet patients’ unique needs.

Takeaway: Consider expansion of range of outcomes. Include more rigorous quantitative evaluations as well as outcomes that emphasize the value of the demonstration (in this case, patient quality of life, family quality of life, coordination of care).
PROGRAM: GUIDED CARE

Organization: Johns Hopkins University
Organizational Type: Delivery System
Location: Nationwide

Program Overview

In 2001, researchers at Johns Hopkins University created the Guided Care model and licensed the model to health care systems. Currently, 18 U.S. health care delivery systems have implemented it. The Guided Care model seeks to reduce spending and improve health outcomes by improving care management for aging Americans with multiple chronic conditions using interdisciplinary care teams and telephone-based care management.

Key Features

- Specially trained nurses assess patients’ needs using formal assessment and planning tools, create care plans to set priorities for realizing patients’ goals, and offer education and support to patients and their caregivers.
- These nurses also monitor patients’ care longitudinally and coordinate care among providers.

Business Model

Johns Hopkins University is part of an accountable care organization (ACO), which rewards participating programs for improving health outcomes while reducing utilization.

Population

This program serves a population of older adults with multiple chronic conditions who are at pronounced risk for high health expenditures in the next year. Some health systems which implemented the model further target a population subset who were at even greater risk for complications. For example, at Holy Family Memorial, nurses used a risk stratification tool to identify patients via medication, diagnoses, and utilization data as well as a patient’s social supports and need for care coordination.

Structure and Services

- 12 months of claims data and predictive modeling used to identify the 20%-25% of patients at highest risk of needing complex care management in the next year (targeting the population most likely to benefit).  

- Registered nurses trained in complex care management complete in-home assessments, create care plans, and coordinate care with providers from various disciplines.

- Activities include assessing patients’ health-related needs and risks, developing patient-centered care plans, coordinating care, following hospital discharge transitioning patients, facilitating communication among providers, integrating health and social services along with physical/behavioral health care, making services and/or care more accessible, and monitoring patients’ progress.

- The program also offers patient self-management strategies and education on tackling issues before need for hospitalization (engaging patients and their families in managing care).

Outcomes

According to a 32-month cluster-randomized trial at eight suburban and urban practices in the Washington-Baltimore area, Guided Care participants experienced a:

- 29% decrease in home health episodes
- 26% fewer skilled nursing facility (SNF) days
- 13% fewer hospital readmissions
- 8% fewer SNF admissions

This study represented over 900 patients and 300 family caregivers.

Implementation

Guided Care presents a well-structured model and pathway for organizations to build infrastructure, train staff, and test a ready-to-go care management program. It now offers an “on-ramp” to organizations that are just starting out to help them identify the population and approaches to serve their high-need patients.

However, some health care systems, like Lahey Health, found it difficult to determine what level of support the population needed, and thereby what the most effective investment would be in chronic care management programs. Determining the different levels of support, i.e., allocating the right resources and at the right time, became a difficult task.

26 Bodenheimer and Berry-Millett, Care Management of Patients with Complex Health Care Needs, 2009
27 C. Boult, L. Reider, B. Leff et al., “The Effect of Guided Care Teams on the Use of Health Services: Results from a Cluster-Randomized Controlled Trial,” Archives of Internal Medicine, March 2011 171(S):460–66
Program Overview

CareMore is a Medicare Advantage plan that provides medical care to its members by partnering with primary care physicians to identify high-risk patients and refer them to its Care Centers, where interdisciplinary care teams can holistically manage patient needs and acute care. CareMore aspires to prevent and reduce disease progression, rather than only treating disease complications, by spending upfront to address chronically ill and frail members’ medical challenges.

Key Features

- Partnerships with network primary care physicians for patient identification and referral
- Care Centers, where multidisciplinary teams coordinate and deliver primary care, specialty care services, and behavioral health care to high-risk patients
- High-touch primary care services by employed staff in Care Centers and oversight of patients’ care for acute needs before, during, and after hospitalizations
- Patient education and encouragement related to prevention, wellness, and health risks, as well as development of emotional connections to encourage shared decision-making with patients

Business Model

CareMore aims to improve care for chronically ill or frail patients—specifically the sickest 15% of its membership that account for nearly 75% of spending. CareMore invests the capitated payments it receives from Medicare Advantage in early interventions and prevention programs for all its members and on supplemental benefits not covered by Medicare’s fee-for-service (FFS) program, including transportation to Care Centers and patient education programs. By helping patients avoid hospitalizations, CareMore gains savings.

Population
The target population is patients with complex care needs who are also Medicare Advantage plan members in California, Nevada, Arizona, Virginia, and Ohio, and Medicaid managed care plan members in Tennessee.

Structure and Services

- Providers identify members who are frail and/or chronically ill and in need of hospital admission or at high risk for hospital admission via a comprehensive assessment upon enrollment
- Extensivist physicians provide care to hospitalized patients and oversee post-discharge care in skilled nursing facilities and other settings
- Frail and/or chronically ill members are enrolled in disease-specific management programs
- Customized electronic health records (EHRs) and remote monitoring allow patients to monitor vitals in their homes, with results immediately shared with the CareMore team
- The program also provides assistance to members in accessing social and other nonmedical support services, as well as transportation to CareMore Care Centers

Outcomes
CareMore results have improved and the program has expanded:

By 2011, CareMore’s Medicare Advantage plan achieved a:

- Lower ↓ 30-day hospital readmissions rate for its Medicare Advantage population (13.6% compared to 19.6% for Medicare FFS).
- 15% ↓ reduction in members’ per-capita health spending in comparison to the regional average
- Shorter ↓ hospital length-of-stay (3.2 days compared to 5.6 day average in Medicare FFS and 4.5 day average for California’s traditional hospitalist programs)

In 2015, CareMore members had (in comparison to Medicare FFS):

- 20% ↓ fewer hospital admissions
- 23% ↓ fewer bed days
- 4% ↓ shorter length-of-stay than beneficiaries covered under FFS Medicare

Implementation- Promoting Sustainability

Because CareMore’s business model depends on Medicare Advantage reimbursement, cuts to reimbursement rates threaten its revenue model and sustainability. In order to overcome this challenge, CareMore has started to diversify by serving Medicaid beneficiaries and partnering with other health systems that are now focusing on risk-based contracting.
PROGRAM: MEDICARE ADVANTAGE PROVIDER COLLABORATION PROGRAM AND COMPASSIONATE CARE

Organization: Aetna
Organizational Type: Payer
Location: Nationwide

Program Overview

Aetna developed a Medicare Advantage Provider Collaboration Program for select medical groups participating in its network. The program aims to enhance case managers’ effectiveness in physician offices. Case managers work in close collaboration with staff and participating physicians in the management of chronic illness, psychosocial barriers, and advanced illness. Reaching Aetna’s Medicare Advantage patients in more than 75 partnerships with medical groups, in 2012, Aetna served more than 100,000 total patients.

Key Features

- Interdisciplinary care teams comprised of nurses, social workers, and behavioral health specialists who trained in change and case management, cultural sensitivity, advanced illness, and interviewing patients. They are also mentored by experienced supervisors
- A proprietary algorithm, PULSE-AIM, that aids in the risk stratification process
- The ActiveHealth® CareEngine® System to identify actionable gaps in care
- For offices with existing care management, Aetna might deliver the Aetna Compassionate Care℠ program which specializes in advanced illness management and specific chronic illness management

Business Model

- Medicare Advantage Provider Collaboration Program for selected participating medical groups
- Cost of Care: Reduced ↓ total cost by 19% (2009), 26% (2010), 33% (2011) in comparison to the costs of other Medicare Advantage members throughout Maine

---

Population

This program serves complex patients (members with advanced illness and chronic illness) as defined by inclusion criteria including risk score, the frequency of admission and Emergency Department (ED) visits, and high-risk diagnoses. The program also uses an advanced illness predictive algorithm, which detects the risk of death within 12 months, and a predictive algorithm for readmission, which identifies opportunities by monitoring transactions and claims. Some locations where this program is delivered also utilize the presence of a depression diagnosis and an algorithm that searches for the presence of actionable care gaps, e.g. drug interactions and/or absence of a record of testing normally with an associated diagnosis or record of treatment.

Structure and Services

The program uses case referrals from physicians participating in the program. ActiveHealth® reports on the actionable care gaps regularly to physicians and staff. Members receive support for case management and decision-making. For example, case managers help guide advanced illness patients and their families through Aetna Compassionate Care, which engages members and their caregivers, provides information for informed decisions and support, and facilitates services including pain relief.
Outcomes

Aetna’s Medicare Advantage Provider Collaboration Program reports the following utilization, cost and quality outcomes:

| Aetna’s Medicare Advantage Provider Collaboration Program* Outcomes vs. Regional Benchmarks |
|-------------------------------------------------|----------------|----------------|
| Admissions                                      | 2009 | 2010 | 2011 |
| 30-Day All-Cause Hospital Readmission Rates     | -38% | -35% | -30% |
| Emergency Department Visits                     | -28% | -28% | -12% |
| Total Cost of Care                               | -19% | -26% | -33% |

<table>
<thead>
<tr>
<th>Aetna’s Medicare Advantage Provider Collaboration Program 1 Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
</tr>
<tr>
<td>-----------------------</td>
</tr>
<tr>
<td>Annual Office Visit</td>
</tr>
<tr>
<td>HbA1c Test</td>
</tr>
<tr>
<td>Semi-Annual Visits by CHF, Diabetes or COPD patients</td>
</tr>
<tr>
<td>Follow-Up Visit by patients discharged from hospital or SNF, within 30 days</td>
</tr>
</tbody>
</table>

*Aetna-NovaHealth Pilot Program is one of Aetna’s Medicare Advantage Provider Collaboration Programs piloted in 2009. Aetna Maine is the comparison data used (the regional benchmarks) for other Medicare Advantage members throughout Maine.

Aetna’s Compassionate Care Program has outcomes of:

• Tripling hospice election rate
• Doubling average Hospice length-of-stay
• Reduced ↓ acute inpatient days (82%)
• Reduced ↓ intensive care unit days (86%)
• Reduced ↓ emergency department visits (77%)
• High satisfaction level among members, caregivers, and families

Implementation

A key ingredient to Aetna’s success with this program is good case manager selection, training, and mentoring. According to a Health Care Transformation Task Force Case Study, nurses report finding this work highly rewarding and

often they and other case managers develop close relationships with patients and their caregivers. This depth in connection is valued by not only patients but their caregivers.

Aetna achieves success in care management by promoting effective coordination between different programs; its care management program for treatment oversight ensures appropriate hand-off to other care management-type programs. This ensures that patients receive proper and holistic care across the continuum.
Program Overview

SCC delivers high-quality comprehensive primary care for Stanford University’s employees and their dependents who are high-risk, medically complex, and high utilizers of health care services. SCC seeks to fulfill patients’ needs and in doing so, minimize referrals by utilizing a team-based, inter-professional approach. Care is provided via the patient portal, email, phone, and home visits. Moreover, as needed, SCC staff members visit patients during hospitalizations and accompany them to specialist visits.

Key Features

- Patient engagement
- Intensive care coordination by Medical Assistants (MAs)
- Enhanced, patient-centered risk assessments
- Medical Scribing (assistants documenting in EHR for physician)
- Home visits
- Two-Phased Care Approach: In Phase 1, the SCC team focuses on patient goals and helps patients achieve them. The team looks at the sources of dysfunction if patients don’t achieve their goals. In Phase 2, the SCC team digs deeper using the Adverse Childhood Experiences (ACE) Survey

Business Model

Stanford University established an optional ACO choice for employees and their dependents in January 2014, and is also self-insured. The SCC is part of the health plan’s services and is offered to high-cost, high-risk plan members in order to reduce utilization, improve the satisfaction and health of patients, and increase the quality of care.

Population

The population is Stanford University employees and their dependents who are high-risk, medically complex, and high utilizers of health services. The eligibility criteria include the following: three or more chronic conditions, five or more medications,
and specific responses to questions about condition management. Most patients have difficulty managing multiple chronic conditions, and 40% have mental health disorders.

**Structure and Services**

*Care Delivery:* Care is delivered using an intensivist primary care team model, which focuses on self-management and behavior change support. A small number of patients receive additional support from licensed clinical social workers (LCSWs) and physical therapists (PTs).

The practice initially assesses gaps in care, looking at a patient’s medical neighborhood, social support, medical status, health trajectory, the ability for self-management, and mental health. In addition to the care needs assessment, the practice utilizes at intake Hibbard’s Patient Activation Model (PAM) measurement tool.

The SCC teams may visit patients weekly until improvement occurs. The teams also support patients through the registration process. Patients use the patient portal frequently to communicate with the team and access information about their illnesses, conditions, and treatments. At six months, patients are reassessed using the PAM. If there is no improvement, the team moves on to a more intensive assessment phase by administering the Adverse Childhood Experiences (ACE) Survey.

*Referral:* An outreach coordinator recruits patients through the monthly meet and greets. These coordinators survey potential patients about persistent or ongoing conditions (they do not use the word “chronic” as patients may not fully understand the meaning of what it means to have a chronic disease).

*FTEs:* Currently, SCC serves 320 patients with three physicians (which translates to approximately 1.3 physician full-time equivalents [FTEs]). The program will reach capacity at 400 patients. Care coordinator panels are about 100 patients per 1.0 FTE.

*Communication:* Communication frequency averages weekly, and the practice updates a “meaningful-touches tracker” to record the types and number of interactions each team has with its patient panels. Much communication occurs through the patient portal (see above). As needed, provider teams follow up with patients.

**Outcomes**

SCC receives reports on performance measures from the Stanford Health Care system. These reports benchmark SCC with other primary care practices.
Measures include:

- Number of telephone calls replied to within a certain time
- Percentage of patients scheduled on the first call
- Percentage of patients within specific clinical goals (e.g., hemoglobin A1c, low-density lipoprotein control, influenza vaccinations, screenings)
- Percent of patients on specific medications

SCC also uses the Healthcare Effectiveness Data and Information Set (HEDIS) care gaps tool, which is provided by its EHR and a Stanford central data warehouse. The Stanford central data warehouse sends the SCC team a weekly “red report” on all patients. This includes both patients whose illness is not in control and the tests and assessments they need. This information also appears in the SCC team dashboard.

The team hopes to achieve the Triple Aim outcomes of improved quality of care, improved patient experience, and lower cost, with an added fourth dimension of staff satisfaction.

- For 2014’s last two reported quarters, patient experience ratings were in the 99th percentile, HEDIS measures were > greater than the 90th percentile, and staff satisfaction was in the 99th percentile.
- SCC collects and uses quality improvement (QI) and utilization data which demonstrated a 59% ↓ reduction in ED visits and a 29% ↓ reduction in hospital admissions between January and December 2014.

Implementation

**Trust:** At the foundation of SCC are trusting relationships. SCC is a high-touch practice, which means that SCC clinicians consider both social and medical complexity. They define these as what the patient brings and experiences (e.g., medically, behaviorally, socially, including lack of confidence and trust) as well as trauma issues, including early childhood adverse events.

**Human-centered design techniques:** Techniques centered around human-centered design were fused into planning processes and the physical space. Co-charting and colocation in the team room provide constant QI exposure and training, which ensures staff work at the top of license.

**Patient input:** Patient input was solicited to help structure and design the SCC workflow and services. The practice also maintains an active Patient Advisory Committee. Engaging patients and their caregivers at the level of system design and system redesign related to the delivery of care may have helped improve both patient experience and care coordination.
Training: New care coordinators shadow experienced care coordinators for a month and receive hands-on training in the EHR and other systems. Care coordinators are viewed by patients as part of the care team because they are in the exam room hearing the conversations between physicians and patients, scribing and co-charting with the physician. Care coordinators are assessed for competencies and are expected to have a deep understanding of care processes flows; they also meet often and debrief, providing more opportunities to learn from experiences.
**Program Overview**

Home Connections is a home-based palliative care program developed between two local commercial payers and a not-for-profit hospice. This program improved symptom management, advance directive completion, and patient satisfaction, and worked to better facilitate the hospice care transitions for patients when appropriate.

**Key Features**

- A community-based program between Home Connections (the home-based palliative care program) and two private insurers
- Upstream services provided from the Hospice Medicare Benefit
- Facilitated transfer to hospice

**Business Model**

The program has an innovative payment model in which two local private insurance payers support the program via a per member per month (PMPM) fee. Referrals come from physicians, hospice and palliative care agencies, local insurers, and the community (via prospective patients themselves, family, caregivers, and friends).

**Population**

Home Connections serves patients in Erie County, New York, and is available to adults, 18 years or older, with advanced chronic illness. The program provides upstream services from the Hospice Medicare Benefit; thus, patients may still receive cure-focused or aggressive treatments during program enrollment and may not have a predicted prognosis of six months or less.

**Structure and Services**

The Home Connections team includes a palliative care trained registered nurse (RN) coordinator, trained volunteers, social worker (MSW), and a palliative care physician (MD). MDs participate in the weekly team meetings to review and discuss goals and plans of care for each patient seen the week before. The RN coordinator calls on the MSW at admission to discuss their roles during team meetings. Services include symptom and pain management, patient education, caring discussions about health-

---


Kerr, Donohue et al., 2014
care goals and decision-making, 24/7 on-call palliative care nurse support, social work visits to improve access to community support services, and volunteer respite care.

When clinically appropriate, and if desired, Home Connections helps with the transition to hospice care. Patients may leave the Home Connections program if they are clinically stable and able to manage self-care, or if they need more intensive care. In the latter case, the program assists in transitions to more supervised environments like hospital, nursing homes, or assisted living facilities.

Outcomes

Completion of advance directives, symptom severity over time, site of death, hospice referral, program satisfaction, and average length of stay were used as outcome measures, measured prospectively between July 1, 2008 and May 31, 2013. Key outcomes include:

• After enrollment, 71% of participants (of 499 enrolled participants) had completed actionable advance directives
• During or after program participation, home was the site of death for 47% of those who died
• Measures for anxiety, dyspnea, appetite, depression, nausea, and well-being showed improvement
• Physicians, patients, and caregivers reported high (93%–96%) program satisfaction scores
• Home Connections participants who subsequently enrolled in hospice had longer average length of stay (77.9 days) compared with all other hospice referrals (56.5 days)
• Costs were lower or about the same for Home Connections participants than non-participants

Implementation

Aligning incentives across parties was critical for creating and sustaining this partnership.

Other critical components that led to effective implementation included: communication, team-based care, care coordination and infrastructure, patient-centered care, transitional care, and patient education.
DEEP DIVE: UPMC INSURANCE SERVICES DIVISION

CASE STUDY

Meeting the Needs of a Seriously Ill Population through the Advanced Illness Care (AIC) Program

Organization Overview

UPMC, a world-renowned health care provider and insurer based in Pittsburgh, PA, is inventing new models of accountable, cost-effective, patient-centered care.

UPMC’s Insurance Services Division has grown to more than 3.2 million members. UPMC is a proven integrated delivery and health finance system (IDFS) — the first of its kind and largest in western Pennsylvania — and the Insurance Services Division (ISD) is leading the way with innovative health plans for virtually all segments of society that deliver better quality and lower costs.

UPMC’s Insurance Services Division provides a full range of group health and commercial insurance, Medicaid, Medicare, Children’s Health Insurance Program, Special Needs Plans, behavioral health, workers’ compensation products and services, and employee assistance programs.

The IDFS structure facilitates collaboration and innovation in the realms of payment and delivery. This case study spotlights one innovative program, the AIC program.39

Figure A1: Overview of UPMC

---

Vision for Population Health: Personalize Care to Patient and Need

UPMC ISD’s vision for population health and serious illness care is central to each site where UPMC programs are implemented: to create member-centric, patient-focused plans for the entire population. UPMC ISD believes in meeting members where they are—physically, mentally, and geographically—in the regions where they live, work, and play, and with the resources that are available to them. Patient identification processes stratify members by need and acuity and provide interventions that match their risk and needs. By creating a member-facing model, UPMC ISD provides members with care where they need it most.

Programmatic Solutions

UPMC ISD offers a variety of interventions across several programs to achieve its vision for Population Health and meet patients’ needs across the serious illness trajectory. Its network of Patient-Centered Medical Homes (PCMH) and other contracted primary and specialty care providers provide a foundation through which members can be referred to additional clinical programs and services. Some examples of programs include UPMC Staying-at-Home and UPMC Living-at-Home, the Home Transitions Program, and the AIC program, which is the focus of this case study.

- **Staying-at-Home** and **Living-at-Home** are versions of the same model that serve members who need support at home, and enrolled patients normally stay in the programs for an average of five years. In this model, nurses and social workers visit the patients in their homes to provide services, such as medication management and care coordination, and connect patients with additional needed services like transportation. Patients are identified using two criteria points: they must be a minimum of 60 years-old and need assistance in activities of daily living. Nurses visit the patients at home and help with medication management and education about medical adherence. PCPs and physician practices refer patients to this program to help them avoid hospitalization.

Staying-At-Home is paid for by the Health Plan while Living-at-Home is the charitable arm of the program that is funded by UPMC’s provider side. Both programs offer the same services and are operated by the same team.

- **Home Transitions Program and the AIC Program:** After UPMC and UPMC ISD identified gaps in care provided to members with serious illness, ranging from communication shortfalls across the health care team and limitations of traditional home health services to inconsistent follow-ups, UPMC ISD, UPMC Palliative and Supportive Institute (PSI), and the system-owned home health agency developed a collaborative effort to support two innovative payer/provider community care models of care:
The Home Transitions program leverages available resources within the home health team and expands services with the CRNP, medical director, and pharmacist.

The AIC program supports patients with poor prognosis and/or life-limiting illness and features a team of specially-trained clinical social workers (LCSWs) and a CRNP to deliver this care.

Both models center around a palliative care-trained Certified Registered Nurse Practitioner (CRNP), who works with a member's PCP to establish a value-based care plan; to prevent unnecessary emergency department visits, admissions to the hospital, and re-hospitalizations; and minimize burdens associated with serious chronic illness.

**Spotlight on AIC Program**

**Overview**

AIC serves UPMC ISD members over 21 years-of-age, experiencing a serious illness, three or more Emergency Room visits, three or more inpatient admissions in the last 12 months, and/or two or more ICU stays within the same hospitalization. AIC is designed to help patients cope with their illnesses while maintaining the highest quality of life possible. Its core feature is home visits by a team of CRNPs, LCSWs, and RNs who partner with PCPs and family members to help patients with advance care planning, decision-making, and achieving goals of care.

One of the important and distinctive values of AIC is the integration of services with the PCP, continuously engaging that provider as an important member of the team during crucial times in each member’s illness trajectory.

**Vision and Business Model: A Payer-supported Program**

UPMC’s AIC program is built on the premise that payers and providers working together can achieve higher quality, more efficient care for patients than either a payer or provider can acting alone. While efficacious primary care transformation must happen at the practice level, support of this transformation can be made through payers’ resources, service capacity, and data. At this time, UPMC’s AIC program is limited in its geographic service area to Allegheny County due to available resources. However, UPMC has expansion plans over the next six to 12 months.

AIC is designed to improve members’ quality of life and offer the concurrent support to meet the Triple Aim: 1) improve patients’ experience of care (which includes patient quality and patient satisfaction), 2) improve the population’s health and 3) reduce health care’s per capita cost. AIC services are delivered in the home with a fee-for-service (FFS) reimbursement structure. Lastly, there is no member cost-sharing.
Population Served

Patients are identified through real-time provider referrals. If referred patients do not meet program criteria, they are connected to other resources or one of the other programs offered. Initially, patients were identified based on their PCP’s response to the “surprise question” (i.e., Would you be surprised if the patient passed away in 12 months?). However, providers were very apprehensive about assigning a date or a time frame for death, so some patients who might have benefitted from the program were denied authorization. When the screening question was changed to, “Do you think this person has a serious illness and would benefit from additional services?” denial rates decreased tremendously. By taking away the emotional burden in assessment, patients were appropriately identified and enrollment increased. UPMC ISD is working to create predictive and stratification modelling to facilitate patient identification.

Structure and Services

After approval through the Insurance Services Division’s clinical review for program enrollment, members are eligible to receive 10 AIC visits per lifetime (of any combination of services). CRNPs and LCSWs visit patients in their homes to provide advance care planning and symptom management and to develop member-centric care plans in coordination with PCPs. RNs provide telephone support and assist with care coordination. Members’ clinical care is further enhanced through oversight and clinical support by the Medical Director, review by the interdisciplinary team, and input from the Insurance Services Division Clinical Pharmacist. Figure A2 describes the process by which the AIC team supports the patient in the home and during care transitions.

Figure A2: Linking Home Care and AIC
UPMC ISD launched a partnership with Vivify Health on August 15, 2016, to create the AIC Remote Monitoring program. The goals of AIC Remote Monitoring include: proactive symptom management, reduction of CRNP and SW in-home visits, increase in patient education, and creation of an opportunity for a scalable program.

UPMC ISD screens the AIC population for feasibility to use remote monitoring, and identified members are given a licensed tablet and instructed to answer symptom management questions twice a week. These answers trigger high or low alerts, which are monitored by teams of RNs who receive a list of actionable alerts. The AIC Remote Monitoring program also provides video education and support. Planned future iterations of the program will allow patients to use their own devices—a “Bring Your Own Device (BYOD)” approach.

Outcomes

The active and hands-on approach to monitoring and management of patients and the population improves the quality and efficiency of service delivery. Practices use per member per month (PMPM) costs, HEDIS® quality outcomes, and utilization measures, including hospital admissions and readmissions, to measure their outcomes. Through patient surveys, patient experiences are recorded, compiled, and studied in a qualitative, case-by-case manner. Moreover, UPMC ISD has studied the total number of planned visits as an additional measure of effective care management and its close relation to the Chronic Care Model processes.

Figure A3 provides outcomes details on the population served from the program’s inception in 2014 through the end of 2016. The number of cases served increased from 2015 to 2016, and the average length of enrollment has grown steadily.

Figure A3: Advanced Illness Care Enrollment
Figure A4: Place of Care

Figure A5: Location of Death

Figure A6: Utilization Metrics
Implementation and Ongoing Iterative Design

UPMC ISD continues to work to strengthen relationships between community and provider partners while also identifying gaps in community and provider resources and assessing health and social determinants to implement and continuously improve programs.

UPMC ISD leaders have revealed that their success with implementation is due to four main strategies, executed while ensuring that their members’ care was not disrupted:

1. Knowing what they don’t know
2. Using rapid cycle improvement
3. Maintaining flexibility with regards to what the program is and is not
4. Using/utilizing a collaborative open dialogue approach with providers

AIC is an example of strong payer-provider collaboration on multiple fronts including patient identification, resource allocation, patient education, patient communication, PCP participation, documentation, facilitation of information, patient engagement, measures of success, and patient satisfaction. By soliciting frequent input from providers and designing an iterative process, UPMC ISD gained the trust of physician groups and optimized the experience for patients and providers.40,41

40 Ahuja, N. Advance Illness Care. Retrieved from PowerPoint Presentation.
Baltimore City Health Department (BCHD) CASE STUDY:
DEEP DIVE ON DEVELOPING AN ACCOUNTABLE
HEALTH COMMUNITY MODEL\textsuperscript{42}

Organization Overview\textsuperscript{43}

The Baltimore City Health Department (BCHD) is a local government agency with the longest history of service of any U.S. city’s public health department.

In April 2017, BCHD was selected for a $4.3 million,\textsuperscript{44} five-year cooperative agreement from CMS under the Center for Medicare and Medicaid Innovation’s (Innovation Center) Accountable Health Communities (AHC) program. With this funding, BCHD has convened several organizations to bridge the gap between clinical providers and social service organizations.

\textit{The Baltimore City AHC model aims to address patients’ health-related social needs by connecting them with social and community services.}

Partner organizations include Maryland Medicaid, HealthCare Access Maryland (HCAM), Baltimore City’s seven major health systems, three federally qualified health centers (FQHCs), and dozens of community-based organizations. BCHD and these organizations share a dedication to understanding, identifying and solving the health-related social needs (HRSNs) of Baltimore City’s Medicaid and Medicare beneficiaries. Through many interventions, these organizations have in the past piloted efforts to meet the HRSNs of Baltimore patients. The AHC program allows these organizations to work together to build on their individual efforts and bridge clinical care and social services to ultimately lower total health care costs, improve their vulnerable population’s health outcomes, and reduce unnecessary utilization.

Community Needs

Baltimore City experiences significant health disparities and ranks the lowest on key health outcomes among Maryland’s jurisdictions. The city’s mortality rate is 30% higher than other cities within the state, and nearly 60% of its total population (361,000+ residents) is composed of Medicaid and Medicare beneficiaries. Figure 2 summarizes some key statistics about the city’s social needs.

Because social factors, not clinical care, drive 70% of health outcomes, BCHD believes that it is crucial to address these HRSNs to drive wellness and improve population health in Baltimore.

Building Partnerships

As Baltimore’s public health authority and a local convener, BCHD has a history of creating city-wide, interdisciplinary collaborations on health issues. BCHD organizes these collaborations by leveraging existing relationships with FQHCs, hospitals, CBOs, and managed care organizations (MCOs) to identify best practices, eliminate silos and scale maximum impact across the city.

Because of the state’s shift to a global budgeting revenue system (an All Payer Model Agreement with CMS), health care institutions in Maryland are highly incentivized to address social determinants and population health. Their commitment to population health and total cost of care creates an environment open to supporting additional services for patients with HRSNs, particularly high utilizers of health care services.

To design the AHC model, BCHD brought together these aligned groups, including CBO partners and health stakeholders, and convened more than 20 meetings, including group and one-on-one meetings. During these meetings, the participants determined the best strategy for workflow implementation, processes for screening and referral, and the role of technology. Participants also worked to develop and secure memorandum of understanding (MOUs) or MOU equivalents with FQHCs, city health systems, CBOs, the local behavioral health authority, and other community partners.

BCHD also worked with the Maryland Medicaid office to discuss the AHC model and its role in and strategies for collaboration, implementation, and sustainability. BCHD and Maryland Department of Health (MDH) established an agreement outlining this collaboration, which includes data coordination, outlines roles and responsibilities, reporting, identification of duplicative services and participation in the AHC Consortium, which is made up of BCHD, Maryland Medicaid, clinical delivery site partners, and HealthCare Access Maryland (HCAM) and develops standard policies and intervention procedures, including a screening tool, a Community Resource Inventory, and AHC navigator training curriculum.

The AHCM

Business Model: AHC Funding and Long-Term Sustainability Plan

CMS will provide funding for the Baltimore AHC model over a period of five years, with BCHD as the bridge organization overseeing flow of funding. BCHD will provide funding for HCAM to support the following activity.

1. Key personnel hiring, training, and deployment (e.g., AHC Navigators and program managers)

Additionally, BCHD will contract with a vendor to house the screening tool, community referral summary, and Community Resource Inventory

Currently in Year 1, the AHC Consortium is developing standard policies and intervention procedures, hiring key staff, establishing a screening tool with the help of the Innovation Center, creating a Community Resource Inventory, and finalizing a curriculum for AHC navigator training. The Community Resource Inventory will be an accurate, updated, sustainable and unified resource inventory of core and supplemental community services that address a breadth of social needs. Additionally, the Community Resource Inventory will include quality assessment and peer reviews of resources as well as technological integration, data sharing and analytics capability for the purposes of tracking and assessing outcomes related to social service connections. BCHD is also working to convene an AHC Community Advisory Board that will reflect the patient perspective and contribute to overall model design.

Next year, as clinical delivery sites begin screening for HRSNs, BCHD plans to direct resources primarily toward AHC Navigator hiring and training, additional convenings of the Advisory Board and AHC Consortium, and supporting improvements in quality improvement infrastructure and technology.

By the end of the five years, BCHD envisions a fully-implemented, robust, and innovative AHC program that will have collected the data and analytic evidence needed to motivate health systems to continue funding the AHC model. Outside
funding (i.e., the grant from CMS) made it possible for hospital systems to turn conversations they were already having about addressing social needs into conversations about crystalizing the work, bringing it together and making this impact a reality. With the appropriate supporting evidence, the convergence of Maryland’s global budgeting with systematic trends towards population health has created an appetite for continued funding after the grant period concludes. The AHC Consortium and Advisory Board will also have the strength to advocate for policy change that will allow providers to bill Medicaid and/or Medicare for connections to social services, instead of using ancillary dollars. With stakeholder engagement, political envisioning, and evidence-based validation, this is another option to create sustainability.

Figure A8: BCHD & Partners*

* Additional behavioral health providers.
Population and Patient Identification

In Year 1, BCHD will work with AHC Consortium and Advisory Board partners to create and pilot a screening tool that pulls from the CMS-designated screening tool and the provider community’s expertise. During Year 2, participating clinical delivery sites (i.e., hospitals, FQHCs, and behavioral health providers) will screen consenting Medicaid and Medicare beneficiaries for their social needs. By the end of five years, screening will have expanded to occur at each provider partner’s labor and delivery department, emergency department and inpatient psychiatry (as applicable). Based on Consortium conversations, partner sites may also screen in ambulatory outpatient or primary care settings.

CMS has developed a screening tool for the AHC model; currently, BCHD is in conversations about integrating the tool effectively into existing clinical workflows. The CMS screening tool includes questions in the categories of Housing Instability, Food Insecurity, Transportation Needs, Utility Needs, and Interpersonal Safety. The full screening tool is available from the National Academy of Medicine.47

Structure and Services

The core components of the Baltimore City AHC model are summarized in the pyramid figure below (Figure A9), organized by level of impact, size, and scale:

---

Figure A9: Summary of BCHD’s Role

1. HRSN screening for Medicaid and Medicare beneficiaries

2. AHC Navigation Hub referral of qualifying beneficiaries, housed at HCAM, to receive support and navigation in accessing HRSN-related services

3. Comprehensive data, technology and QI infrastructure to support resolution of HRSNs, track outcomes, and drive continuous program improvement

4. Convening of community and healthcare stakeholders and city and state agency partners to establish alignment around both creating and evaluating community-clinic linkages within the city

Figure A10 describes the complexity of the Baltimore health care system and illustrates how patients’ needs will be met as they are served by AHC interventions.
As illustrated in Figure 4, patients will complete the HRSN screening tool once per visit. If screened positive, patients will be stratified according to risk (low or high). Based on this risk-stratification level, patients will receive a tailored, at-point-of-care
Community Referral Summary (low risk), or a referral to HCAM’s AHC navigation hub for full resource connection and navigation services (high risk).

Low-Risk patients receive a Community Referral Summary, generated by the Community Resource Inventory. The community referral summary will include eight core and supplemental needs, and identify each resource with a physical address, brief summary of offerings, website, criteria for application and benefits and/or costs associated.

High-Risk patients receive outreach from an AHC Navigator, who will conduct navigation services in full. These services include a risk assessment and personal interview in the community or the patient’s home. Using evidence-based techniques of motivational interviewing and lessons learned in their community-based health worker (CHW) training program, Navigators will assess patients’ health status indicators and social determinants. The Navigators will then develop personal action plans to address each of the HRSNs, help patients navigate and access resources (either by self-referral if the patient is able or with the help of the Navigator), follow-up with patients on each goal of the care plan, and help troubleshoot barriers to obtaining resources. Navigators will record care plans and update patient profiles in real time.

Overall, AHC Navigators will facilitate patient needs assessments, provide information about the local health care system, along with community and social services and how to access them; refer patients to services, agencies and resources; act as resource advocate for patients; facilitate clear, culturally- and language-appropriate communication; document activities and keep records of cases; and most importantly, provide follow up for patients based on their needs.

**Planned Outcomes**

Outcome metrics will be drawn from existing state and federal measurement priorities for providers (i.e., HEDIS quality measures).

These may include the following:

- **Care Utilization**: primary care utilization; emergency department readmissions; appointment no-shows
- **Clinical Experience**: provider satisfaction; patient satisfaction/retention
- **Clinical Outcomes**: blood pressure; Hemoglobin A1C; number of postpartum visits

---

49 Needs include: housing instability, utility needs, transportation needs, food insecurity, interpersonal violence, education, employment and income, and behavioral health
50 Based on the Prochaska and DiClemente Stages of Change model
Planning for Implementation

BCHD has several objectives for implementation: think big and communicate often, avoid duplication of efforts across health care systems, determine the checkpoints, prevent unmanageable workloads for staff, draw upon experiences and expertise, be and stay open-minded and improve programs through iteration, and outline a technology roadmap includes planning for legal issues. Additionally, BCHD is committed to QI processes for every work flow and effort. These objectives and BCHD’s progress towards them are elaborated as follows:

Thinking big and communicating often: CMS issued the AHC funding announcement in January 2016. Upon seeing this opportunity, Dr. Leana Wen, the BCHD Health Commissioner, and Sonia Sarkar, Chief Policy and Engagement Officer, convened stakeholders to discuss the potential for a systems-level intervention rather than siloed, institution-specific. The two met with and spoke to executives of the Baltimore City health systems and included CBOS and health centers in the process as well as the patient voice. They found champions within each partner and drafted MOUs or MOU like agreements with each site (21 MOUs) over the three-month proposal-writing process. During the CMS review process, the AHC Consortium continued to meet, share resources, and identify and solve gaps in care.

Avoiding duplication of efforts: An important directive for BCHD’s convening strategy was to ensure that efforts were not duplicated; BCHD leadership have emphasized that AHC conversations are about building upon existing efforts in population health and expanding capacity.

Checkpoints: The screening, referral and navigation processes contain several checkpoints in order to avoid duplicative case management and/or social service need program services. The AHC Consortium plans to further refine robust protocols in Year 1 to ensure nonduplication of program services.

Preventing unmanageable workloads: Due to the city’s high prevalence of social need and poverty, positive screening, based on data from CRISP (Maryland’s health information exchange), BCHD anticipates that upwards of 40% of patients will screen positive for HRSNs. To prevent AHC Navigator workforce, physician, and staff burnout from overwhelming, unmanageable volume, BCHD plans to design a phase-in screening model to enable provision of navigation services to at least 2,925 patients (and screen an appropriate number of patients to get to that number).

Building on everyone’s existing knowledge and experience: BCHD plans to draw upon learned lessons from its AHC Consortium partners and their models, such as Johns Hopkins Medicine’s J-CHiP program, as well as local regional partnership models.

Always have an eye on the ‘so what?’ of the program: Because impact matters most, throughout the implementation process the Baltimore City AHC Consortium makes
sure to circle back to the core premise of the model – better care for patients and more effective service delivery.

*Roadmap for technology:* BCHD will outline a technology roadmap for CRISP integration that includes: 1) identifying and planning for how to resolve legal issues and 2) figuring out how to support functionality that will capture HRSN data in the patient care plan record. As a backup, and in the interim, BCHD plans to have all care management information stored with the care manager, either at the provider or with the Navigator at HCAM.

*Commitment to QI processes for every work flow and effort:* In collaboration with the Advisory Board and CMS, BCHD will draft and develop a data-driven QI plan for decision-making to optimize and accelerate outcomes. The QI plan will be reviewed and updated annually.
Appendix B: Complete Review of the Literature

Methods

We identified reviews of serious illness programs by first conducting a preliminary scan of “white papers” — defined as technical or other reports published on websites of known health policy, advocacy and government organizations (e.g., National Academy of Sciences, Robert Wood Johnson Foundation, Center to Advance Palliative Care) — to efficiently identify current approaches to providing serious illness care and describe the range of terminology, populations, and programs that fit under the umbrella of “serious illness.” In addition, we solicited recommendations for inclusion in the synthesis from experts in the field of serious illness care, including both members of our project team and advisory panel. Finally, we identified additional resources from the reference lists of the white papers and papers contributed by the experts. From this process, it quickly became evident that a multitude of key health care organizations — including many representative of the hospital industry, government agencies, insurers, and health care policy or advocacy groups, among others — have been deeply engaged in a national conversation about the current state of serious illness care, with a proliferation of research on interventions for individuals with serious illness over the last decade.

Our search identified a large number of systematic reviews and/or meta-analyses focused on outcomes of programs for populations that fall under the definition of a “serious illness population” but used alternative labels or population definitions. Importantly, despite the range of population definitions and programs, these reviews share common elements and areas of overlap relevant to serious illness care. Accordingly, we conducted a synthesis of reviews rather than of individual studies in an effort to collate high-quality, existing evidence gathered from a range of populations under the broader concept of serious illness care. To our knowledge, this large body of evidence has not been synthesized to-date.

Key questions that we sought to answer with the synthesis included:
1. What serious illness care populations are included in the programs reviewed?
2. What outcomes are improved by serious illness programs?
3. What is the strength or quality of existing evidence for serious illness care programs?
4. What specific program structures and services are associated with success?
5. What implementation considerations are described in the literature?
Inclusion and Exclusion Criteria

Evidence was synthesized from reviews that included studies of multi-component programs focused on a population of individuals with serious illness, including at least one of the following: multiple chronic conditions, functional impairment or frailty, advanced illness (i.e., cancer, heart failure, or dementia), and high-need/high-cost individuals. Papers were excluded if they were published before 2002, were unavailable in English, or included only non-U.S. based interventions. Because serious mental illness and pediatric serious illness populations may require unique and specialized services not generalizable to the wider population of individuals with serious illness, we also excluded papers that focused exclusively on these subpopulations (Table B1). The papers identified from the initial white paper scan were also eligible for inclusion themselves if they reported results of a literature review.

Table B1

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population of seriously ill individuals</td>
<td>Does not include U.S.-based programs</td>
</tr>
<tr>
<td>Includes programs with multiple features/components</td>
<td>Population focus is pediatrics or serious mental illness</td>
</tr>
<tr>
<td>Includes multiple programs/models</td>
<td>Published before 2002</td>
</tr>
<tr>
<td>May be peer-reviewed or white/grey literature</td>
<td>Not available in English</td>
</tr>
</tbody>
</table>

Data Collection

Three reviewers on the research team (Robin Whitney, Sibel Ozcelik and Janice Bell) abstracted the following data from the included reviews: publication details, review methodology, population, scope (number and type of studies or programs included), names of specific programs reviewed, features/components associated with success, implementation considerations and barriers, outcomes, and strength/quality of evidence.

Results

A total of 28 review papers met the inclusion criteria and were included in the final synthesis. Collectively, the reviews assessed outcomes of 869 studies or programs, including 426 randomized controlled trials. However, these are not 869 unique programs, as some studies were included in multiple reviews. Of the 28 final review papers, 13 were systematic reviews or meta-analyses, nine were expert syntheses or evidence briefs, and seven were summaries of Medicare demonstration programs. Sixteen of the reviews graded the quality of the evidence, 17 identified common features of successful programs, and 10 discussed implementation (Table B2).
Table B2

<table>
<thead>
<tr>
<th>Methods</th>
<th>n</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systematic review</td>
<td>13</td>
<td>Bouman, 2008; Boult, 2009;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Finlay, 2002; Gomes, 2013;</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Higginson, 2010; Kavalieratos, 2016; Singer, 2016; Smith, 2012; Smith, 2014; Stall, 2014; Stuck, 2002; Totten, 2016; Zimmerman, 2008</td>
</tr>
<tr>
<td>Level 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other peer-reviewed</td>
<td>9</td>
<td>Anderson, 2015; Bott, 2009; Brown, 2012; Colligan, 2017; El-Jawahri, 2011; Ingber, 2017; McCall, 2011; Peikes, 2009; Ruiz, 2017</td>
</tr>
<tr>
<td>Level 3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Because the systematic reviews offer evidence of the highest grade, the number of Level 1 systematic reviews that reference specific concepts within each category are included in parentheses.

**Population**

Across the reviews, the terminology used to describe individuals with serious illness varied widely, as did the population foci reported for serious illness care programs. We organized serious illness populations into five categories stemming from the primary motivations for program development: 1) high need/high cost; 2) illness or condition; 3) insurance; 4) age; and 5) service. The categories are not mutually exclusive. Indeed many of the reviews included population definitions that touched on multiple categories. (Table B3). By far, most reviews focused on programs that defined their populations by condition—typically multiple or advanced chronic conditions—populations that might arguably fall under the high need/high cost category as well.
Table B3: Serious Illness Populations

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of Reviews</th>
<th>Labels</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Need/High Cost</td>
<td>7</td>
<td>High need/high cost</td>
</tr>
<tr>
<td></td>
<td></td>
<td>High Cost</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Higher than average costs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>At risk for hospital admission or death</td>
</tr>
<tr>
<td>Condition</td>
<td>20</td>
<td>Chronic illness, chronic conditions (CC), disability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Two or more chronic conditions (or CC plus disability)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(Advanced) condition requiring disease management (Diabetes mellitus (DM), heart failure (HF), coronary artery disease (CAD), cancer, chronic obstructive pulmonary disease (COPD), dementia)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Complex health care needs</td>
</tr>
<tr>
<td></td>
<td></td>
<td>“poor health”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Terminal or life limiting illness</td>
</tr>
<tr>
<td>Insurance</td>
<td>8</td>
<td>FFS Medicare</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medicare beneficiaries</td>
</tr>
<tr>
<td>Age</td>
<td>4</td>
<td>(Community dwelling) older adults age &gt;65 years</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Older adults</td>
</tr>
<tr>
<td>Service</td>
<td>4</td>
<td>Palliative care or hospice</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Long Stay Nursing Facility Residents</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Community-based primary care setting</td>
</tr>
</tbody>
</table>

Features of Successful Programs

Identifying features of serious illness programs that are associated with successful outcomes was a stated goal in many of the reviews. However, identifying specific features that contribute to success is challenging for several reasons. First, most serious illness programs are multifaceted and most studies are not designed to assess the independent or relative contribution of individual program features. Second, comparisons between programs are complicated by the heterogeneity of program features and their descriptions. For example, commonly mentioned program features such as “care coordination” or “comprehensive assessment” were often not further defined in the literature, despite lack of clarity around what exact interventions might be included in those terms. Due to challenges such as these, many of the reviews included in our synthesis did not yield data sufficient to identify program features associated with success.

Of the final reviews, however, 17 did attempt to identify program features associated with success, despite methodological challenges. Most did so either by: 1) tabulating program features and identifying those that were more common among successful programs than among unsuccessful programs, or 2) Including qualitative
assessments of what contributed to program success. The most common feature identified was appropriate targeting and selection of high-risk individuals; followed by care coordination or patient navigation; transition management; and face-to-face contact between coordinators and patients and providers.

Table B4. Number of Reviews Identifying Specific Program Features as Associated with Success

<table>
<thead>
<tr>
<th>Program Feature</th>
<th>Total (n=17)</th>
<th>Level 1 (n=7)</th>
<th>Level 2 (n=5)</th>
<th>Level 3 (n=5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Targeting</td>
<td>8</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Face-to-Face Contact</td>
<td>7</td>
<td>0</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Transition Management</td>
<td>7</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Care Coordination or Navigation</td>
<td>7</td>
<td>1</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Multidisciplinary Teams</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Comprehensive Assessment</td>
<td>5</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Regular interprofessional interactions</td>
<td>5</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Self-Management or Coaching</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Medication Management</td>
<td>4</td>
<td>1</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Home-based Interventions</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Patient/Caregiver Engagement</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Enhanced Access (e.g., 24/7 access)</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Evidence Based Care Planning</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Community referrals/resources</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Nurse or MSW Involvement</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Specialized Training for Staff</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Routine Patient Monitoring</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Outcomes

The collective evidence for serious illness care programs evaluated more than 50 outcomes, subsequently categorized as: a) health service use and costs; b) experience; c) health; or d) care process outcomes.
Health Service Use and Costs

The most commonly studied outcomes of serious illness care programs were broadly categorized as health service use and costs (Table B5), with all reviews including at least one measure in this category and all but four reviews showing a reduction in at least one measure.

Reduced hospital admissions was the most commonly demonstrated health service outcome, being the commonly studied outcome across the reviews generally (18 reviews) and having the most evidence from peer reviewed systematic reviews (Level 1=7). In total, 13 reviews (Level 1=6) demonstrated a reduction in this outcome, with inconsistent effects or no effects shown in the remaining five reviews (Level 1=1). Relatedly, of the three reviews including hospital bed days (Level 1=2), all reported a reduction, and of four reviews including hospital readmissions (Level 1=1), two reviews (Level 1=0) reported a reduction. Comparatively fewer reviews included readmissions, with two reviews (Level 3) finding a reduction and two reviews (Level 1=1, Level 3=3) finding inconsistent or no effects. From this, we can conclude that there is strong evidence for reduced hospital admissions (but far less evidence for reduced readmissions) associated with serious illness programs across a range of population definitions. As this was the most frequently studied outcome, we obviously cannot make comparisons of the strength or consistency of the evidence for hospital admission reduction relative to other outcomes.

Not surprisingly a similar body of evidence, albeit with mixed results, suggests a reduction in total health care costs—presumably driven by reduced hospital admissions, which are known to comprise the greatest share of health care costs. Seventeen reviews addressed total costs with 10 reviews (Level 1=6) demonstrating reduced costs, 10 (Level 1=3) showing inconsistent or no effects and two reviews (Level 1=1) demonstrating an increase in total health care costs with serious illness programs. These findings are also consistent with the evidence for reduction in overall health care use, with nine reviews (Level 1=5) including this outcome, five reviews (Level 1=3) showing a reduction, and four (Level 1=2) showing no effects or inconsistent effects. One study (Level 3) showed reduced primary care costs and limited inconsistent evidence for reduced hospital to home costs with serious illness care programs.

Reductions in ED use were demonstrated in five reviews (Level 1=1); however, three other reviews (Level 1=0) showed inconsistent evidence for this outcome and another three reviews (Level 1=1) showed no effect. One review (Level 3) reported decreased Intensive Care Unit (ICU) days associated with serious illness care programs.

---

One review (Level 1) reported inconsistent evidence for specialty visit use and three reviews (Level 1=1) found inconsistent evidence for reduced home-based intervention costs. Four reviews, all peer reviewed systematic reviews, included long-term care or nursing home admissions as outcomes (either total number or bed days), with all reporting reductions associated with serious illness care programs. Two of four reviews (Level 1=0) reported increased hospice use, the third reported increased hospice days, and the fourth found inconsistent or no effects.

Inconsistent or no effects were also reported for use of chemotherapy among advanced cancer patients (two reviews; Level 1=0) and cost effectiveness of serious illness care programs (one review Level 1=1).
### Table B5

<table>
<thead>
<tr>
<th>Health Service Use and Costs</th>
<th>Direction of Effect</th>
<th>Finding “+” evidence</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital Admissions - number</td>
<td>Decreased</td>
<td>+</td>
<td>6</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Hospital Admissions - bed days</td>
<td>Decreased</td>
<td>+</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Hospital Readmissions - number</td>
<td>Decreased</td>
<td>+</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Overall Health Care Costs</td>
<td>Decreased</td>
<td>+</td>
<td>6</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>No effect</td>
<td>+</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Increased</td>
<td>+</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Overall Health Care Use</td>
<td>Decreased</td>
<td>+</td>
<td>3</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>ED Use</td>
<td>Decreased</td>
<td>+</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>No effect</td>
<td>+</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>ICU Days</td>
<td>Decreased</td>
<td>+</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Specialty Visit Use</td>
<td>Decreased</td>
<td></td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Home-Based Intervention Costs</td>
<td>Decreased</td>
<td></td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>LTC/Nursing Home Admission - number</td>
<td>Decreased</td>
<td>+</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>LTC/Nursing Home Admission - bed days</td>
<td>Decreased</td>
<td>+</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Use of Hospice</td>
<td>Increased</td>
<td>+</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Hospice LOS</td>
<td>Increased</td>
<td>+</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Use of Chemotherapy</td>
<td>N/A</td>
<td></td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Cost Effectiveness</td>
<td>N/A</td>
<td></td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

### Experience Outcomes

Experience outcomes (Table B6) were reported in several reviews, with both patients (10 reviews; Level 1=7) and caregivers (five reviews; Level 1=4) consistently reporting improved satisfaction with advanced illness care programs. Caregiver burden was reduced in one review (Level 1=1).

Table B6
Experience | Direction of Effect | Finding “+” evidence “|” inconsistent or NS | Level 1 | Level 2 | Level 3
---|---|---|---|---|---
Experiences/Satisfaction Patients | Improved | + | 7 | 1 | 2
Experiences/Satisfaction Caregivers | Improved | + | 4 | 1 | 0
Caregiver Burden | Decreased | + | 1 | 0 | 0
Physician Experience | Improved | + | 0 | 0 | 1

**Health Outcomes**

Patient symptoms and symptom burden were commonly studied with six reviews (Level 1=6) reporting reductions and one review (Level 1=1) reporting inconsistent or no effects. Three reviews considered pain separately with two reviews (Level 1=2) reporting improvements and one (Level 1=1) reporting no effects with serious illness care.

Five of seven reviews (Level 1=5) reported improvements in quality of life (Level 1=4); whereas, two (Level 1=1) found inconclusive or no effects. Of five reviews reporting physical health status (Level 1=2), patients reported improvements in three reviews (Level 1=1); inconsistent or no effects in two reviews (Level 1=1). Psychosocial health status (five reviews; Level 1=3), functional health status (three reviews; Level 1=3), functional autonomy (one review; Level 1=1), and positive health behavior change (one review; Level 1=1) improved in all reviews that reported these outcomes.

Only one review (Level 1) included existential or spiritual concerns reporting improvement. Of three reviews that considered caregiver burden, two reported decreases (Level 1=1) and one reported inconsistent or no effects (Level 1=1). Finally, two reviews (Level 1=2) found lower mortality rates and two reviews (Level 1=2) reported increased rates of death at home with serious illness care programs.
Table B7

<table>
<thead>
<tr>
<th>Health Outcomes</th>
<th>Direction of Effect</th>
<th>Finding “+” evidence</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Symptoms</td>
<td>Decreased</td>
<td>+</td>
<td>6</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td></td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Pain</td>
<td>Decreased</td>
<td>+</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td></td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Increased</td>
<td>+</td>
<td>4</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>N/A</td>
<td></td>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Physical Health</td>
<td>Improved</td>
<td>+</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>No Improvement</td>
<td>+</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Functional Status</td>
<td>Improved</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Functional Autonomy</td>
<td>Improved</td>
<td>+</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Psychosocial Health</td>
<td>Improved</td>
<td>+</td>
<td>3</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Positive Health Behavior Change</td>
<td>Improved</td>
<td>+</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Existential or Spiritual Concerns</td>
<td>Improved</td>
<td>+</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Mortality</td>
<td>Decreased</td>
<td>+</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Death at Home</td>
<td>Increased</td>
<td>+</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Care Process Outcomes

Limited evidence was available to describe quality of care and support outcomes associated with serious illness care programs (Table 8; 10 reviews; Level 1=5). The most commonly studied outcomes in this category were: quality of care; care planning, broadly defined; and more specifically, advance care planning (e.g., advance directive completion). Quality of care improved in three of three reviews (Level 1=1), advance care planning improved in two of two reviews (Level 1=1); however, of the three reviews that considered care planning broadly (Level 1=3), improvements were noted in only one. Physician-patient communication improved in one review (Level 1=1); however, inconsistent or no effects were reported for referrals (Level 1=1), clinician adherence to guidelines (Level 1=1) and process quality measures (Level 1=1). Evidence for physician experiences with advanced illness care programs was mixed with one review (Level 1=0) finding improvement and one review (Level 1=0) finding no effects. One review (Level 3) found improvements in quality of primary care and hospital to home care but no improvements in home based care quality.
### Table B8

<table>
<thead>
<tr>
<th>Care Process</th>
<th>Direction of Effect</th>
<th>Finding “+” evidence</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Care</td>
<td>Improved</td>
<td>+</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Care planning</td>
<td>Improved</td>
<td>+</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Advanced Directive Completion, ACP</td>
<td>Increased</td>
<td>+</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Clinician Adherence to Guidelines</td>
<td>-----</td>
<td></td>
<td></td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Process Quality Measures</td>
<td>-----</td>
<td></td>
<td></td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Patient-Physician Communication</td>
<td>Improved</td>
<td></td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Primary Care Quality</td>
<td>Improved Quality</td>
<td>+</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Hospital to Home Quality</td>
<td>Improved Quality</td>
<td>+</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Home Based Quality</td>
<td>No Improved Quality</td>
<td>+</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

### Implementation Considerations

One of the critical tasks of our review was to identify implementation considerations that would be informative for organizations undertaking the design or modification of a serious illness program. However, few of the included reviews (10 of 28) discussed implementation. Reviews that discussed implementation based their findings on qualitative program synthesis or interviews with stakeholders of successful and unsuccessful programs. The most commonly identified implementation consideration was the need to build strong relationships between program staff and patients and caregivers as well as key medical care providers (e.g., primary care providers), and the need to leverage health technology for decision support and continuous quality improvement. Other considerations included tailoring program design to the local context, working towards organizational culture change to support program success, hiring appropriately trained and experienced staff, finding ways to pool resources, and implementing in organizations with better infrastructure to support these programs (e.g., accountable care organizations).
### Table B9

<table>
<thead>
<tr>
<th>Implementation Considerations</th>
<th>Total (n=10)</th>
<th>Level 1 (n=1)</th>
<th>Level 2 (n=6)</th>
<th>Level 3 (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on building relationships and promoting communication (patient-provider and/or among providers)</td>
<td>5</td>
<td>0</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Technology-supported decision support and continuous improvement</td>
<td>5</td>
<td>0</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Consider local context</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Create environment for successful leadership, work towards culture change and buy in at all levels</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Hire appropriately experienced staff</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Measure program outcomes</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Combine qualitative and quantitative methods for patient targeting</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Pool resources or implement in settings with better infrastructure to support program (e.g., not FFS)</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Reduce physician workload</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Patient input on governing boards</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

### Summary

On the whole, the evidence for serious illness care programs is promising, with positive outcomes reported related to health service use and costs; experience; health; and care processes. Given the heterogeneity in program components it is not possible to disentangle the effects of specific serious illness care program intervention components on specific outcomes. By far, the evidence is most robust for health service use outcomes—specifically for reductions in admission. Further research is warranted to focus on other outcomes including outpatient service use and advanced illness care outcomes (hospice, advance care planning). Studies of cost effectiveness of serious illness care programs should also be prioritized.

Although less frequently studied than health service use, the evidence for improvements in health is quite consistent, with most reviews that addressed this outcome category finding improvements—including physical health, psychosocial health, symptom burden and quality of life. The evidence for reduced mortality was similarly consistent and positive, albeit addressed in only a few reviews.

By far, the most limited evidence was for care process outcomes. And while the results in reviews of these outcomes are quite promising, further studies are clearly needed to better understand these outcomes, ideally, in studies designed to contribute evidence for future dissemination and implementation.
Appendix C: Works Cited

Bibliography: Reviews on the Effectiveness of Serious Illness Care Models

Resources for 2017 Serious Illness Framework Development

Contact: Robin L. Whitney, PhD, RN, Research Director, Hillblom Center on Aging, Assistant Adjunct Professor, Internal Medicine, UCSF Fresno, rwhitney@fresno.ucsf.edu


Appendix D: Feedback from Convening Sessions

KEY OBSERVATIONS FROM PANEL DISCUSSION
CRITICAL PATHWAYS TO IMPROVED CARE FOR SERIOUS ILLNESS
CONVENING SESSION 1: MARCH 10, 2017

Convening Session 1 introduced the SIP Framework, initially named the Serious Illness Care Implementation Framework, and offered a taxonomy/common language for understanding the population, interventions, and outcomes for a serious illness care model. This provides a macro-level context for identifying the underlying factors that help make programs and interventions successful. We began engaging with these concepts during our session and collected the following observations that we will use to further refine the framework, grade available evidence for programs and interventions, and surface key implementation steps.

Observations

1. The patient’s voice should be elevated in the model and discussions surrounding it.
2. Revisions of the framework should include more information about choosing meaningful measures of program success.
3. The framework should identify which interventions are most important for program success.
4. Interventions should:
   a. Emphasize continuity of care as patients transition through the continuum.
   b. Create strong connection points within teams and between providers.
   c. Consider the importance of relationships between the providers and the patient/family/caregivers.
   d. Include multidimensional assessment as a key element of care delivery.
   e. Reference best practices and demonstrated strategies where possible (see #6).
5. Implementation recommendations should:
   a. Recognize how payment impacts the structure and sustainability of programs.
   b. Note the impact of organizational culture on program creation/scaling and the potential for stakeholders to feel threatened by new models that may change their work.
   c. Underscore the importance of organizational leadership for setting the vision, allocating resources, and inspiring buy-in.
d. Include change management techniques.
e. Feature staff education and coaching / core competencies.

6. While there is evidence supporting effectiveness of overall programs for improving quality and lowering cost, limited evidence (such as randomized controlled trials) exists regarding the effectiveness of specific interventions. There is also minimal data on the comparative effectiveness of varying applications of interventions, for example, whether differences in visit frequency or team composition impact success. However, there is strong consensus and validity related to identified interventions. Our literature review can both assess the current evidence and surface research gaps, and we may find that a less traditional framing of the evidence may be required.

7. There are tensions around alternative options to deliver an intervention such as via primary care vs. specialty, integrated vs. stand-alone.

8. Organizations considering program creation/scaling should assess their current assets and core competencies and determine what capabilities are missing that could be developed or outsourced.

9. One barrier to quality serious illness care more broadly construed is a deficit in medical education and training - the panelists recommend more and earlier training/education for healthcare and social sciences.
Convening Session 2 reviewed the revised SIP Framework and invited an expert group of stakeholders to provide insight into serious illness care delivery, which will inform the design and implementation of the framework moving forward. We collected the following observations from the discussion that we will use to further refine the framework for inclusion in the forthcoming white paper and to inform the development of a future payment model simulator.

Observations
Panelists identified several barriers to program success that could be addressed in the discussion around the SIP Framework.

1. **Resources**: A program may have limited resources to provide the range of needed services to the populations that need them the most. A program may also compete for resources with other programs and initiatives in the same organization. Aligning resource needs to the business case and value proposition is a good strategy. In addition, program developers can think creatively about how to meet resource needs such as capitalizing on existing capabilities and creating alignment with other services/initiatives.

2. **Care breaks down at the “synapses” – transitions between settings, providers, and payers**: Care often occurs in silos, so a program will need to integrate various components of serious illness care. Patient “churn” (i.e., switching insurance coverage) can also disrupt care.

3. **Challenges of multiple programs and funding mechanisms**: Financial incentives may be misaligned when multiple programs collaborate. The willingness of plans and providers to enter value-based or risk-based payment models may help align these incentives. In addition, organizational leadership can create a coherent internal financial model despite multiple external payment models.

4. **Patient and community perceptions**: Patients often do not understand their own prognoses and options, creating barriers to effective decision making. Patients and families often do not know about the availability of quality care because of confusing terminology and misperceptions of what is involved in various types of care. Smaller and community-based health care organizations can play an important role in shaping these perceptions through their actions at a local level.

5. **Interoperability and technical barriers**: Limits on the ability to transfer information between providers erode care transitions. When establishing a program, consider addressing technical barriers to exchanging the most essential information first. For example, determine how to track where a patient is receiving care or know in near real time when a patient is having an acute episode.
Panelists also identified **key facilitators** that are helpful or essential to program success.

6. **Communication:** Continuous contact and strong relationships between and within providers and with the patient and family is a key factor in program efficacy. Programs should also engage and build partnerships with community groups and other programs, along with payers.

7. **Population health:** To address some of the funding challenges described above, innovative programs and partnerships may find success and support in population health models.

8. **Executive leadership:** Having buy-in from senior management, executive sponsorship, and programmatic champions is critical to program success because the philosophy, ideologies, and priorities of leaders influence resource availability and other forms of organizational support. One way to engage senior leaders is to create and promote a “burning platform” that expresses the need for the program and its potential impact on key performance indicators like readmissions, length of stay, mortality, and cost. Senior leaders often do not have expertise in program implementation or quality improvement, so the industry could offer education for leaders on how to be effective sponsors or champions in launching a program within an organization and measuring success.

9. **Sustainability:** Programs should build a culture and structure that is sustainable beyond individual people or leaders. Succession planning is necessary to create a sustainable program, and programs should cultivate future leaders with 1) broad understanding of the program and environment, and 2) alignment with the mission of the organization. In addition, a program should devise both an early and a long-term strategy on workforce development. The Baldrige Performance Excellence Program offers one framework for creating a high-performing organizational management system.

10. **System to measures program quality and success:** Cost/finances and quality go hand in hand; lead with quality, and financial savings will follow. To achieve this, programs should develop and systematically implement systems for collecting true “outcome data” in ways that are useful not just for “accountability,” but for driving “quality improvement.”

11. **Learn by doing:** The panelists recognize that there are areas where the evidence is limited, and believe that observational analysis of what works in the field and the use of logic models can fill the gap and provide a disciplined path for program implementation. Organizations can “learn by doing,” using the art of care delivery in addition to the science to innovate and lead.
Finally, panelists identified a few options for us to consider that might to make the SIP Framework more useful for program design and implementation.

12. **Elevate the voices of patients and families** even more in the SIP Framework and supporting text.

13. **Think global AND local**: Emphasize the *regional nature of the healthcare market* in discussion the variation that may occur in programs.

14. **Build in learning mechanisms**: Note the importance of staff assessments, environmental scans, and other factors to evaluate in the process of iterative program design and redesign.

15. **Provide guidance on where to start**: This overarching SIP Framework may be overwhelming to a small organization considering development of a program. We need to identify the first and essential components to help these programs know where and how to begin.

16. **Include operational details**: A greater level of operational details will be helpful to providers considering implementation to help translate the SIP Framework to practice.

17. **Reference other models**: Note areas in which the SIP Framework draws from specific other models that have been developed (e.g., the eight domains of palliative care).