Unpacking complex interventions that manage care for high-need, high-cost patients: a realist review

Eva Chang, Rania Ali, Nancy D Berkman

ABSTRACT
Objective Payers, providers and policymakers in the USA are interested in developing interventions that reduce preventable or modifiable healthcare use among high-need, high-cost (HNHC) patients. This study seeks to describe how and why complex interventions for HNHC patients lead to more appropriate use of healthcare services. Design A realist review which develops programme theories from causal explanations generated and articulated through the creation of context–mechanism–outcome configurations. Methods Electronic databases (including PubMed and Embase) and grey literature from January 2000 to March 2021 were searched. All study designs were included if the article provided data to develop our programme theories. Included studies were conducted in the USA and focused on interventions for adults, HNHC patients. Results Data were synthesised from 48 studies. Identifying HNHC patients for inclusion in interventions requires capturing a combination of characteristics including their prior use of healthcare services, complexity of chronic disease(s) profile, clinician judgment and willingness to participate. Once enrolled, engaging HNHC patients in interventions requires intervention care providers and patients to build a trusting relationship. Tailored, individualised assistance for medical and non-medical needs, emotional support and self-management education empowers patients to increase their participation in managing their own care. Engagement of care providers in interventions to expand support of HNHC patients is facilitated by targeted outreach, adequate staffing support with shared values and regular and open communication. Conclusions Building relationships with HNHC patients and gaining their trust is a key component for interventions to successfully change HNHC patients’ behaviors. Identifying HNHC patients for an intervention can be best achieved through a multipronged strategy that accounts for their clinical and psychosocial complexity and prior experiences with the healthcare system. Successful interventions recognise that relationships with HNHC patients require the sustained engagement of care providers. To succeed, providers need ongoing emotional, financial, logistical and practical resources.

STRENGTHS AND LIMITATIONS OF THIS STUDY
⇒ To the best of our knowledge, this is the first review study using a realist approach to assess US-based complex healthcare interventions.⇒ Our focus on high-need, high-cost (HNHC) patients is important for policymakers and payers since the cost of care for HNHC patients accounts for a disproportionately large share of healthcare costs.⇒ A realist review approach allows us to provide explanations for why interventions for HNHC patients may be effective.⇒ While we included grey literature to more comprehensively identify interventions for HNHC patients, scant descriptions of interventions for HNHC patients and the experiences of patients and providers limited our ability to build context–mechanism–outcome configurations and programme theories.⇒ Although we only included literature of studies conducted in the USA, many of the mechanisms identified in this review are likely to be applicable to HNHC patient interventions in other countries.

INTRODUCTION
In the USA, patients referred to as ‘high-need, high-cost’ (HNHC) have become a particular focus for payers, health systems and providers. Although a small percentage of the total patient population, HNHC patients account for a disproportionately large share of high-cost healthcare service use, particularly emergency department (ED) and hospital inpatient care. Poor control of chronic conditions, especially when coupled with functional limitations, mental health conditions, substance abuse and social needs can result in patients’ over-reliance on potentially preventable or modifiable ED and hospital care. Payers, notably the Centers for Medicare and Medicaid Services (CMS), are moving from fee-for-service payment arrangements to alternative payment models that require healthcare systems and providers to provide more cost-efficient care. The viability of these models can depend, in large part, on their ability to reduce the cost of care for HNHC patients.

Many interventions have been implemented that aim to reduce HNHC patients’ inappropriate healthcare use and improve...
their quality of care and health outcomes. Like other systematic reviews on HNHC patients, our recently completed systematic review found that the quantitative evaluations of these complex interventions primarily focused on measuring changes in healthcare costs and utilisation. Overall, these complex interventions demonstrated an inconsistent impact on these outcomes. Further, little evidence measuring other key outcomes, including changes in patient engagement or quality of care, limited the systematic review’s ability to explain ‘why’ the interventions may not have been successful.

To help explain what may (or may not) be happening in these complex interventions, we conducted a companion realist review. Realist reviews use the available literature as the basis for developing theories to explain why an intervention is likely to work, how, for whom, in which circumstances and to what extent. Our goal was to be able to provide stakeholders with a greater understanding of the inner workings of the complex interventions intended to address the needs of HNHC patients. Specifically, we aimed to explain under what set of circumstances and why complex interventions for HNHC patients could lead to more appropriate use of healthcare services and better health-related outcomes. Our overarching research question was ‘what are the mechanisms in interventions serving HNHC patients that lead to reductions in potentially preventable or modifiable healthcare use and result in improved health outcomes and cost savings?’

METHODS

Study design

We used a realist review approach to develop programme theories explaining and describing how complex interventions for HNHC patients work (or fail), for whom and in what particular contexts and settings, as supported by evidence from qualitative and quantitative studies. The approach facilitates unpacking and understanding the causal processes for achieving outcomes within complex interventions. Consistent with this approach, we developed context–mechanism–outcome (CMO) configurations. CMOs are the building blocks for developing programme theories that help explain the underlying (often unseen and intangible) causal mechanisms that underpin interventions. Realist review findings provide support for theories about why outcomes may differ because of subtle contextual conditions.

This review was part of a report that also contained a best fit framework synthesis that identified characteristics associated with patients being HNHC and a systematic review of the effectiveness of interventions for this population. The report was performed by the RTI-University of North Carolina Evidence-Based Practice Center for the Agency for Healthcare Research and Quality (AHRQ). We followed the Realist And Meta-narrative Evidence Syntheses: Evolving Standards (RAMESES) publication standards for realist reviews. Detailed methods and findings from the full review are reported elsewhere. A group of seventeen content and methodological experts were involved in shaping the review and providing feedback on the refined programme theories.

Programme theory development

The team, with input from our experts, first conceptualised a map of a ‘patient journey’ to illustrate how HNHC patients may be inappropriately using the healthcare system. We identified categories of interventions intended to improve the HNHC patient journey, based on a scan of the literature. After team discussions and review of existing theories, we identified that our initial programme theory would have to incorporate the following concepts: claims only strategies were not sufficient for identifying HNHC patients; HNHC patients are clinically and socially complex and interventions needed strategies to engage them meaningfully; and providers were more likely to participate in interventions that considered the differences in their experiences treating HNHC patients compared with a general patient population. Through iterative review of the literature and discussions with our experts, we developed our initial programme theories. We then used the data from included studies to refine our concepts to form our final realist programme theories.

Search strategy

We identified potentially relevant articles for the realist review through one search strategy that encompassed all components of the review and conducted additional targeted searches as needed. An experienced information specialist searched MEDLINE via PubMed, the Cochrane Clinical Trials Central Register, CINAHL, Embase, PsycINFO, Web of Science, Academic Search Premier and Scopus from 1 January 2000 to 4 March 2021. We also searched for grey literature from several relevant organisational and government websites for unpublished literature and non-peer reviewed reports and consulted with content experts to help identify relevant literature. Search strategy details can be found in online supplemental appendix 1.

Study selection and data extraction

To increase the efficiency of our search and screening process, reviewers screened titles and abstracts simultaneously for the best fit framework, systematic review and realist review. Studies were eligible if they focused on providing care for non-institutionalised US adults who were considered HNHC based on having high healthcare use or cost, measured over ≥6 months. We considered any study design eligible for inclusion. During full-text screening, we considered all articles that were included for the best fit framework and systematic review, as well as other identified articles that would be useful for developing our programme theories. Two reviewers independently screened the titles, abstracts and full texts.


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In keeping with realist review principles, we evaluated articles for their relevance and robustness in answering our key questions and their contribution to theory building and testing.\textsuperscript{16} Data were abstracted into NVivo (V.12) using a coding framework grounded in our initial CMOs. Coding of all included studies proceeded as both an inductive and deductive process, that is, we continued to identify and add to the coding framework as we proceeded.

We used RAMESES project standards to guide our judgments in quality appraisal, considering relevance, trustworthiness, plausibility of the argument and methodological rigour.\textsuperscript{16–19}

**Data synthesis and programme theory refinement**

After all included studies were coded, one investigator sorted and grouped excerpts from studies by concepts and developed initial, partial CMO configurations. A second investigator reviewed the CMOs for agreement with their own interpretation. The team then examined the CMOs alongside the developing programme theories and iteratively reworked the CMOs as more data were added and feedback was provided by our experts. Our final programme theories were developed after considering our full set of CMOs.

**Patient and public involvement**

Patients were not directly involved in the conduct of the review. However, patients and the public were invited to review and provide feedback on a draft of the full report during the public posting period (26 February 2021 to 26 March 2021).

**RESULTS**

Figure 1 shows the flow of article selection. In total, 48 studies (51 articles) contributed to developing and refining our programme theories. By design, all studies were conducted in the USA to ensure they reflect the experiences of patients in the US healthcare system. The majority of studies were published in the peer-reviewed literature. Approximately 21% (10 studies) were found in the grey literature, including government reports evaluating large-scale complex interventions for CMS. See online supplemental appendix 2 for additional details about the included studies.

We developed 39 CMO configurations, based on data in the included studies, and used these to iteratively refine three key programme theories to explain mechanisms of interventions for HNHC patients. Programme theory 1 describes the pathway for identifying and targeting participants for HNHC patient interventions. Once patients are enrolled, building and maintaining trusting relationships between patients and care providers can help interventions succeed. We set out key considerations for engaging HNHC patients (programme theory 2) and for engaging care providers (programme theory 3) so that each has the necessary emotional support and practical resources to develop and maintain effective, ongoing relationships. Figure 2 shows the relationship among the three programme theories. Online supplemental appendix 3 includes the data and CMO configurations that underpin the programme theories.
Programme theory 1: identifying and targeting HNHC patients for inclusion in interventions

A first challenge for interventions intending to reduce potentially preventable or modifiable high-cost healthcare use among HNHC patients is to accurately identify those who are most likely to inappropriately use services in the near future. Selecting patients exclusively based on prior high costs could miss individuals at the beginning of a high use period.1 Alternatively, identification based solely on chronic disease status will include individuals who are managing their conditions as best as can be expected.1 Therefore, identifying HNHC patients requires capturing their complexity based on a combination of prior use, chronic diseases, barriers to accessing care and willingness to participate.

Data for identifying HNHC patients

Administrative claims data and electronic health records specifying disease complexity and healthcare use and cost history are often included in models.20–29 While these data are necessary, no existing algorithm or model specification alone has been able to reliably predict future high-cost use.27 30 One barrier to developing accurate projections is ‘regression to the mean’ (the tendency for high use and cost in a baseline period to return to an average level in the follow-up period).27 31 32

Greater accuracy of projections may be facilitated by: limiting projections to participants with healthcare use that is the focus of an intervention (ie, care that is potentially preventable or modifiable);33 capturing the continuum of care across care settings and payers, including public health agencies and community-based organisations;2 27 28 30 33–35; focusing on service use in ‘real time’;2 29 33 36 37 if possible, while a patient is still hospitalised;26 32; and, when considering ED visits, focusing on visits that occur in clusters because a cluster pattern has been found to be associated with HNHC patient ED service use.38 39

Clinical data can identify complex chronic disease. Indicators include having multiple chronic conditions,1 functional limitations and high scores on clinical risk severity measures.28–31 36 40–43 Data on behavioural health conditions (mental health diagnoses and substance use disorders) and social needs (eg, poverty, social isolation) may improve algorithms.1 2 26 35 38 41 44 However, selecting the correct claims to use to identify these conditions can be obfuscated by the co-occurrence of multiple medical conditions.38 Fewer visits may be associated with behavioural health conditions than expected.38

Individually assessing and enrolling patients

Additional information obtained during the intake assessment can further refine predictions of patient risk of future inappropriate use of services. Self-assessment tools can capture patients’ own evaluations of their risk and their readiness to manage their conditions.42 45 46

Figure 2 Framework of optimising interventions for HNHC patients
Healthcare system-related barriers that have negatively affected patients’ ability to self-manage their conditions can be identified, such as prior experiences and distrust of providers and logistical and cost challenges.33 48 49 51

The intake assessment is facilitated by being conducted in-person and can determine a patient’s willingness to be monitored and comply with the intervention.32 33 34 40 50 52-54 Current providers can help judge appropriateness.30 52 54

Notably, socioeconomically disadvantaged or marginalised HNHC patients may appear less willing to participate.56–58 and recognising subtle indicators or extending periods of outreach and trust building may be necessary.54 55 Excluding patients who are more difficult to engage may reinforce and exacerbate disparities.54 Enrolling patients before hospital discharge can increase participation because many live in difficult social circumstances and may be challenging to locate once they return to the community.26 44 56

Programme theory 2: engaging HNHC patients in interventions
HNHC patients may have a history of personal and healthcare system barriers that kept them from receiving appropriate care. Programme theory 2 posits that patients can be successfully engaged in interventions to change their health behaviours if (1) care providers can gain a patient’s trust, and (2) interventions are individualised to meet each patient’s unique complex combination of medical and behavioural health conditions and social needs.

Addressing patients’ life circumstances and prior experiences
Personal circumstances, such as behavioural health conditions, trauma stemming from early life, extreme poverty, low literacy26 35 40 41 50 58 and prior negative experiences with the healthcare system,35 49 57 58 can prevent patients from seeking and accepting help. System-level barriers, such as lack of insurance, inadequate cultural competence or poor communication by providers (eg, inadequate translation services),35 37 40 43 50 58 can increase patient distrust and marginalisation. The healthcare systems’ inability to accommodate patients’ personal circumstances (eg, homelessness) can further inhibit HNHC patients from receiving needed services.48 58 Disrespect and discrimination from providers can lead patients to distrust and avoid specific providers or settings and lower their likelihood of engaging with their treatment.57

Building relationships with care providers
HNHC patients need to trust the individuals providing intervention services.40 Care managers, community navigators and social workers are often tasked with building a trusting relationship with HNHC patients.36 41 55 58-60 Providing assistance with basic life needs (eg, arranging transportation) or help with care adjacent needs (eg, modifying cooking practices to improve diet) can help with establishing trust.48 49 42 44 44 35 57 59 61-63

Patients value care teams that support them in managing their health and welfare, especially care managers who listen and are easy to talk to, who explain things in lay terms and who act as navigators to other care providers.40 41 48 57 60 64 Supportive care teams and HNHC patient peer support groups can create an environment that motivates HNHC patients to improve their health behaviours.35 57 58 HNHC patients feel supported and motivated by interactions with their care managers when they include feedback, especially after taking small steps on their own, and frequent, longer visits.40 48 57 58 61

Providing individualised care
HNHC patients respond to interventions that are individualised, tailored, flexible and offer access to non-medical services. Allowing interventions to be flexible in addressing the diverse needs of individual patients empowers providers to work with patients and their families to develop tailored strategies that accommodate the diversity of needs across the patient population.33 34 39 40 44 48 50 65

Non-medical issues may drive patients’ ability to benefit from healthcare-focused interventions so interventions may need to first address psychosocial needs and facilitate access to services that address these needs.33 34 40 41 44 48 For example, co-occurring problems like substance abuse and housing instability may need to be addressed concurrently or even before managing healthcare.26 48

Interventions that teach patients how to obtain needed medical and non-medical services on their own enhance patients’ confidence and self-efficacy.26 37 42 44 56 58 61 62 The optimal length of time participating in an intervention differs across individual HNHC-participants and an appropriate end may be based on successfully demonstrating personal intervention objectives (eg, self-management behaviour).40 50

Recognising barriers to patient change
An intervention establishing successful relationships with HNHC patients may not lead to reductions in hospitalisations or ED visits in the short term.64 Some patients may continue to prefer visiting the ED because of financial concerns (ie, a lack of copayments) or a perception of receiving better quality of care.51 58 66 Patient-centred success may need to be evaluated in relation to incremental goals, such as changes in self-care behaviours and better relationships with providers, rather than achieving more ultimate healthcare utilisation or cost goals.48 56 64 Gradual improvements in patients’ experiences with their care providers may eventually lead to long-term benefits in health behaviours and clinical outcomes.64

Programme theory 3: supporting care providers participating in interventions
Care providers affect the success of interventions through their actions and inactions. Programme theory 3 posits that obtaining provider buy-in and building processes to support their efforts helps improve intervention performance. Care providers often include physicians and nurses, with additional services provided by care managers, social workers, community health workers (CHWs), nutritionists and behavioural health specialists.31 32 41 42 44 44 56 58 64 67 68
Gaining support for and from care providers

Organisational support is crucial throughout an intervention. Early support from organisational leaders and physician champions can help smooth the path for implementing new processes into care settings. Garnering support from physicians and practice staff is facilitated by tailored, face-to-face outreach and their belief that the intervention will benefit their patients’ care. The additional time needed to care for HNHC patients and support for provider participation should be acknowledged in intervention designs. These may include financial incentives such as higher provider reimbursement for treating HNHC patients, capitation payments that pay providers a set amount per patient that accounts for patient complexity, physician enrolment incentives and counting HNHC patients as more than one patient on physician panels.

Managing and relieving care provider workload and stress

In addition to increased workloads and responsibilities, providers participating in HNHC patient interventions may experience increased emotional strain from focusing on sicker patients. Increased stress may result in higher turnover among physicians, care managers and other care providers. Interventions can both change how care is provided and assist care providers by including resources that support confidence and skills building. Support may include trainings, dedicated time to implement new processes and an increased number of support staff. Providers may be organised into care teams to both deliver more coordinated care to HNHC patients and provide mutual support for each other. Within care teams, physicians can focus on providing high-quality patient clinical care, while other care providers, like care managers and social workers, lead many of the supportive tasks (e.g., building trust, managing medication, referring to community resources). CHWs add non-clinical, peer perspectives on patient needs and challenges. Care team members can be provided with emotional and technical support through peer counselling across offices and healthcare systems.

Maintaining communication across care providers

Strong communication and co-ordination among care team members related to meeting patients’ needs can ultimately help teams achieve long-term intervention goals. Regular, open communication among care team members fosters cohesive coordinated teams with shared values and commitments. Tools to ensure regular communication among care team members include regularly scheduled newsletters, email feedback and team meetings. Team meetings at different organisational levels are important forums for exchanging information. Organisation-wide meetings may be used to discuss broader performance goals and meetings at the practice level may discuss practice-specific issues, including trainings and individual physician performance.
to assess success in relation to intermediate outcomes and extend the follow-up time in measuring final results.

**Limitations**
This review has several limitations. The literature that was the basis for our analysis was primarily intervention studies, also included in a companion systematic review, that contained contextual and descriptive information. Many studies of intervention outcomes included little qualitative information about participants’ and providers’ experiences in the intervention, which may have limited our ability to identify contextual considerations and mechanisms. Therefore, our theory development is reflective of the patient and provider experiences from the subset of studies that included more descriptive information. While we consulted existing theories to develop our initial programme theories, given limitations in time and resources, we were unable to further refine our final programme theories by exploring theoretical literature concerning other interventions or system dynamics that might have improved our understanding of the mechanisms of interventions for HNHC patients.

We limited the included literature to studies conducted in the USA because the review is intended to be relevant to the US healthcare system. However, while access to healthcare and social services in the USA differs from that in other countries, many of the mechanisms identified in this review are likely to be applicable to HNHC patient interventions in other countries. Finally, given the interpretive and inductive nature of the realist methodology, other researchers may arrive at different interpretations of the data, resulting CMOs and programme theories explaining interventions for HNHC patients. Further refinement, confirmation and refutation of the programme theories should and are expected to occur as additional evidence emerges in this literature.

**Implications for practice and research**
Table 1 summarises the provider and organisational recommendations based on the review’s findings.

<table>
<thead>
<tr>
<th>Programme theory</th>
<th>Provider recommendations</th>
<th>Organisation recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identifying and targeting high-need, high-cost (HNHC) patients</td>
<td>Engage with patients in-person to assess willingness to participate</td>
<td>Use patient data from multiple sources (eg, claims, electronic health records, self-assessments) to capture patient complexity across multiple settings</td>
</tr>
<tr>
<td></td>
<td>Watch for subtle indicators of engagement from disadvantaged or marginalised patients</td>
<td>Use ‘real-time’ data, if possible, to identify patients who need intervention</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Allow patients to provide self-assessments to refine predictions of cost and use</td>
</tr>
<tr>
<td>Engaging HNHC patients</td>
<td>Be aware that life circumstances and negative past experiences with the healthcare system may inhibit HNHC patient’s ability to engage</td>
<td>Design flexible interventions that empower providers to be responsive to individual patient needs</td>
</tr>
<tr>
<td></td>
<td>Address basic needs (ie, food, housing) before focusing on intervention outcomes to establish trust with patients</td>
<td>Develop interventions to address underlying behavioural health and social needs</td>
</tr>
<tr>
<td></td>
<td>Build trusted relationships between patients and providers to build self-confidence and motivate appropriate behaviours</td>
<td>Redefine success to be patient-centred (eg, improved behaviours or interactions)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assess intermediate outcomes or extend the follow-up time so patients and providers have the time to build relationship</td>
</tr>
<tr>
<td>Engaging providers</td>
<td>Integrate the skills of all team members into the practice’s workflow</td>
<td>Develop financially supportive care models to motivate providers</td>
</tr>
<tr>
<td></td>
<td>Provide team members with practical, constructive feedback about patient care approaches to share knowledge and resources that improve patient care</td>
<td>Balance workloads and responsibilities to enhance provider satisfaction</td>
</tr>
<tr>
<td></td>
<td>Meet care team members face to face to build a cohesive care team</td>
<td>Co-locate care teams members to build strong working relationship and to facilitate coordination</td>
</tr>
</tbody>
</table>
Careful targeting of HNHC patients for interventions, providing individualised patient services and supporting care providers with necessary emotional and practical resources may lead to gradual, improved long-term benefits in health behaviours and clinical outcomes. These recommendations are intended to be useful in thinking through the design and implementation of interventions for HNHC patients.

Our findings point to several areas of future research. Our choice of conducting a realist review was informed by content experts who anticipated that limited evidence of the effectiveness of these interventions would be available. To some extent this proved true. Outcomes data from these interventions tended to measure gross changes in utilisation and cost and reported virtually no health or process outcomes. We abstracted the qualitative reporting in these studies to understand the role of context and the mechanisms that are triggered through these interventions, and we used this information to develop our realist programme theories. However, even though many of these interventions are quite large, costly and integral in implementing healthcare delivery reform, the ‘black box’ of what occurs in the intervention is often not reported in studies. For example, we sought to examine whether the subset of interventions that emphasise trust was more likely to have successful outcomes, but we found that the number of reported outcomes across all studies was too limited and distal to make meaningful comparisons.

Future research studies can therefore return to these same and similar interventions and obtain additional data to round out the theories that we found across studies, as well as to uncover others. It can focus on gaining a better understanding of the role of patient trust by developing tools to measure trust and testing how patient trust impacts outcomes. Research examining the experiences of individuals providing and receiving HNHC patient interventions will help elucidate the often-unobservable mechanisms or responses to the resources provided by interventions.

Conclusions
To our knowledge, this is the first realist review investigating how and why interventions for HNHC patients lead to reductions in potentially avoidable use and cost. We found that building relationships with HNHC patients and gaining their trust is a key mechanism in interventions successfully changing patients’ behaviours. Identifying HNHC patients for an intervention can be best achieved through a multipronged strategy that accounts for the complexity of prior healthcare experiences, clinician judgement and willingness to engage in an intervention. Additionally, we found that successful interventions recognise that relationships with HNHC patients require the sustained engagement of care providers. To succeed, providers need the emotional, financial, logistical and practical resources necessary to engage and maintain relationships with HNHC patients.

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Contributors
EC and NB were involved in developing the protocol, all stages of data collection and management, analysis and writing of the manuscript and are the guarantors. RA was involved in literature searching, screening and writing the manuscript. NB acquired funding. All authors read and approved the final manuscript.

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Disclaimer
Investigators worked with AHRQ staff to develop the scope, analytic framework and key questions for this review. AHRQ had no role in study selection, quality assessment or synthesis. AHRQ staff provided project oversight, reviewed the report to ensure that the analysis met methodological standards and commented on the draft for peer review. Otherwise, AHRQ had no role in the conduct of the study; collection, management, analysis and interpretation of the data; and preparation, review or approval of the manuscript findings.

Competing interests
None declared.

Patient and public involvement
Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication
Not applicable.

Ethics approval
Not applicable.

Provenance and peer review
Not commissioned; externally peer reviewed.

Data availability statement
Most of the data generated or analysed for this study are included in this published article, associated appendices or in the full report referenced in the study. Any additional data are available from EC upon request.

Supplemental material
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Appendix 1. Literature search strategies

**PubMed**

Search Query

#1
Search: 

```
("high utilizer" OR "high utilizers of health care" OR "high utilizing" OR "super utilizers"
OR "super utilizing" OR "frequent utilization" OR "frequent utilisation" OR "frequent utilizers"
OR "heavy utilization" OR "heavy utilizers" OR "high attenders" OR "repeat users" OR "hyperusers"
OR "revolving door patients" OR "hyperutilization" OR "overutilization" OR "recividism") OR "frequent
users") OR "frequent user" OR "medically complex" OR "high need"
```

Sort by: Best Match

#2
Search: 

```
("Africa"[Mesh] OR "India"[Mesh] OR "Developing Countries"[Mesh])
```

Sort by: Best Match

#3
Search: 

```
(#1 NOT #2)
```

Sort by: Best Match

#4
Search: 

```
(#1 NOT #2) Filters: Publication date from 2000/01/01; Humans; English; Adult: 19+ years
```

Cochrane Clinical Trials Central Register, CINAHL, Embase, PsycINFO, Web of Science, 
Academic Search Premier, Scopus

Search Query

#1
Search: 

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("high health care cost"[Title]) OR ("high cost"[Title]) Filters: Humans, English, Adult: 19+
years, from 2000/1/1 - 3000/12/12
```

#2
Search: 

```
("high utilizer" OR "high utilizers of health care" OR "high utilizing" OR "super utilizers"
OR "super utilizing" OR "frequent utilization" OR "frequent utilisation" OR "frequent utilizers"
OR "heavy utilization" OR "heavy utilizers" OR "high attenders" OR "repeat users" OR "hyperusers"
OR "revolving door patients" OR "hyperutilization" OR "overutilization" OR "recividism") OR "frequent
users") OR "frequent user" OR "medically complex" OR "high need"
```

Filters: Humans, English, Adult: 19+ years, from 2000/1/1 - 3000/12/12

#3
Search: 

```
(#1 NOT #2) Filters: Humans, English, Adult: 19+ years, from 2000/1/1 - 3000/12/12
```

#4
Search: 

```
("Africa"[Mesh] OR "India"[Mesh] OR "Developing Countries"[Mesh]) Filters: Humans, English, Adult: 19+
years, from 2000/1/1 - 3000/12/12
```

#5
Search: 

```
(#3 NOT #4) Filters: Humans, English, Adult: 19+ years, from 2000/1/1 - 3000/12/12
```

Grey Literature Searches

ClinicalTrials.gov
SIREN Evidence Library
HSRProj
National Academy of Medicine
Center for Health Care Strategies
Centers for Medicare and Medicaid Services
Camden Coalition
Commonwealth Fund
Robert Wood Johnson Foundation
California HealthCare Foundation
Grey Literature Report
Institute for Healthcare Improvement
Centers for Disease Control and Prevention
Human Resources Services Administration
Social Work Abstracts
Kaiser Family Foundation
## Appendix 2. Table of studies that were coded to develop context-mechanism-outcome configurations

<table>
<thead>
<tr>
<th>Author, Year</th>
<th>Title</th>
<th>Document type</th>
<th>Study design (methods)</th>
<th>HNHC population</th>
<th>Setting</th>
<th>Study objectives</th>
<th>Intervention?</th>
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<tbody>
<tr>
<td>Adam et al., 2010</td>
<td>Effects of Team Care of Frequent Attendees on Patients and Physicians</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (observational study analysis)</td>
<td>Adults with frequent clinic visits</td>
<td>1 residency clinic in Minnesota</td>
<td>To measure the effect of the intervention on patient-rated wellbeing and overall satisfaction and on health care use.</td>
<td>Y</td>
</tr>
<tr>
<td>Bayliss et al., 2019</td>
<td>Using Self-Reported Data to Segment Older Adult Populations with Complex Care Needs</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (latent class analysis)</td>
<td>Elderly patients with advanced illness</td>
<td>1 health system in Colorado</td>
<td>To explore two data-driven methods to segment a heterogeneous population of older adults with potentially complex care needs into clinically meaningful subgroups using self-reported information.</td>
<td>N</td>
</tr>
<tr>
<td>Bell et al., 2015</td>
<td>A Randomized Controlled Trial of Intensive Care Management for Disabled Medicaid Beneficiaries with High Health Care Costs</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (RCT analysis)</td>
<td>Disabled, Medicaid patients with mental health and/or substance abuse problems and comorbid physical conditions determined to be at risk for high future healthcare costs</td>
<td>Washington State</td>
<td>To evaluate outcomes of a registered nurse–led care management intervention for disabled Medicaid beneficiaries with high health care costs.</td>
<td>Y</td>
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<tr>
<td>Billing et al., 2007</td>
<td>Improving The Management Of Care For High-Cost Medicaid Patients</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (predictive analysis)</td>
<td>Adult, disabled, fee-for-service Medicaid patients</td>
<td>New York City</td>
<td>To identify patients at high risk of future hospitalization</td>
<td>N</td>
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<tr>
<td>Birmingham et al., 2017</td>
<td>Emergency department use and barriers to wellness: a survey of emergency department frequent users</td>
<td>Peer-reviewed literature</td>
<td>Mixed methods (cross-sectional analysis, interviews)</td>
<td>Adult (18+ years), frequent ED users</td>
<td>Hospital (urban, level 1 trauma center)</td>
<td>To characterize frequent ED users, including their reason for presenting to the ED and identifies perceived barriers to care from the users’ perspective.</td>
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<tr>
<td>Brannon et al., 2018</td>
<td>Towards a Learning Health System to Reduce Emergency Department Visits at a Population Level</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (predictive analysis)</td>
<td>Residents who had any encounter at one of the health systems used to predict future high ED use</td>
<td>3 health systems in Michigan</td>
<td>To describe the development and validation of a predictive model that harnesses data from the three health systems in the region and outline the care coordination intervention to provide context for how the predictive model is being utilized in a learning cycle.</td>
<td>N</td>
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<tr>
<td>Study Authors</td>
<td>Study Title</td>
<td>Research Design</td>
<td>Population</td>
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<tr>
<td>Capp et al., 2017</td>
<td>Coordination Program Reduced Acute Care Use And Increased Primary Care Visits Among Frequent Emergency Care Users</td>
<td>Peer-reviewed literature</td>
<td>Medicaid patients who are frequent ED users</td>
<td>ED/hospital followed by home visits in Colorado</td>
<td>To compare participants in the B2C program with patients who received standard care (the control group) with respect to three outcomes: ED use, hospital admission, and primary care use.</td>
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<tr>
<td>Chan et al., 2019</td>
<td>“It’s Like Riding Out the Chaos”: Caring for Socially Complex Patients in an Ambulatory Intensive Care Unit (A-ICU)</td>
<td>Peer-reviewed literature</td>
<td>Homeless HNHC patients</td>
<td>Federally qualified health center in Portland, Oregon</td>
<td>To identify what multidisciplinary staff caring for HNHC patients perceive as (1) the principal needs and barriers they are addressing, and (2) the key ingredients for addressing patients' needs.</td>
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<tr>
<td>Colligan et al, 2016</td>
<td>Risk Factors for Persistent Frequent Emergency Department Use in Medicare Beneficiaries</td>
<td>Peer-reviewed literature</td>
<td>FFS Medicare patients</td>
<td>National</td>
<td>To examine frequent ED use among Medicare beneficiaries by (1) estimating the probability of transitioning into and out of frequent ED use during 2 consecutive years; (2) understanding what sociodemographic, primary care, and clinical characteristics correlate with persistent frequent ED use during 2 years; and (3) describing differences in characteristics among patients who were persistent frequent ED users versus less frequent and nonusers and those who died in 2010.</td>
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<tr>
<td>Crane et al., 2012</td>
<td>Reducing Utilization by Uninsured Frequent Users of the Emergency Department: Combining Case Management and Drop-in Group Medical Appointments</td>
<td>Peer-reviewed literature</td>
<td>Low-income, uninsured patients who had used inpatient or emergency department services more than 6 times in the previous 12 months</td>
<td>1 primary care practice in Hendersonville, North Carolina</td>
<td>To report the first-year results of a coordinated, team-based approach that integrates medical and behavioral health care and case management primarily through drop-in group visits, targeting a cohort of low-income, uninsured patients with previously high rates of ED and inpatient use.</td>
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<tr>
<td>Dally et al., 2002</td>
<td>The Impact of a Health Education Program Targeting Patients With High Visit Rates in a Managed Care Organization</td>
<td>Peer-reviewed literature</td>
<td>High utilizer adults (18-64 years) with a chronic condition (arthritis, hypertension, diabetes) with commercial insurance (Kaiser Permanente)</td>
<td>managed care organization in Ohio</td>
<td>To determine if a mailed health promotion program, Healthtrac, could reduce the number of ambulatory care visits while improving the health status of adults 18 to 64 years old, who were consistently high utilization of ambulatory care at Kaiser Permanente of Ohio (a midsize group model MCO).</td>
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<td>Reference</td>
<td>Title</td>
<td>Study Type</td>
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<td>Study Population</td>
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<tr>
<td>Das et al., 2019</td>
<td>Drivers of preventable high health care utilization: a qualitative study of patient, physician and health system leader perspectives</td>
<td>Qualitative (interviews of health system leaders, HNHC patients or their primary caregivers, and physicians)</td>
<td>5 health systems in 3 cities: New York City; Gainesville, Florida; and Chicago, Illinois</td>
<td>To identify drivers of preventable utilization from the perspectives of three stakeholder groups in the US: health system leaders; HNHC patients or their primary caregivers; and physicians.</td>
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<tr>
<td>Durfee et al., 2018; Blue et al., 2017</td>
<td>The impact of tailored intervention services on charges and mortality for adult super-utilizers</td>
<td>Mixed methods (observational study analysis, interviews, review of reports)</td>
<td>Adult (18 years or older) intensive outpatient clinic in Denver, Colorado</td>
<td>To evaluate a practice transformation intervention that implemented team-based care and risk stratification to match specific primary care resources based on need and an intensive outpatient clinic for super-utilizers.</td>
<td>Y</td>
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<tr>
<td>Finkelstein et al., 2020</td>
<td>Health Care Hotspotting — A Randomized, Controlled Trial</td>
<td>Quantitative (RCT analysis)</td>
<td>Hospitalized patients with medically and socially complex conditions, all with at least one additional hospitalization in the preceding 6 months</td>
<td>To evaluate the Camden Coalition of Healthcare Providers “hotspotting” program</td>
<td>Y</td>
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<tr>
<td>Fleming et al., 2017</td>
<td>Patient Engagement at the Margins: Health Care Providers’ Assessments of Engagement and the Structural Determinants of Health in the Safety-net</td>
<td>Qualitative (ethnographic and interview research of healthcare providers)</td>
<td>Patients of 2 complex care management programs (diagnosis of chronic illness and 3+ hospitalizations or high risk for future hospitalizations)</td>
<td>To investigate how complex care management health care providers describe engagement for high-cost patients—the “super-utilizers” of the health care system—who often face complex challenges related to socioeconomic marginalization including poverty, housing insecurity, exposure to violence and trauma, cognitive and mental health issues, and substance use.</td>
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<tr>
<td>Ganguli et al., 2017</td>
<td>What can five high cost patients teach us about healthcare spending?</td>
<td>Mixed methods (case studies with interviews with patients and their caretakers, claims analysis, and chart review)</td>
<td>High cost, adult Medicare patients or caregivers</td>
<td>To examine five of the highest cost patients at an urban academic medical center in a case series</td>
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<tr>
<td>Gross et al., 2013</td>
<td>Building a Citywide, All-Payer, Hospital Claims Database to Improve Health Care Delivery in a Low-Income, Urban Community</td>
<td>Quantitative (cross-sectional analysis)</td>
<td>Residents of Camden, New Jersey who used healthcare services</td>
<td>To describe the methods used to develop Camden’s hospital claims data set, as well as results showing the population health insights obtained from this data set.</td>
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<tr>
<td>Author(s)</td>
<td>Study Title</td>
<td>Material Type</td>
<td>Study Design</td>
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<tr>
<td>Hardy et al., 2018</td>
<td>Understanding Frequent Emergency Department Use Among Primary Care Patients</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (cross-sectional analysis)</td>
<td>Patients with frequent ED use</td>
<td>Large primary care safety net clinic in North Carolina</td>
<td>to examine patterns of repeat ED utilization during a 1-year period among patients with established primary care, then analyzed these patterns to uncover unmet medical and psychosocial needs.</td>
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<tr>
<td>Hasselman, 2013</td>
<td>Super-Utilizer Summit: Common Themes from Innovative Complex Care Management Programs</td>
<td>Conference summary</td>
<td>Qualitative (summary of themes and recommendations)</td>
<td>HNHC Medicaid patients</td>
<td>NA</td>
<td>To bring together leaders from super-utilizer programs across the country, states, the Centers for Medicare &amp; Medicaid Services, the Robert Wood Johnson Foundation (RWJF) Aligning Forces for Quality (AF4Q) alliances, health plans, and other key stakeholders to share strategies for changing how our health care system interacts with these high-need, high cost patients to explore how Medicaid could best advance models for HNHC patients.</td>
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<tr>
<td>Hibbard et al., 2016</td>
<td>Adding A Measure Of Patient Self-Management Capability To Risk Assessment Can Improve Prediction Of High Costs</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (cross-sectional analysis of patients)</td>
<td>Adult patients affiliated with Fairview Health Services (a Pioneer Accountable Care Organization)</td>
<td>1 large health system in Minnesota</td>
<td>To explore whether supplementing a clinical risk score with a behavioral measure could improve targeting of the patients most in need of supports that reduce their risk of costly service utilization</td>
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<tr>
<td>Horn et al., 2016</td>
<td>The Economic Impact of Intensive Care Management for High-Cost Medically Complex Patients: An Evaluation of New Mexico’s Care One Program</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (observational study analysis)</td>
<td>Medically complex patients with a chronic medical condition, high cost (top 1%) in the past year, and at high risk for future hospitalization</td>
<td>Academic medical center in Albuquerque, New Mexico</td>
<td>To evaluate the economic impact of Care One, an intensive chronic care, primary care-oriented program designed to target high-cost, complex patients.</td>
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<tr>
<td>Kanzaria et al., 2017</td>
<td>Persistent Frequent Emergency Department Use: Core Group Exhibits Extreme Levels Of Use For More Than A Decade</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (predictive analysis)</td>
<td>nonelderly adult frequent ED users</td>
<td>State of California</td>
<td>To examine the persistence of frequent ED use over an eleven-year period, describe characteristics of persistent versus nonpersistent frequent ED users, and identify predictors of persistent frequent ED use.</td>
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<td>Reference</td>
<td>Title</td>
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<td>Population Description</td>
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<td>Katzelnick et al., 2000</td>
<td>Randomized Trial of a Depression Management Program in High Utilizers of Medical Care</td>
<td>Peer-reviewed literature Quantitative (RCT analysis)</td>
<td>nonelderly, depressed adults with frequent ambulatory visits</td>
<td>163 physician practices affiliated with 1 of 3 included HMOs in Wisconsin, Washington, and Massachusetts</td>
<td>To determine the impact of offering a systematic primary care-based depression treatment program to depressed “high utilizers” not in active treatment.</td>
<td>Y</td>
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<tr>
<td>Kelley et al., 2020</td>
<td>Patient Navigation to Reduce Emergency Department (ED) Utilization Among Medicaid Insured, Frequent ED Users: A Randomized Controlled Trial</td>
<td>Peer-reviewed literature Quantitative (RCT analysis)</td>
<td>Non-elderly, Medicaid patients with high ED use</td>
<td>1 ED in New Haven, CT</td>
<td>To determine whether an ED-initiated Patient Navigation program (ED-PN) designed to improve health care access for Medicaid-insured frequent ED users could decrease ED visits, hospitalizations, and costs.</td>
<td>Y</td>
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<tr>
<td>Kimmy et al., 2019</td>
<td>Evaluation of the Independence at Home Demonstration: An Examination of the First Four Years</td>
<td>Peer-reviewed literature Quantitative (observational study analysis)</td>
<td>Frail, elderly, Medicare FFS patients</td>
<td>14 home-based care practices</td>
<td>To determine the impact of the demonstration on beneficiaries’ Medicare expenditures and other health-related outcomes</td>
<td>Y</td>
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<tr>
<td>Lin et al., 2017</td>
<td>ED-Based Care Coordination Reduces Costs for Frequent ED Users</td>
<td>Peer-reviewed literature Quantitative (RCT analysis)</td>
<td>Frequent ED users</td>
<td>1 ED in Boston, Massachusetts</td>
<td>To evaluate a pilot quality improvement intervention implemented in an urban academic medical center ED to improve care coordination and reduce ED visits and hospitalizations among frequent ED users.</td>
<td>Y</td>
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<tr>
<td>Long et al., 2017</td>
<td>Effective Care for High-Need Patients: Opportunities for Improving Outcomes, Value, and Health</td>
<td>Workshop summary Qualitative (summary of 3 workshops of experts and stakeholders)</td>
<td>NA</td>
<td>NA</td>
<td>To report and reflect on the following issues: (1) key characteristics of high-need patients; (2) the use of a patient categorization scheme—or a taxonomy—as a tool to inform and target care; (3) promising care models and attributes to better serve this patient population, as well as insights on “matching” these models to specific patient groups; and (4) areas of opportunity for policy-level action to support the spread and scale of evidence-based programs.</td>
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<tr>
<td>Study Authors</td>
<td>Study Title</td>
<td>Research Design</td>
<td>Sample Description</td>
<td>Setting</td>
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<td>Mautner et al., 2013</td>
<td>Generating Hypotheses About Care Needs of High Utilizers: Lessons from Patient Interviews</td>
<td>Peer-reviewed literature Qualitative (interviews of patients)</td>
<td>Former patients of the Camden Care Management Team intervention (hospitalized patients with medically and socially complex conditions, all with at least one additional hospitalization in the preceding 6 months)</td>
<td>NA</td>
<td>To characterize high utilizer patients and their perceptions of their health and health care, and to identify barriers and facilitators to health and health care from these patients’ perspectives.</td>
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<tr>
<td>McCall et al., 2010</td>
<td>Evaluation of Medicare Care Management for High Cost Beneficiaries (CMHCB) Demonstration: Massachusetts General Hospital and Massachusetts General Physicians Organization (MGH)</td>
<td>Mixed methods (RCT analysis, surveys, interviews)</td>
<td>High cost, high risk Medicare FFS patients</td>
<td>5 counties in Massachusetts (Norfolk, Suffolk, Middlesex, Essex, and Plymouth)</td>
<td>To evaluate the implementation, reach, and effectiveness of the Massachusetts General Hospital intervention.</td>
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<tr>
<td>McCall et al., 2010</td>
<td>Evaluation of Medicare Care Management for High Cost Beneficiaries (CMHCB) Demonstration: VillageHealth’s Key to Better Health (KTBH)</td>
<td>Mixed methods (RCT analysis, surveys, interviews)</td>
<td>High cost, high risk Medicare FFS patients with chronic kidney disease</td>
<td>6 nephrology practices in 3 New York counties (Suffolk, Nassau, and Queens)</td>
<td>To evaluate the implementation, reach, and effectiveness of the Village Health’s Key to Better Health intervention.</td>
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<tr>
<td>McCall et al., 2010</td>
<td>Evaluation of Medicare Care Management for High Cost Beneficiaries (CMHCB) Demonstration: Texas Senior Trails (TST)</td>
<td>Mixed methods (RCT analysis, surveys, interviews)</td>
<td>Multimorbid Medicare FFS patients</td>
<td>48 counties in western Texas</td>
<td>To evaluate the implementation, reach, and effectiveness of the Texas Senior Trails (TST) intervention.</td>
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<tr>
<td>McCall et al., 2010</td>
<td>Evaluation of Medicare Care Management for High Cost Beneficiaries (CMHCB) Demonstration: The Health Buddy® Consortium</td>
<td>Mixed methods (RCT analysis, surveys, interviews)</td>
<td>High cost, high risk Medicare FFS patients with heart failure, diabetes, or chronic obstructive pulmonary disease diagnosis</td>
<td>2 large multispecialty group practices in central Oregon and central Washington</td>
<td>To evaluate the implementation, reach, and effectiveness of the Health Buddy intervention.</td>
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<td>Authors</td>
<td>Evaluation</td>
<td>Methods</td>
<td>Characteristics</td>
<td>Settings</td>
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<tr>
<td>McCall et al., 2010</td>
<td>Evaluation of Medicare Care Management for High Cost Beneficiaries (CMHCB) Demonstration: Care Level Management (CLM)</td>
<td>Mixed methods (RCT analysis, surveys, interviews)</td>
<td>High cost, high risk Medicare FFS patients with chronic conditions</td>
<td>Home-based primary care practices in California, Florida, and Texas</td>
<td>To evaluate the implementation, reach, and effectiveness of the Care Level Management intervention.</td>
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<tr>
<td>Peikes et al., 2018</td>
<td>Evaluation of the Comprehensive Primary Care Initiative: Fourth Annual Report</td>
<td>Mixed methods (observational study analysis, interviews, review of reports)</td>
<td>High risk, Medicare FFS patients with 2+ chronic conditions and hospital visits.</td>
<td>502 primary care practices in 8 states (Arkansas, Colorado, New Jersey, Oregon, New York, Ohio, Kentucky, and Oklahoma)</td>
<td>To examine: (1) who participated in CPC; (2) the supports practices received; (3) how practices implemented CPC and changed the way they delivered health care; (4) the impacts of CPC on clinicians’ and staff members’ experience; and (5) the impacts of CPC on patient experience, cost, service use, and quality-of-care outcomes for attributed Medicare fee-for-service (FFS) beneficiaries.</td>
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<tr>
<td>Powers et al., 2020</td>
<td>Impact of Complex Care Management on Spending and Utilization for High-Need, High-Cost Medicaid Patients</td>
<td>Peer-reviewed literature Quantitative (RCT analysis)</td>
<td>HNHC Medicaid patients with complex health and social needs</td>
<td>1 care center in Memphis, Tennessee</td>
<td>To evaluate the impact of a complex care management program on spending and utilization for high-need, high-cost Medicaid patients.</td>
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<td>Raven et al., 2020</td>
<td>A randomized trial of permanent supportive housing for chronically homeless persons with high use of publicly funded services</td>
<td>Peer-reviewed literature Quantitative (RCT analysis)</td>
<td>Chronically homeless adults with high ED or hospital use</td>
<td>Santa Clara county, California</td>
<td>To examine whether randomization to permanent supportive housing (PSH) versus usual care reduces the use of acute health care and other services among chronically homeless high users of county-funded services.</td>
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<tr>
<td>Roberts et al., 2015</td>
<td>Working With Socially and Medically Complex Patients: When Care Transitions Are Circular, Overlapping, and Continual Rather Than Linear and Finite</td>
<td>Peer-reviewed literature Quantitative (observational study analysis)</td>
<td>Heterogeneous “high-utilizer” patients with medical and social complexity</td>
<td>Midwestern, urban core safety-net health system</td>
<td>To describe a successful approach targeted at working with patients who require a more intense and lengthy care coordination intervention to self-manage and reduce the cost of caring for their medical conditions.</td>
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<tr>
<td>Shah et al., 2011</td>
<td>Evaluation of Care Management for the Uninsured</td>
<td>Peer-reviewed literature Quantitative (observational study analysis)</td>
<td>Non-elderly, low-income, uninsured adults with high ED or hospital use</td>
<td>3 sites in a network of county and community clinics in Kern County, California</td>
<td>To determine whether the CMP reduces ED visits and hospitalizations among frequent users.</td>
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<td>Study Authors</td>
<td>Title</td>
<td>Study Design</td>
<td>Target Population</td>
<td>Setting</td>
<td>Primary Objective</td>
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<tr>
<td>Sherry et al., 2016&lt;sup&gt;40&lt;/sup&gt;</td>
<td>Bridging the Silos of Service Delivery for High-Need, High-Cost Individuals</td>
<td>Peer-reviewed literature</td>
<td>Qualitative (case studies)</td>
<td>5 community-based interventions</td>
<td>To examine 5 innovative community-oriented programs that are successfully coordinating medical and nonmedical services to identify factors that stimulate and sustain community-level collaboration and coordinated care across silos of healthcare, public health, and social services delivery and to construct a conceptual framework depicting community health systems that highlights 4 foundational factors that facilitate community-oriented collaboration: flexible financing, shared leadership, shared data, and a strong shared vision of commitment toward delivery of person-centered care.</td>
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<tr>
<td>Tanio et al., 2013&lt;sup&gt;41&lt;/sup&gt;</td>
<td>Innovations At Miami Practice Show Promise For Treating High-Risk Medicare Patients</td>
<td>Peer-reviewed literature</td>
<td>Qualitative (descriptive)</td>
<td>High-risk, low-to-moderate-income Medicare patients</td>
<td>To describe a number of innovations adopted at ChenMed, a primary care-led group practice headquartered in Florida that serves low-to-moderate-income elderly patients, largely through the Medicare Advantage program.</td>
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<tr>
<td>Thompson et al., 2018&lt;sup&gt;42&lt;/sup&gt;</td>
<td>Community Navigators Reduce Hospital Utilization in Super-Utilizers</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (observational study analysis)</td>
<td>Low-income patients with frequent hospital use</td>
<td>To ascertain the effectiveness of community navigators in reducing hospital utilization and costs in super-utilizers.</td>
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<tr>
<td>Urato et al., 2013&lt;sup&gt;43&lt;/sup&gt;</td>
<td>Evaluation of the Extended Medicare Care Management for High Cost Beneficiaries (CMHCB) Demonstration: VillageHealth’s Key to Better Health (KTBH)</td>
<td>Report</td>
<td>Mixed methods (RCT analysis, surveys, interviews)</td>
<td>High cost, high risk Medicare FFS patients with stage 3 chronic kidney disease</td>
<td>To evaluate the implementation, reach, and effectiveness of the Phase II Key to Better Health intervention.</td>
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<td>Vickery et al., 2020&lt;sup&gt;44&lt;/sup&gt;</td>
<td>Integrated, Accountable Care For Medicaid Expansion Enrollees: A Comparative Evaluation of Hennepin Health</td>
<td>Peer-reviewed literature</td>
<td>Quantitative (observational study analysis)</td>
<td>Adults with higher ED or hospital use</td>
<td>To evaluate HH’s targeted attempts to intervene with enrollees with the highest use of health care services.</td>
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<td>Author(s)</td>
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<td>Wilbur et al., 2013</td>
<td>Partnering Managed Care and Community-Based Services for Frail Elders: The Care Advocate Program</td>
<td></td>
<td>Peer-reviewed literature Qualitative (interview of patients)</td>
<td>Frail, elderly, Medicare managed care patients Medicare managed care plan in California (telephone based)</td>
<td>To describe a demonstration program that uses master’s-level care managers (care advocates) to link Medicare managed care enrollees to home- and community-based services, testing whether referrals to noninsured services can reduce service usage and increase member satisfaction and retention.</td>
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<td>Wong et al., 2018</td>
<td>Identifying Latent Subgroups of High-Risk Patients Using Risk Score Trajectories</td>
<td></td>
<td>Peer-reviewed literature Quantitative (latent class analysis)</td>
<td>Veterans with an inpatient admission and categorized in the top 5th percentile of risk for hospitalization VA</td>
<td>To identify and describe latent subgroups of high-risk patients with a recent hospitalization and receiving primary care from the VA.</td>
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<td>Yang et al., 2017; Yang et al., 2019</td>
<td>Identifying High Health Care Utilizers Using Post-Regression Residual Analysis of Health Expenditures from a State Medicaid Program</td>
<td></td>
<td>Peer-reviewed literature Quantitative (predictive analysis)</td>
<td>Adult (18-60 years) Medicaid patients in Texas predicted to be high healthcare users across multiple years State of Texas</td>
<td>To identify high health care utilizers using residuals from a regression-based health care utilization adjustment model to analyze the variations in health care expenditures.</td>
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<td>Yoon et al., 2019; Zulman, 2019</td>
<td>Impact of Primary Care Intensive Management on High-Risk Veterans' Costs and Utilization: A Randomized Quality Improvement Trial</td>
<td></td>
<td>Peer-reviewed literature Mixed methods (RCT analysis, surveys)</td>
<td>Primary care VA patients at high risk for hospitalization who had a recent acute care episode VA medical centers 5 VA medical centers</td>
<td>To assess whether augmenting usual primary care with team-based intensive management lowers utilization and costs for high-risk patients.</td>
<td>Y</td>
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<td>Zulman et al., 2014</td>
<td>Partnered Research in Healthcare Delivery Redesign for High-Need, High-Cost Patients: Development and Feasibility of an Intensive Management Patient-Aligned Care Team (ImPACT)</td>
<td></td>
<td>Peer-reviewed literature Mixed methods (evidence synthesis, needs assessment interviews of patients, survey of providers, impact evaluation of pilot)</td>
<td>HNHC patients VA Palo Alto Health Care System</td>
<td>To describes a partnership between health services researchers, operational leadership, and clinicians in the VA healthcare system that led to the successful design, implementation, and evaluation of a novel intensive management program or HNHC patients in the VA Palo Alto Health Care System.</td>
<td>Y</td>
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ED = emergency department; FFS = fee-for-service; HNHC = high need, high cost; NA = not applicable; RCT = randomized controlled trials; VA = Veterans Health Administration
Appendix 3. Context-Mechanism-Outcome (CMO) configurations and supporting data for identified program theories

Program Theory 1: CMO configurations and supporting data for identifying and targeting HNHC patients for inclusion in interventions

Data source needs for identifying and enrolling HNHC patients

CMO 1.1. Including historic information obtained from claims and other electronic health records, that can identify prior high cost and/or use of healthcare services [C], adds to intervention designers’ confidence in creating an algorithm [M] that will result in targeting patients who are at the greatest risk of being HNHC in the future [O].

Relevant data extracts/summary information from included literature
Participants were drawn from adult Medicaid patients attributed to CareMore primary care physicians (PCPs). Program eligibility criteria were aimed at identifying patients at risk for poor outcomes and unnecessary spending, as well as those most likely to benefit from complex care management. The criteria drew from analyses suggesting that combining predictive models, historical claims, and clinician judgment is the most effective approach to identifying patients for complex care management. Eligible patients were first required to meet at least 1 of the following criteria: top 5% of total medical expenditures (TME) in the prior 12 months, top 5% of Chronic Illness Intensity Index (CI3) score, or care team member nomination.26

Predicted future health care costs are based on the Predictive Risk Intelligence SysteM (PRISM) medical cost risk score developed and implemented by Washington State Medicaid programs (Court et al. 2011). PRISM combines diagnostic and pharmacy data to predict future expenditures based on grouping algorithms from two risk adjustment models widely used by State Medicaid programs, the Chronic Illness and Disability Payment System (Kronick et al. 2000) and Rx-Medicaid (Gilmer et al. 2001), both of which have predictive accuracy comparable to commercial alternatives. The PRISM risk score is a ratio calculated by dividing the individual’s expected monthly future expenditures by the average monthly future expenditures of all Medicaid SSI recipients. The risk score equals 1.0 if the individual’s expected expenditures equal the average expenditures of the group.20

One program said they use predictive modeling so that they are not “held hostage waiting for claims to come down the road.” Washington State uses predictive modeling to begin to identify the target populations. Using its Health Service Encounter algorithm, the state examines 15 months of integrated health care claims to determine future medical costs and inpatient risk scores. The state has found that conditions such as diabetes, cardiovascular disease, mental health and substance abuse are common among the superutilizing subset of patients. It uses different approaches to further stratify subgroups for complex care management including identifying individuals with extreme ED [emergency department] utilization (e.g., approximately 80 to 130 ED visits in 15 months), high expected future medical costs (predicted by high utilization and costs in the past), high prospective inpatient risk scores, and significant gaps in care and quality indicators.20

The programs represented at the Summit generally use historical claims data as a foundation to understand the size and scope of super-utilization. Claims analysis is an iterative process and includes identifying areas of high cost and high utilization, and/or identifying groups of recipients with a high number of diagnoses. With this initial broad brush information, programs are able to further shape and define the target population. For example, Community Care of North Carolina (CCNC), which includes 14 regional networks that manage the care of Medicaid beneficiaries, will analyze at least 12 months of data in order to understand which chronic illness and mental health indicators are contributing to a high number of ED visits.20

"After an individual’s records were linked across data sets, the process of flagging individuals as “high utilizers” began. Instead of using charges or receipts to define high utilizers, the decision was made to rely on the number of emergency department (ED) and inpatient visits made by an individual over the prior 12-month period."18

There are two key elements to the success of these new efforts to target and improve care for high-cost Medicaid cases. First, it is essential to be able to identify in advance patients who are likely to have high costs in the future. Many high-cost occurrences (such as injury, acute illness, or cancer) might be episodic, and high spending in one year might not mean high spending in subsequent years.4

We conducted a retrospective analysis of secondary data from the Medicare program and other linked sources. We used 3 databases, including the Chronic Condition Data Warehouse, hierarchic categorical condition scores, and timeline files. The Chronic Condition Data Warehouse includes fee-for-service billing history for services reimbursed under Medicare Parts A, B, and D, as well as data about beneficiary demographic characteristics, linked at the beneficiary level with a unique identification number.4

We used data from three health systems to develop, evaluate, and implement a model for the prediction of high ED utilization in Washtenaw and Livingston counties: Michigan Medicine and St. Joseph Mercy Health System (operators of all EDs in Ann Arbor and Livingston County) and Integrated Health Associates (IHA), a multispecialty medical practice with clinical sites in both counties.6

Administrative data from DH’s [Denver Health’s] data warehouse were used to obtain demographic, medical, psychological/behavioral health and service utilization and claims data. The tight administrative and clinical integration among all care settings facilitates data capture across the continuum of care.13
After an individual’s records were linked across data sets, the process of flagging individuals as “high utilizers” began. Instead of using charges or receipts to define high utilizers, the decision was made to rely on the number of emergency department (ED) and inpatient visits made by an individual over the prior 12-month period. This step eliminated potential variability related to differences in treatments and payers. Rather than assigning an artificial cutoff, the nuances of the local population were allowed to set the threshold for what constituted high utilization. The Coalition defined high utilization as “any individual with total emergency or inpatient visits greater than 1.5 standard deviations above the mean.” This definition resulted in any individual with 3 or more inpatient visits, or 6 or more ED visits, being flagged in the database as a high utilizer.\textsuperscript{18}

The site for this study was the Duke Outpatient Clinic (DOC), a large primary care safety net clinic in Durham, North Carolina. Patients at the DOC have a high prevalence of multimorbidity, mental illness, and socioeconomic challenges. Beginning in 2012, the clinic initiated an extensive redesign process to better meet complex population health needs and reduce avoidable utilization of ED and inpatient care. This study was conducted to direct further quality improvement efforts. Multiple methods were applied, including both retrospective quantitative analysis of clinical data and an in-depth chart review. The study team extracted electronic health record data for all patients enrolled at the DOC between July 1, 2014, and June 30, 2015. The team matched these data to ED encounter data for the same year period from 2 local hospitals within the Duke University Health System, where DOC patients receive a vast majority of their emergency and hospital care. Lastly, the team conducted 30 chart reviews for 10 of the highest ED utilizers for each of the 3 leading chief complaints to uncover additional details surrounding their frequent ED use patterns.\textsuperscript{19}

The literature contains varying definitions for super-utilizer. The definition used for this analysis was adapted from the work of Johnson, et al. and defined super-utilizers as adult patients (≥ 18 years of age) who, along with having an admission (analysis index admission) during the requisite timeframe, had at least two other admissions in the year prior, or at least one other admission along with a serious mental health diagnosis... In order to focus the analysis on cost savings that could be linked to our interventions, patients on chemotherapy, patients with orthopedic complications, patients diagnosed with HIV, and patients who had repeated admissions for emergency dialysis were excluded from analysis.\textsuperscript{13}

To be most effective, complex care management programs should target patients at risk of persistently high spending and those whose spending and health outcomes are amenable to complex care planning and engagement. Many complex care management programs use claims data and historical utilization patterns to identify eligible patients. Recent research has highlighted the limitations of this approach—historically high-cost patients often return to normal patterns or spending, or they have drivers of high spending not amenable to complex care management.\textsuperscript{16}

“Determining an ideal definition for a high-need patient requires a delicate balance. A highly constrained definition will risk missing people, potentially depriving them of needed resources. On the other hand, casting an overly broad definition might include people who are not high-need and do not need additional resources. Abrams noted that basing identification of high-need patients exclusively on cost will miss many people, and if the focus is exclusively on chronic conditions, a large number of people may be identified whose chronic conditions are under control.”\textsuperscript{28}
CMO 1.1a Reliance on only one type of data like claims or diagnosis data [C] may provide an incomplete picture of a patient’s situation [O] which may undermine provider confidence in the selection process [M].

Relevant data extracts/summary information from included literature

During the first site visit, physicians at both sites reported that they were initially very enthusiastic about the Health Buddy® program, because it offered a promising way to effectively support patients with chronic disease…physicians reported disappointment that many of the patients they believed could be helped by the [Health Buddy®] program were not eligible to participate in the program because they had not been identified through the claims based algorithm developed by HHN [Health Hero Network].

Risk assessments of the TST [Texas Senior Trails] participant population were conducted to inform the development of individualized care plans and assign participants to one of three risk categories to determine the level of service to be provided to each participant….TST reported that the high-risk intervention was provided to approximately 5% to 7% of the TST participant population that had depression and/or potentially critical health problems that required immediate attention….What might explain the lack of success in TST’s demonstration? Ineffective Targeting. One explanation may be the inability to accurately target beneficiaries at greatest risk of intensive, costly, service use (as distinct from the need for general care management)….When TST learned that one of its participants was admitted to the hospital, it reassigned this individual to its high-risk intervention, and when appropriate, a care manager visited the beneficiary in the hospital to determine the cause of the hospitalization and identify any new health or social issues to be addressed. Not surprisingly, TST adopted a strategy of targeting beneficiaries at greatest risk of a hospitalization and higher costs. Their targeting strategy was unsuccessful—and costly. The program was unable to predict future complications with any precision for those with initially stable, less costly, conditions. Lacking direct access to patients’ medical records, the health coaches often began working with beneficiaries with incomplete information.

R. Corey Waller, MD, the program director for a super-utilizer program at Spectrum Health Medical Group’s Center for Integrated Medicine in West Michigan, noted the danger of relying on only one type of data—like claims or diagnosis—because it might not provide an accurate picture of the patient’s situation. Experience has taught him that “relying only on one type of data makes you more vulnerable to inaccuracies.” As an emergency room physician, Dr. Waller noted that the chaotic conditions of the ED and the frequent lack of historical patient information can lead to inaccurate or missed diagnoses.

The screening process includes administrative data screening to determine eligibility by usage criteria, followed by an in-person screening to determine other eligibility criteria and ability to consent. Randomization occurred after consent. A proprietary platform integrates study data with real-time data feeds from multiple sources. Staff screened potential participants based on their use of county-funded services over the prior 1-2 years. Our research team developed an electronic triage tool that uses administrative data to predict the likelihood of future high use of county-funded services. To meet criteria, potential participants must have used various combinations of the ED and psychiatric ED, medical and psychiatric inpatient stays in the County-funded public hospital, and/or jail over the past 1-2 years, at high enough levels to meet a threshold score. We embedded the triage tool into the study database and generated a list of potentially eligible participants with the highest scores, redoing the calculation throughout the enrollment period. All county agencies or service providers could refer individuals they suspected met eligibility criteria, but study staff always used the list generated by the triage tool to confirm initial eligibility. County staff used this list to outreach to the highest using individuals…. Despite selection criteria that identified those at highest risk for frequent utilization, and thus, most likely to experience mental health and substance use disabilities, we found the 88 percent of individuals randomized to PSH entered housing and remained housed, on average, for 93 percent of the time in the study. Engagement and retention in housing is an important priority for policy makers.

Traditional electronic data such as diagnostic codes and laboratory values may not capture essential information on factors that drive care needs, including function, personal preferences, and social resources, that can only be reported by individuals themselves. Identifying and characterizing complex needs subpopulations requires patient-reported information to help match care delivery to personal needs. Although newer data from electronic health records (EHRs) such as symptom assessments and ICD-10 codes that capture functional status can improve our ability to identify complex needs subpopulations, subjective information can add a level of specificity unlikely to be captured with objective coding.
CMO 1.2 Capturing a patient's use of services in “real time,” if possible, while the patient is still hospitalized [C], adds to the intervention service provider's confidence that a patient is identified during a period of urgent need for the services [M], resulting in intervention services being initiated prior to or during a period of high use and not during a later period, when service use may have already declined (regression to the mean) [O].

Relevant data extracts/summary information from included literature
More than half of patients approached in the ED refused to participate, possibly due to competing concerns about their illness or participating in research. Those who enrolled may have been more engaged, and thus, more likely to respond to the intervention, than those who declined. Identifying and approaching patients in real time may be time consuming and resource intensive, but this approach has been found to be more effective in addressing the needs of some populations of high utilizers than using historical claims data to identify and “segment” high utilizers with aligned interventions.26

In order to identify chronic frequent users, rather than those with an isolated health event requiring multiple visits, we identified patients with the most ED visits during both the 30-day period and the 12-month period preceding the introduction of the program.27

The Summit participants unanimously agreed that access to real-time information—such as notifications of ED visits or inpatient admissions—and a strong analytics team provide a critical foundation for super-utilizer programs. One leader referred to data as “oxygen for our program.” Programs place a high priority on developing a robust data repository that can be mined to identify groups of patients that might respond well to complex care management.20

Eligible patients were identified through real-time automated methods and recruitment occurred while patients were still hospitalized. Patient intake included an in-depth patient assessment to determine nonmedical barriers to improved health.13

This “real time” approach of using a hospital admission as a triggering event was perceived as useful for two reasons. First, patients with a hospital admission are much more likely to have a subsequent admission in the next twelve months than patients without an admission, which improves the potential case-finding capacity of the algorithm. But, equally important, effective discharge planning is likely to be a critical component of any intervention strategy for high-cost, high risk patients.4

What might explain the lack of success in TST’s demonstration? Ineffective Targeting. One explanation may be the inability to accurately target beneficiaries at greatest risk of intensive, costly, service use (as distinct from the need for general care management)...When TST learned that one of its participants was admitted to the hospital, it reassigned this individual to its high-risk intervention, and when appropriate, a care manager visited the beneficiary in the hospital to determine the cause of the hospitalization and identify any new health or social issues to be addressed. Not surprisingly, TST adopted a strategy of targeting beneficiaries at greatest risk of a hospitalization and higher costs. Their targeting strategy was unsuccessful—and costly. The program was unable to predict future complications with any precision for those with initially stable, less costly, conditions. Lacking direct access to patients’ medical records, the health coaches often began working with beneficiaries with incomplete information.32

Patients are identified through daily electronic health record census and readmissions reports, as well as large retrospective health system data sets. When at all possible, the patient is introduced to the program and offered enrollment while an inpatient.38

We learned that for B2C to reduce the use of acute care, outreach to and enrollment of high utilizers had to happen in real time in the ED.7

What might explain the lack of success in the Phase II KTBH [Key to Better Health] Demonstration? One explanation may be the targeting of beneficiaries at greatest risk of intensive, costly, service use (as distinct from the need for general care management). Responding to KTBH’s request, CMS [Center for Medicare & Medicaid Services] staff selected a very costly, complex set of Medicare beneficiaries for their intervention and comparison groups. As a result, the comparison group exhibited substantial regression-to-the-mean (RtoM) effects. While the randomized experimental design should cancel out RtoM effects and isolate a pure intervention effect, the large churning of beneficiaries from lower (higher) to higher (lower) cost groups over time adds considerable statistical noise to the test of savings. Even still, we would have considered the Phase II original intervention to be a success if it had saved 5.4% of costs. Large increases in demonstration period costs in less costly beneficiaries in the base period make it very difficult for intervention staff to target those at highest financial risk. It is much easier to target beneficiaries during the intervention period who actually incur major flare-ups and hospitalizations. Unfortunately, these beneficiaries have already incurred major expenditures by the time they receive intensive disease management services.43

There are two key elements to the success of these new efforts to target and improve care for high-cost Medicaid cases. First, it is essential to be able to identify in advance patients who are likely to have high costs in the future. Many high-cost occurrences (such as injury, acute illness, or cancer) might be episodic, and high spending in one year might not mean high spending in subsequent years.4
However, because of limited resources and lag time in acquiring data, our experience in other environments has suggested that some providers and payers are interested in non–“real time,” retrospective analyses. Accordingly, we also examined patients with any claims in 2000–2003, to predict subsequent admissions in 2004 (regardless of whether they had a hospital admission in 2003 or any prior year). This “archival” approach to case finding is somewhat less robust (it finds fewer patients) than the “real time” method and only brief findings for this approach are presented for comparative purposes.4

Data elements for identifying and enrolling HNHC patients

CMO 1.3. Considering patients' chronic conditions, functional limitations, or clinical severity scores [C] adds to intervention designers' confidence in identifying HNHC patients [M] who will benefit from intervention services [O1] and who are at risk of having future high healthcare use and cost [O2].

Relevant data extracts/summary information from included literature
Supplemental material

Three categories of high-cost users—beneficiaries who had multiple chronic conditions, were hospitalized, or had high total costs—were identified by CBO [Congressional Budget Office] for study of persistence of Medicare expenditures over time. Beneficiaries that were selected based upon hospitalization or being in the high total cost groups had baseline expenditures that were four times as high as expenditures for a reference group. Beneficiaries selected based upon presence of multiple comorbid conditions had baseline expenditures that were roughly twice as high as expenditures for a reference group. Subsequent years of costs remained higher for all three cohorts than the reference group; however, total expenditures declined the most for those beneficiaries who were identified as high cost due to a hospitalization followed by beneficiaries who had had high total costs in the base year. Subsequent costs were virtually unchanged for beneficiaries with multiple chronic conditions.31

Denver Health reported challenges in using utilization data alone to find patients at chronic high risk of acute care use—but identifying these patients was important for the success of 21st Century Care. That is, Denver Health assumed that 21st Century Care could reduce service use (such as hospitalizations and ED visits) by identifying patients with chronic care needs and then delivering preventive care to preempt higher-cost acute care later on. Over the course of the award, however, Denver Health learned that many of its highest-cost patients were only temporarily high cost, suggesting that many of them would have returned to moderate- or low-cost status even without intervention. For example, under its risk stratification algorithm, Denver Health identified so-called super utilizers—all of whom were Tier 4—as people with three or more hospital admissions in a 12-month period, or two or more admissions and a mental health diagnosis. These people accounted for about 30 percent of adult facility costs. By analyzing pre-intervention data, however, research staff at Denver Health showed that, even without special intervention, fewer than half of these super utilizers at a single point in time were still in the category seven months later, and only 28 percent were in the category at the end of 12 months (Johnson et al. 2015b). Because of this challenge using utilization data alone to find chronic high-risk patients, Denver Health, as noted previously, added clinical information (in the form of both CRGs [clinical risk grouping] and clinical data such as lab results) to its second and third iterations of the risk-stratification algorithm (although lab results were later removed in subsequent algorithm iterations). Denver Health reported that each revision to the algorithm helped to identify patients who would benefit most from 21st Century Care’s intensive services.34

Denver Health recognized that people with exceptionally high service use at one time did not necessarily continue to have exceptional service use in the future. Over the course of the award, Denver Health integrated clinical information into its risk-stratification algorithm to try to better identify patients who would benefit from intervention.34

Key Finding #1: Several vulnerable subpopulations of Medicare FFS beneficiaries were less likely to agree to participate in the CLM [Care Level Management] demonstration program. Of all CLM intervention beneficiaries, 65% verbally consented to participate in the CMHCB [Medicare’s Care Management for High Cost Beneficiaries] demonstration at some point during the intervention period. We found that Medicaid enrollees and institutionalized beneficiaries were less likely to be participants; both groups are costly and high users of acute care services. In general, participants tended to be healthier than nonparticipants using baseline characteristics including the prospective HCC [hierarchical condition categories] score. However, beneficiaries with higher concurrent HCC scores based on the first 6 months of the demonstration were more likely to participate than healthier beneficiaries. This suggests that CLM made some inroads into engaging those with acute clinical deterioration. Further, as CLM’s program matured, they appeared to be more successful engaging sicker and more costly beneficiaries based on baseline health status; however, those with Medicare/Medicaid dual enrollment and the institutionalized were still less likely to become participants. These findings suggest alternative recruiting and outreach strategies are needed to reach dual Medicare/Medicaid enrollees and beneficiaries who are institutionalized.34

Key Finding #1: The HBC [Health Buddy® Consortium] program was able to engage beneficiaries who were at higher risk of acute clinical deterioration as measured by the concurrent HCC [hierarchical condition categories] score. Of the HBC original intervention beneficiaries, 45% verbally consented to participate in the CMHCB [Medicare’s Care Management for High Cost Beneficiaries] demonstration at some point during the intervention period; 40% of the refresh population agreed to participate. For the HBC program, we find that beneficiaries with medium and high concurrent HCC scores were more likely to be participants. Beneficiaries with higher prospective HCC scores and baseline Charlson comorbidity scores were less likely to be participants. This suggests that the HBC program was less able to engage the historically sicker Medicare beneficiaries but more able to engage those at higher risk of acute clinical deterioration as measured by the concurrent HCC score.33

While the high-need patient population is diverse, a synthesis of analyses reported in the literature identified three criteria that could form a basis for defining and identifying this population: total accrued health care costs, intensity of care utilized for a given period of time, and functional limitations.24
Medicare FFS [fee-for-service] beneficiaries with a primary residence in one of five designated counties including Boston, Massachusetts, and surrounding areas, and a high level of disease severity as indicated by Hierarchical Condition Categories (HCC) scores and high health care costs based on Medicare claims filed during calendar year 2005. Beneficiaries with HCC risk scores $\geq 2.0$ and annual costs of at least $2,000$ or HCC risk scores $\geq 3.0$ and a minimum of $1,000$ annual medical costs are eligible for the MGH's CMP [Massachusetts General Hospital's Care Management Program].

Eligible patients were identified by using standard criteria: a risk score in the 90th percentile for 90-day hospitalization from a validated risk-prediction algorithm (13) and a recent hospitalization or emergency department visit.

Although high utilizers differed significantly from other patients in their medical and behavioral health needs, their presenting complaints were not categorically different from those of low utilizers—they simply had more visits for the same types of complaints utilizers were more likely to present to the ED multiple times for the same complaint. However, most high utilizers had 4 unique chief complaints, suggesting that these patients generally have several, rather than a few, reasons for seeking emergency care. No clearly defined pattern of complaints existed for high utilizers. High utilization in such patients is less likely to be caused by clearly defined disease processes and more by a complex mix of multiple chronic medical conditions and psychosocial factors, making it difficult to predict future utilization or identify specific patient needs based on their chief complaint.

Washington State uses predictive modeling to begin to identify the target populations. Using its Health Service Encounter algorithm, the state examines 15 months of integrated health care claims to determine future medical costs and inpatient risk scores. The state has found that conditions such as diabetes, cardiovascular disease, mental health and substance abuse are common among the super-utilizing subset of patients. It uses different approaches to further stratify subgroups for complex care management including identifying individuals with extreme ED utilization (e.g., approximately 60 to 130 ED visits in 15 months), high expected future medical costs (predicted by high utilization and costs in the past), high prospective inpatient risk scores, and significant gaps in care and quality indicators.

Judgment about whether the patient is amenable to management is based on an interview with the patient by the care team and a review of medical records. The assessment of whether the patient is entered into Care One is based on a judgment that the patient has a chronic medical condition, is at high risk for future hospitalization, and is willing to attend outpatient visits and comply with therapy. Other specific exclusions from the Care One program include a single high-cost medical event (e.g., a trauma), residence outside of the hospital’s catchment area, and chronic alcohol or drug abuse.

CMO 1.4. Considering patients’ behavioral health and social risk factors (e.g., mental health and substance use disorder diagnoses and social needs) using pre-existing or novel data sources [C] adds to intervention designers’ confidence in identifying HNHC patients [M] who will benefit from intervention services [O1] and who are at risk of having future high healthcare use and cost [O2].

Relevant data extracts/summary information from included literature
The screening process includes administrative data screening to determine eligibility by usage criteria, followed by an in-person screening to determine other eligibility criteria and ability to consent. Randomization occurred after consent. A proprietary platform integrates study data with real-time data feeds from multiple sources. Staff screened potential participants based on their use of county-funded services over the prior 1-2 years. Our research team developed an electronic triage tool that uses administrative data to predict the likelihood of future high use of county-funded services. To meet criteria, potential participants must have used various combinations of the ED and psychiatric ED, medical and psychiatric inpatient stays in the County-funded public hospital, and/or jail over the past 1-2 years, at high enough levels to meet a threshold score. We embedded the triage tool into the study database and generated a list of potentially eligible participants with the highest scores, redoing the calculation throughout the enrollment period. All county agencies or service providers could refer individuals they suspected met eligibility criteria, but study staff always used the list generated by the triage tool to confirm initial eligibility. County staff used this list to outreach to the highest using individuals. Despite selection criteria that identified those at highest risk for frequent utilization, and thus, most likely to experience mental health and substance use disabilities, we found the 86 percent of individuals randomized to PSH entered housing and remained housed, on average, for 93 percent of the time in the study. Engagement and retention in housing is an important priority for policy makers.

Individuals with disability, transportation challenges, homelessness, mental health conditions, and with substance abuse or chemical addiction may be hard to find and engage when they are not actively in treatment. Partnering with public health agencies and community-based organizations was identified as an approach that allows health care organizations to more successfully identify and engage these hard-to-reach populations, some of whom harbor mistrust of health care professionals. Although such partnerships would ideally build on shared data for surveillance, programs had developed approaches in the absence of a formal data sharing system. For example, the Gatekeeper program in Ohio developed a community referral model to identify high-risk individuals in partnership with a network of trained community volunteers such as bank tellers, police officers, paramedics, and pharmacists. Volunteers initiated referrals directly to the Gatekeeper program for older adults who identified as being potentially at risk or who might benefit from community services.

The data on diagnostic history and characteristics of subsequent admissions may also provide some help in conceptualizing intervention design. The relatively high rates of chronic disease suggest the importance of a comprehensive, multidisciplinary approach to any intervention, using what we already know about improving chronic disease management (such as the chronic care model). But the extraordinarily high levels of substance abuse among high-risk patients and the history of mental illness even among the population without serious and persistent mental illness make clear that any intervention will have to take these factors into account. Whatever is on the shelf from chronic disease management vendors for commercial plans and Medicare will require a serious overhaul for adaptation to these populations.

There are also other important questions that remain unanswered. From claims records we can say little about the social and personal characteristics of these patients. This is a population living in extreme poverty, and a broad range of factors (educational, behavioral, and coping capacity) likely complicate their lives. We have documented their mental illness and substance abuse problems, and there are also potentially high levels of homelessness and housing instability. Getting more and better information about these issues will require further work, but it is clearly critical to any intervention design. However, the potential impact of solving these problems may also be large, even for the most apparently daunting problems such as the high number of mental illness admissions. For some high-risk patients, an effective, supportive housing environment might be enough to tip the balance, allowing sufficient life stabilization to address previously intractable health and mental health problems. An emerging body of research indicates that these “social service” interventions can have a major impact on the use of health services.

Eligible patients were identified through real-time automated methods and recruitment occurred while patients were still hospitalized. Patient intake included an in-depth patient assessment to determine nonmedical barriers to improved health.

Our findings also show the importance of including patients with mental health disorders in an intervention program. John Billings and Maria Raven noted that more than a third of high utilizers have at least one claim with a mental health disorder diagnosis. Other studies have However, more than half noted that people with mental health disorders have higher rates of receiving ED and inpatient care. Most of the patients enrolled in our study had either depression or anxiety. While Bridges to Care [B2C] did not target people with severe mental health needs (such as those recently hospitalized at a psychiatric facility), to our knowledge, the program is unique in having a behavioral health provider screen every enrollee for mental health disorders—and then address those conditions as appropriate.
Participating super-utilizer programs reported a high prevalence of behavioral health diagnoses in high-utilizers through claims data. Indeed per capita Medicaid costs increase significantly with the addition of a mental health diagnosis, substance abuse diagnosis, or mental health plus substance abuse diagnosis.  

All stakeholders identified poorly managed serious mental illness among HNHC [high need, high cost] patients as a significant driver of preventable high health care utilization. Patients often had inadequate access to mental-health and substance-abuse resources. This was because outpatient programmes did not exist, were inconveniently located or were not financially feasible to attend. This left patients without any options other than the ED for care. Additionally, several patients acknowledged that feeling depressed negatively impacted their care routines and contributed to missing provider appointments which, over time, compounded the severity of their diseases. Importantly, patients also pointed out that the stigma surrounding mental illness was detrimental to their desire to seek out treatment even if it were available. Some patients also felt that policies such as the Florida Mental Health Act (known as the Baker Act) and its equivalent in New York State (known as Kendra’s Law), which allow for involuntary institutionalization and examination of an individual with possible mental illness for up to 72 hours, did not adequately address or help mitigate the root causes of substance abuse and mental-health disorders. This increased preventable ED and/or hospital utilization for psychiatric needs.  

Most high utilizers had ≥4 unique chief complaints, suggesting that these patients generally have several, rather than a few, reasons for seeking emergency care. No clearly defined pattern of complaints existed for high utilizers. High utilization in such patients is less likely to be caused by clearly defined disease processes and more by a complex mix of multiple chronic medical conditions and psychosocial factors, making it difficult to predict future utilization or identify specific patient needs based on their chief complaint….most high utilizer ED visits appeared to occur close together in clusters…. Patients with psychiatric complaints, for example, may present repeatedly in a short period of time because of inadequate outpatient psychiatric follow-up. ED visits cluster together even when the complaints are different, suggesting that other external factors not necessarily linked to their complaints (such as social problems or emotional distress) are driving utilization. Abdominal pain, chest pain, and shortness of breath topped the list as the most common chief complaints and most common cause of admissions. All 3 complaints can lead to extensive and costly workup in an ED and/or inpatient ward because of their obvious potential to correspond to serious, life-threatening medical conditions. However, they often also can be seen in low-acuity conditions and symptoms related to mental illness or substance abuse. The chart review in this study highlighted the inherent difficulty in determining whether patterns of high utilization for these 3 complaints are related more to medical conditions or social/behavioral factors. Although nearly all of the patients in the chart review had mental illness and/or substance abuse, far fewer visits than expected were clearly linked to these conditions.  

The Camden Coalition conducts a cluster analysis to identify the various subpopulations. This involves sorting cases (usually by patient utilization history) into groups, or clusters, so that the degree of association is strong between people in the same cluster, and weak between members in different ones. Some programs stratify the typologies by the different social needs faced by the patients such as homelessness, joblessness, and language preference—further indicating what interventions would be the most effective. Although the super-utilizer population is heterogeneous, the pilot programs did note a common thread across the subpopulations: the prevalence of childhood trauma. Many care management teams were working to understand and address the impact of early childhood trauma.  

Both the taxonomy developed by the Harvard T.H. Chan School of Public Health and the one developed by The Commonwealth Fund segment high-need individuals based on medical characteristics because this is a feasible starting point for most health care systems. Recognizing that a taxonomy focused on medical characteristics may neglect other factors that are key drivers of need, the taxonomy working group built on these efforts to offer a conceptual starter taxonomy that incorporates functional, social, and behavioral factors into a medically oriented taxonomy, not as independent segments but as factors that influence the care model or care team composition most likely to benefit particular patient segments (Figures S-2 and Table S-1). This starter taxonomy can provide guidance for health system leaders and payers on how to embed social risk factors, behavioral health factors, and functional limitations in a taxonomy for high-need patients. Patients would first be assigned to a clinical segment, with follow-on assessment of behavioral health issues and social services needs to determine the specific type of services that are required. Key behavioral health factors most likely to affect care delivery decisions include substance abuse, serious mental illness, cognitive decline, and chronic toxic stress and key social risk factors include low socioeconomic status, social isolation, community deprivation, and house insecurity.  

In the early stages of the CMHCB demonstration, CMP leadership learned that many high-cost, complex patients have mental health issues that were not effectively addressed by the current model of health care delivery or its pilot program. As a result, the program allocated greater resources to support mental health, hiring a social worker to assess the mental health needs of CMP participants and support them in accessing psychiatric care as needed or provide treatment if appropriate.
Social determinants of health. All stakeholders emphasized the importance of inadequate health literacy, unstable housing conditions, and lack of adequate social support in driving preventable high health care utilization. Low health literacy made it difficult for many HNHC patients to manage complex medical conditions on their own, adversely impacting their ability to follow through with day-to-day self-care regimens. They also felt that for some HNHC patients with unstable housing conditions, being in the ED or an inpatient care setting was desirable, as it was the only avenue, as one HNHC patient put it, to 'get a meal...have a television...stay overnight'. Finally, health system leaders as well as most physicians felt that the interplay between lack of social support and poor disease control was often a reason for presenting to the ED.

Social determinants of health by sub-themes, with illustrative quotes from stakeholder interviews:

- **Inadequate health literacy**: Physician: ‘Health literacy and overall education level is probably the biggest impact on the ability to self-manage these conditions’.
- **Unstable housing**: Physician: ‘Eventually, [many] of them become homeless or [have] poor living conditions and those patients...arrive because of weather conditions or for other reasons to the ED to seek shelter and respite’.
- **Limited social support**: Health system leader: ‘[Workable solutions] probably have to do with…social support and reduction of isolation and helping them negotiate the complexities’.
- **Insurance challenges**: Patient: ‘I have Medicaid and some of the doctors don’t take [it], and so you say to yourself, well, even if I get an appointment, are they going to take me? So just go to the emergency room and let them handle it from there’.
- **Financial burden**: Patient: ‘A lot of times [we're] on a fixed income and you need to see a specialist...You may have a co-pay with your specialist. It could add up if you go excessively. It’s easier to go to the [ED] and get what you need’.12

**Additional subjective or in-person assessments of HNHC patient eligibility**

CMO 1.5 Incorporating patients’ self-assessments of “subjective” characteristics about themselves (e.g., willingness to participate) [C] adds to intervention designers’ confidence in identifying HNHC patients [M] who will benefit from intervention services [O1] and who are at risk of having future high healthcare use and cost [O2].

Relevant data extracts/summary information from included literature
Using the Medicare Health Risk Assessment [HRA], we explored two data-driven methods to segment a heterogeneous population of older adults with potentially complex care needs into clinically meaningful subgroups using self-reported information. Input variables for the segmentation analyses were patient-reported variables drawn from the Medicare HRA, a component of the Medicare Annual Wellness Visit designed to identify patient-reported modifiable risk factors and health needs. Required elements include self-assessment of health status, psychosocial risks, depression, behavioral risks, and Activities of Daily Living and Instrumental Activities of Daily Living. Care delivery systems can add additional questions. The Medicare HRA is designed to help clinicians address patient-reported risks for preventable adverse outcomes. Although the HRA is most commonly applied at the point of care, if data are systematically collected, representative, and stored in extractable formats, they can be used to inform program development, population health, and outcomes research. Although content collected through patient-reported outcomes may duplicate content obtainable through more traditional clinical data such as ICD codes, ICD codes alone are unlikely to capture subjective responses to questions about pain, loneliness, and independent activities of daily living (for example). In this project, HRA data revealed meaningful subgroups that might not have been obvious from other electronic clinical data and could inform specific clinical interventions. Important differentiators included function, falls, perceived health status, emotional well-being, pain, and presence or absence of an advance directive. Two large subgroups comprised relatively healthy individuals who could benefit from watchful waiting and routine preventive care plus (for one group) life care planning. Much smaller subgroups could be targeted for more intensive and tailored care management. The size of these subgroups can inform resource allocation within delivery systems.

Traditional electronic data such as diagnostic codes and laboratory values may not capture essential information on factors that drive care needs, including function, personal preferences, and social resources, that can only be reported by individuals themselves. Identifying and characterizing complex needs subpopulations requires patient-reported information to help match care delivery to personal needs. Although newer data from electronic health records (EHRs) such as symptom assessments and ICD-10 codes that capture functional status can improve our ability to identify complex needs subpopulations, subjective information can add a level of specificity unlikely to be captured with objective coding.

Judgment about whether the patient is amenable to management is based on an interview with the patient by the care team and a review of medical records. The assessment of whether the patient is entered into Care One is based on a judgment that the patient has a chronic medical condition, is at high risk for future hospitalization, and is willing to attend outpatient visits and comply with therapy. Other specific exclusions from the Care One program include a single high-cost medical event (e.g., a trauma), residence outside of the hospital’s catchment area, and chronic alcohol or drug abuse.

As we enrolled patients into the group we found that, despite a broad range of medical and behavioral health problems, the common feature they shared and what ultimately served to bring them together as a group was their status of being “on the fringe,” as they described themselves. Nearly every patient had experienced a number of barriers and frustrations in accessing medical care that the DIGMA [drop-in group medical appointments] team seems to have successfully addressed.

Moreover, recognition that computer-based designations of being at risk for costly care (also decorously called predictive analytics) vary considerably, furnish no specific guidance, and are inaccurate is increasing. Most patients in the small, at-risk subgroup will not use such care, whereas care becomes relatively rationed for most patients not designated as such—including those who may require it. Nevertheless, health care executives embrace the paradigm of high-risk intensive management despite its flaws. Meanwhile, many of its shortcomings can be remedied by a few standardized, patient-reported measures that forecast a patient's risk for costly care in a similar manner to predictive analytics, specifically the risk for direct services. For example, patients may simply indicate that they are only somewhat or not very confident that they can manage and control most of their health problems; have had moderate or severe pain during the past 4 weeks; have been bothered extremely or quite a bit during the past 4 weeks by emotional problems, such as anxiety, irritability, depression, or sadness; believe that the medications they are receiving may be causing illness; and have been prescribed more than 5 medications. Although some payers and providers may disagree with the specific metrics, none should assert that a patient's standardized self-report is an improper tool for guiding care. They may consider this method too old-fashioned or novel for implementation, but its modesty and low cost are remarkable.
Dr. Wasson notes the limitations of relying on risk scores derived from electronic data. We agree that patient-reported indices have many advantages. Electronic indices, such as the Veterans Health Administration’s Care Assessment Needs Score (1), also have potential advantages as a screening method in health care systems in which such data can be calculated on a population level. Some high-risk patients identified by the Care Assessment Needs Score did not need or were unlikely to benefit from intensive management, and intensive management teams in our study spent substantial time triaging the heterogeneous populations by reviewing health records, contacting primary care providers, and having telephone or in-person visits. Our results suggest that selecting patients for intervention would ideally combine the use of algorithm-based risk scores with measures focused on such issues as those raised by Dr. Wasson, including whether patients believe that they are activated in managing their health or have difficulty managing their prescriptions.40

Data were collected through computerized administrative databases and HRA questionnaires to measure outcomes for utilization, health risk scores, and self-efficacy.41

Patient activation refers to an individual’s knowledge, skills, and confidence related to self-management. The construct is commonly measured using the Patient Activation Measure, which is a thirteen-item interval-level scale with strong psychometric properties that generates a score between 0 and 100. A Patient Activation Measure level may be assigned based on the score, from level 1 (least activated) to level 4 (most activated). Studies show that Patient Activation Measure results are predictive of most health behaviors, clinical indicators, and hospital and emergency department (ED) use. Research also shows that less activated patients with chronic illness are more likely to experience care coordination problems, compared to more activated patients. Numerous studies also indicate that compared to more activated patients, less activated ones with chronic disease are less likely to effectively manage their conditions (for example, they are less likely to adhere to medication regimens), have healthy diets and get regular exercise, regularly monitor symptoms and clinical measurements, ask questions in the medical encounter, and report satisfactory care experiences. These findings suggest that less activated patients may benefit more from care coordination and care management services than patients who have equal disease burden but are more proactive about managing their health.41

In this study we used the four Patient Activation Measure levels. Level 1 indicates that a person does not yet understand the important role that patients play in determining their health, and level 4 indicates that a person is proactive about his or her health and engages in many positive health-related behaviors. Compared with lower-risk patients, high-risk patients were twice as likely to be sixty years or older and were somewhat more likely to be lower income (Exhibit 1). High-risk patients were also almost twice as likely to be depressed and more than twice as likely to be at the lowest Patient Activation Measure level. Furthermore, in 2011 high-risk patients were three times more likely to have had an ED visit and fourteen times more likely to have had a hospitalization. Fairview Health Services, a Pioneer ACO [Accountable Care Organization], uses the Patient Activation Measure to allocate its resources more efficiently to support patients. For example, Fairview’s care coordinators and health coaches, who manage high-risk patients, use the Patient Activation Measure level to decide how intensely to follow and manage specific patients. Nurses supporting patients during care transitions use a similar approach, in which the Patient Activation Measure score determines the frequency and focus of their posthospital support efforts.41

As we demonstrated in a previous article, although they are very sick, these patients remain surprisingly functional despite their illness(es) (Roberts et al., 2012). Additional important general observations include the following: these individuals are very resilient, highly resourceful, and are extraordinarily patient with the healthcare system. At enrollment, many are overwhelmed; disengaged; nontrusting; and lacking in a feeling of self worth or deserving of services (making it critical to have psychology expertise integrated into the team structure). Furthermore, this patient group wants to be perceived as agreeable (e.g., may know they will be unable to keep their next appointment for some reason but would not offer that unless asked).48

...physicians reported disappointment that many of the patients they believed could be helped by the [Health Buddy®] program were not eligible to participate in the program because they had not been identified through the claims based algorithm developed by HHN [Health Hero Network].33
CMO 1.6 Considering patients' self-assessments of health system-related risk factors and experience [C] adds to intervention designers' confidence in identifying HNHC patients [M] who will benefit from intervention services [O1] and who are at risk of having future high healthcare use and cost [O2].

Relevant data extracts/summary information from included literature

At enrollment, the concept of self-management is not familiar to most of them. Systems, like the Housing Authority, Medicaid, and health systems, often add to their burden. Examples include applications for benefits are frequently difficult to figure out and time consuming to file, applicants often feel disrespected or treated as if they were helpless, and agency staff are often not adequately sensitive to client issues regarding low/no literacy. In addition, for non-English speaking, translation services can be inadequate, cultural competency is a problem, and mailed annual reapplication notices (such as for Medicaid) are difficult to recognize as something official and may be disregarded.38

Example from CSHP illustrating the program's theory of action "Patient A in Kansas City has multiple chronic conditions and poly-substance abuse, a history of homelessness, frequent ED visits, and no PCP [primary care provider]. At the initial contact with the care team, the patient stated that he would "never want to conform to the rules." The care team's strategy is to first establish firm trust. They accomplished this by identifying opportunities to provide basic help, such as involving family members in explaining the impact on diet of modifying cooking practices, supplying a scale and log to support the modification, organizing and explaining the purpose of medications, arranging for transportation and enabling the patient to do so, scheduling and accompanying patients to medical and social service appointments.14

Long wait times Patient: "When I go to the emergency room, they [say], "When you get out of here go see your GI doctor". But, that's not the way it works...Last time I called to get in the next day, they told me he had 17 patients, and couldn't see me. In three months, you don't know what could happen. So, the next thing is [back to] the ED'.12

Mismatch arises from patients' social circumstances limiting access to services, behavioral issues interfering with care engagement, and lack of health system flexibility to address these barriers. A staff member reflected on the inability for a patient to receive services due to homelessness: "He was homeless when we made the referral and doesn’t...fit into [the] standard hospice system.... Health care systems are designed for these neat packages of people that are housed, have family support, have access to other resources, are not actively using substances.... The services aren’t really designed for complex folks, so that can be really frustrating and exhausting.” (SUMMIT LCSW)12

A few [stakeholders] even suggested that sometimes it felt easier to take an ambulance to the ED and access different services at the same place and time rather than arrange transport for multiple visits including PCP, specialists, bloodwork, etc.12

Economic determinants of health care. Patients identified insurance-related factors and financial burden of upfront costs (such as co-payments) as reasons for frequent ED visits and hospitalizations. For example, several patients on Medicaid reported knowing that many physicians in their community did not accept their insurance. To avoid losing time by contacting multiple primary care offices, they would go to the ED directly. Also, for underinsured and uninsured patients, the ED was the only health care setting where they could receive health care without having to deal with implications of their insurance status or co-pays right away. Many patients also reported the negative impact of financial burden on their medication adherence as a driver of frequently presenting to the ED. They felt that some of these visits can be prevented if medications and essential medical devices were not so expensive.12

Survey of frequent ED patients while in ED

Barriers to care: % agree, could have multiple barriers
It is easy for me to make time to get to necessary med appts: 78%
I always remember to schedule my annual check-ups, tests, and/or screenings: 65%
I feel like I receive better quality health care in the ED than I do in my usual place of care (PCP, clinic): 48%
whether certain services would be helpful to the patient, in the event the ED or health system decided to offer the service:
After-hours options for minor health issues besides the ED: 63%
A nurse to work with you one-on-one to help manage health care needs: 53%
Transportation to get to medical appointments on-time: 46%

While 42% did not think that a PCP would be helpful, many said that they had one.5
CMO 1.7 An enrollment process that includes an extensive period of outreach and trust building [C] adds to an intervention provider’s confidence [M] in determining a participant’s willingness and ability to participate in the intervention [O].

Relevant data extracts/summary information from included literature

CCM [complex care management] providers looked for indicators that patients were willing to engage during initial patient encounters and enrollment, and looked for signs of successful engagement in ongoing assessments of patients’ communication and actions. When CCM providers first met patients, positive indicators that they were willing to engage included verbally agreeing to take part in the program, returning phone calls to the CCM team or answering the phone when CCM team members call, being receptive to a home visit, and showing up to an initial appointment. CCM providers continued to assess engagement over time by considering how frequently patients missed appointments, how well they adhered to medication and treatment regimes, how much progress they made towards behavioral changes such as reducing substance use or increasing exercise, and how candidly and regularly they communicated with the CCM team. A social worker said that she considers patients likely to engage over time when “we reach out to them by phone and we make an appointment and they show up.”16
Program Theory 2: CMO configurations with supporting data for engaging HNHC patients in interventions to improve their management of their chronic conditions, supporting context-mechanism-outcome relationships

Patients' challenges to self-care prior to and during the intervention

CMO 2.1. Past experiences with the healthcare system including encountering barriers accessing medical care and disrespect from providers [C] cause patients to distrust the system and providers [M] which inhibit patients from accepting and seeking appropriate help and medical care [O].
Relevant data extracts from included literature

More than half of participants (n = 12) related stories of encounters that had upset them; several explicitly mentioned withdrawing from outpatient providers by choosing not to attend appointments with those providers as a result. Over a third of participants switched providers because of dissatisfaction with those relationships. Others who had not switched chose not to follow a given provider’s instructions as a result of these negative interactions. Most of the stories of negative health care encounters focused on feeling disrespect from providers, while others specifically described feeling discriminated against by providers because of race or sex.29

Several participants in this study expressed that they felt that their care sometimes was compromised by perceived disrespect from health care providers, citing race-, sex- or SES [socioeconomic status]-based discrimination.29

When answering questions about trusting their health care providers, almost half (n = 9) of participants stated that they distrusted a particular (usually hospital-based) provider. Respondents generally expressed trust in their primary care providers.29

Nearly every patient had experienced a number of barriers and frustrations in accessing medical care that the DIGMA team seems to have successfully addressed.10

“Patient A in Kansas City has multiple chronic conditions and poly-substance abuse, a history of homelessness, frequent ED [emergency department] visits, and no PCP [primary care provider]. At the initial contact with the care team, the patient stated that he would “never want to conform to the rules.”…His sister reflects, “He used to use the ER [emergency room] for everything…."

Challenges associated with accessing health care delivery systems Transportation barriers. Some patients reported that primary care offices were inconveniently located and difficult to access due to transportation barriers. A few even suggested that sometimes it felt easier to take an ambulance to the ED and access different services at the same place and time rather than arrange transportation for multiple visits including primary care, specialists, bloodwork, etc. For patients who could utilize private or public transportation to get to a primary care clinic, the distance often made the trip extremely time-consuming as well as costly. Preventability of ED use appeared contingent upon logistic ease of access to services.

Long wait times. All stakeholders identified scheduling challenges at primary care clinics as an important driver. Many patients reported that they were unable to schedule first-time or follow-up appointments quickly (same-day, next day or even in upcoming weeks) and instead had to wait several months. Furthermore, if a disease exacerbation occurred after regular clinic hours or overnight, patients felt that they had no other options but to seek care in the ED.12

Survey of frequent ED patients while in ED

Barriers to care: % agree, could have multiple barriers

It is easy for me to make time to get to necessary med appts: 78%
I always remember to schedule my annual check-ups, tests, and/or screenings: 65%
I feel like I receive better quality health care in the ED than I do in my usual place of care (PCP, clinic): 48%
whether certain services would be helpful to the patient, in the event the ED or health system decided to offer the service:
After-hours options for minor health issues besides the ED: 63%
A nurse to work with you one-on-one to help manage health care needs: 53%
Transportation to get to medical appointments on-time: 46%
While 42% did not think that a PCP would be helpful, many said that they had one.5

Mismatch arises from patients' social circumstances limiting access to services, behavioral issues interfering with care engagement, and lack of health system flexibility to address these barriers. A staff member reflected on the inability for a patient to receive services due to homelessness: “He was homeless when we made the referral and doesn’t fit into [the] standard hospice system….Health care systems are designed for these neat packages of people that are housed, have family support, have access to other resources, are not actively using substances….The services aren’t really designed for complex folks, so that can be really frustrating and exhausting.” (SUMMIT [Streamlined Unified Meaningfully Managed Interdisciplinary Team] LCSW [licensed clinical social workers])6

29
CMO 2.2. Previous and current personal life circumstances and characteristics (e.g., mental illnesses, substance abuse, emotional or physical traumas, extreme poverty, and low literacy) [C] results in feelings of stigma in patients [M] that inhibit them from seeking help and medical care [O].

Relevant data extracts from included literature
A predominance of the participants (n=12) told stories of childhood instability...Significant subthemes included early life traumas, such as death of a parent or other loved one, and abusive relationships with primary caregivers throughout childhood. Some described state agencies as their primary caregivers. Transiency was noted, often in the context of escape from abusive relationships (n = 5), and often resulted in living on the streets or gang and drug involvement, even as children. Only 2 individuals specifically described how events in childhood affected their health during adulthood. Nevertheless, many participants related stories of how this instability may have manifested in health issues, especially with regard to mental health. For example, one woman described:

“I had sexual and physical abuse from my parents since I was a baby, since I was 3 or 4. Mother has been very abusive over the years. Every time we went somewhere she was hitting me, punching me, scratched me, and I’d cover it up.”

This individual described ongoing difficulty obtaining effective treatment for the post-traumatic stress disorder that repeatedly sent her to the ED. She reported being frequently “suicidal” and “in crisis” as a specific result of childhood abuse, for which she was “in and out of hospitals too much.” She reported a shared goal with her therapist of accessing consistent community-based mental health care rather than relying solely on the ED. Nearly half of the respondents (n = 8) named their mother or a mother figure as their most important primary caregiver. The other half referred to a variety of other caregivers, such as grandparents, other relatives, or the state, or they declined to answer; these situations were described by some participants as traumatic, and by others as a normal course of events. Of participants who described instability in childhood, half noted familial estrangement in adulthood (n = 6). When asked if there was someone they could depend on now for help, most participants spoke of having only 1 or 2 individuals that they could rely on, if any, suggesting a lack of social support in adulthood for nearly all of these respondents.

Patients may have a variety of barriers that prevent them from accessing traditional primary care venues, particularly those settings that do not allow patients to walk in at their convenience or patients who may need intensive services during a personal crisis. Patients with difficult life circumstances also may be more likely to not show for an appointment.

Patients in this quality improvement program tend to be younger than those targeted by previously described care transition models and many have unstable health insurance, a history of substance use, and significant mental illness. Nearly all are from socially disadvantaged communities plagued by poor health status, and low literacy is common. Many are struggling with difficult life circumstances such as an alarming number have been emotionally or physically traumatized;...and many have inadequate, or no, family and social support systems. At enrollment, the concept of self-management is not familiar to most of them.

There are two key elements to the success of these new efforts to target and improve care for high-cost Medicaid cases. First, it is essential to be able to identify in advance patients who are likely to have high costs in the future. Many high-cost occurrences (such as injury, acute illness, or cancer) might be episodic, and high spending in one year might not mean high spending in subsequent years. Second, and equally critical, is the ability to actually affect the care pathways and outcomes of these patients. Because of the circumstances that define their Medicaid eligibility (extremely low income and medical disability) and other factors that are likely to be associated with their social and personal environment (such as homelessness, substance use, or low educational achievement), these patients will undoubtedly present major challenges.

All stakeholders identified poorly managed serious mental illness among HNHC patients as a significant driver of preventable high health care utilization. Patients often had inadequate access to mental-health and substance-abuse resources. This was because outpatient programmes did not exist, were inconveniently located or were not financially feasible to attend. This left patients without any options other than the ED for care. Additionally, several patients acknowledged that feeling depressed negatively impacted their care routines and contributed to missing provider appointments which, over time, compounded the severity of their diseases. Importantly, patients also pointed out that the stigma surrounding mental illness was detrimental to their desire to seek out treatment even if it were available. Some patients also felt that policies such as the Florida Mental Health Act (known as the Baker Act) and its equivalent in New York State (known as Kendra’s Law), which allow for involuntary institutionalization and examination of an individual with possible mental illness for up to 72 hours, did not adequately address or help mitigate the root causes of substance abuse and mental-health disorders. This increased preventable ED and/or hospital utilization for psychiatric needs.

Low health literacy made it difficult for many HNHC patients to manage complex medical conditions on their own, adversely impacting their ability to follow through with day-to-day self-care regimens.
Economic determinants of health care. Patients identified insurance-related factors and financial burden of upfront costs (such as co-payments) as reasons for frequent ED visits and hospitalizations. For example, several patients on Medicaid reported knowing that many physicians in their community did not accept their insurance. To avoid losing time by contacting multiple primary care offices, they would go to the ED directly. Also, for underinsured and uninsured patients, the ED was the only health care setting where they could receive health care without having to deal with implications of their insurance status or co-pays right away. Many patients also reported the negative impact of financial burden on their medication adherence as a driver of frequently presenting to the ED. They felt that some of these visits can be prevented if medications and essential medical devices were not so expensive.\(^{12}\)

CMO 2.3. System-level barriers including inadequate systemic support (e.g., Medicaid, translation services, housing) and lack of cultural competency \([C]\) engenders feelings of distrust and marginalization among patients \([M]\) that inhibit their ability to access appropriate healthcare services \([O1]\) and to participate in interventions \([O2]\).

Relevant data extracts from included literature

...some have no income while others have income that it is insufficient to meet basic survival needs making it challenging to pay even minimal co-pays for prescriptions; many live in unstable housing or in dangerous neighborhoods. Systems, like the Housing Authority, Medicaid, and health systems, often add to their burden. Examples include applications for benefits are frequently difficult to figure out and time consuming to file, applicants often feel disrespected or treated as if they were helpless, and agency staff are often not adequately sensitive to client issues regarding low/no literacy. In addition, for non-English speaking, translation services can be inadequate, cultural competency is a problem, and mailed annual reapplication notices (such as for Medicaid) are difficult to recognize as something official and may be disregarded.\(^{18}\)

Many participants faced a variety of barriers to appropriate care, including lack of stable income, health insurance, legal residency, English language proficiency, knowledge of the health system and chronic disease management, stable housing, social support, and transportation. Many also had issues with cultural barriers, mental illness and substance abuse (despite informal program eligibility criteria that excluded some patients with these conditions), and traumatic experiences that made stabilizing their chronic conditions more difficult.\(^{14}\)

Many patients are unable to afford even a minimal copayment that may be expected at time of a nonemergent outpatient visit and may choose to access the ED where a copayment may not be required.\(^{10}\)

We found that patients with low health literacy (measured by the REALM-SF) reduced ED utilization to a greater degree than patients with higher health literacy. We hypothesize that patients with lower health literacy may have encountered more barriers to accessing primary care or had greater social needs than those with higher literacy and thus, differentially benefitted from individualized assistance from a patient navigator. These preliminary results suggest that care coordination programs that aim to reduce avoidable ED use and hospital admissions may have a greater impact among patients with lower health literacy.\(^{25}\)

In the current study, KCCP Care Managers identified multiple barriers to active participation in the intervention including basic needs for food, shelter, and transportation that took precedence over program participation; depression; not having a phone or being unable to manage a phone due to mental illness or addiction; language or other cultural barriers; and mistrust of the system (Cristofalo et al. unpublished data).\(^{3}\)

Social determinants of health. All stakeholders emphasized the importance of inadequate health literacy, unstable housing conditions, and lack of adequate social support in driving preventable high health care utilization.... They also felt that for some HNHC patients with unstable housing conditions, being in the ED or an inpatient care setting was desirable, as it was the only avenue, as one HNHC patient put it, to ‘get a meal... have a television... stay overnight’. Finally, health system leaders as well as most physicians felt that the interplay between lack of social support and poor disease control was often a reason for presenting to the ED.\(^{12}\)
Relationship building with care providers

CMO 2.4. Interventions and care team members initially address patients’ basic needs and explain things in lay terms [C] to establish trust with the patient [M] resulting in building a relationship with their patients [O].

Relevant data extracts from included literature

Patients generally had positive impressions of their care managers. During semi-structured interviews with a sample of high-risk patients and caregivers from deep-dive practices, patients who reported having regular contact with their care manager or who were open to working with their care manager felt that the care manager was an asset to their care team. Patients particularly valued care managers who listened to them and explained things in lay terms, helped to manage medications and chronic conditions, followed up after a hospitalization, and helped to navigate the health care delivery system and community resources.35

“…The patients that have been on SUMMIT [Streamlined Unified Meaningfully Managed Interdisciplinary Team] for a while have a really solid relationship with us, that makes a huge difference. They are able to call. They are telling us what their needs are. They can make it to appointments and…coordinate all of those needs a little bit better when they know that we’re going to be reliable and [here] is where they can come for help.” (SUMMIT Physician).8

They [the program staff] expected that its program would have the greatest impact by preventing acute health care events among beneficiaries who were initially not having significant health issues; however, case managers found that they spent a lot of time dealing with urgent issues for patients who “spiraled out of control.” Although initially some patients were skeptical about the MGH [Massachusetts General Physicians Organization] CMP [Care Management Program], overall, patients quickly formed relationships with case managers, including several who requested daily contact with their case managers to help them with their numerous issues.

The care team’s strategy is to first establish firm trust. They accomplished this by identifying opportunities to provide basic help, such as involving family members in explaining the impact on diet of modifying cooking practices, supplying a scale and log to support the modification, organizing and explaining the purpose of medications, arranging for transportation and enabling the patient to do so, scheduling and accompanying patients to medical and social service appointments. Within weeks, the patient has started scheduling transportation and keeping his appointments independent of the care team, and now states that he cares about his health. His sister reflects, “He used to use the ER [emergency room] for everything. Now he asks when his appointment is.”14

Convenience And Access Our model emphasizes convenience and access, starting with location. Our centers—in the range of 6,500–10,000 square feet—are located in urban areas with a high density of low-to-moderate-income seniors. For our patients’ convenience, we offer a broad set of additional services on site, including dental care, digital x-ray, ultrasound, and acupuncture, as well as five to fifteen high-volume specialists. Our average health maintenance organization (HMO) patient received 86 percent of his or her ambulatory encounters at our centers in 2011, although the most expensive aspects of care occurred outside of our centers—for instance, hospitalizations, surgeries, and imaging. Patients find the one-stop-shop approach to care highly appealing.41

“We found in our case series that trust was a key theme in the relationship between patients and their clinicians or the health system. Lack of trust in individual doctors or institutions, as well as unrealistically high expectations of the same, appeared to be an important driver of higher costs Patient trust seemed to be informed by both patient factors (prior experience, socioeconomic status, activation) and clinician factors (quality of care, communication skills). Among the five patients, trust appeared to be an important driver of higher costs when patients or families had trust in their clinicians or when needed care was low acuity or standard; however, higher activation (in particular, the confidence and ability to advocate for care) was associated with higher costs when trust seemed lacking, particularly when the stakes were high (in critical illness) and the course uncertain.”….Observations highlight challenges with trust in the setting of increasing medical complexity, specialization, and team-based care. Important to teach docs communication skills that earn trust, particularly around goals of care, and to better match patients to appropriate docs and care managers to ensure trusting relationships.”47
CMO 2.5. When care managers support patients with medical and non-medical problems [C], patients are reassured [M1] and gain confidence [M2] in their ability to manage their own care [O].

Relevant data extracts from included literature
Care management is a vital piece of the puzzle, pulling together community resources without which recovery would be impossible. Successful case management also includes assisting with teaching some of these patients basic life skills, for example, not to find housing for them, but rather direct them where to go to get housing assistance. These small, positive steps are then shared with the group, which further reinforces a growing sense of confidence. Additionally, efforts to tailor-make health education programs to improve health literacy and numeracy may be warranted for patients to effectively self-manage some of their care needs.

Coalition staff may help schedule further medical appointments as necessary, continue to help organize transportation, accompany patients to medical appointments, check-in after medical appointments to help the patient implement the instructions given by the provider, and continue to organize medications. Home visits in later stages increasingly focus on self-care management skills, health care navigation skills, enhancement of self-efficacy and independence, care plan adjustment and coaching.

CMO 2.6. Patients are more motivated [M] to improve their health behaviors [O] when they feel cared for by their providers and other support groups [C].

Relevant data extracts from included literature
Participants reported that “caring” providers were particularly important in the trajectories of their illnesses and lives, emphasizing the compassion of the Care Management Team. Providers from the intervention were described as dependable, sensitive, and thoughtful, suggesting that these traits in providers may resonate for individuals whose childhoods lacked caregivers with these qualities. Conversely, participants emphasized the importance of caring, trusting, and longitudinal relationships with providers, both on the Care Management Team and with primary care providers. Comorbid mental illness, especially depression, makes managing chronic illnesses such as diabetes more challenging. Consistent, positive relationships with primary care providers have been shown to decrease rates of hospitalization and ED use for complex patients who struggle with a combination of multiple chronic illnesses, mental illness, and psychosocial challenges.

Frequent, longer visits built relationships with the care team and other patients. The emotional support provided by the group seemed to be a key factor in assisting patients to find solutions to their health and social problems. Half of participants indicated the importance of “feeling cared for” by providers (n = 10). This theme recurred throughout the interviews, especially during descriptions of the Care Management Team. When asked about the best part of the intervention, rather than describing specific services, most participants described the importance of the emotionally supportive interactions they experienced. These participants reported that the experience of feeling cared for was a motivation to improve their own health behaviors (n = 10) (Table 2). Diabetes, depression, and hypertension were the most commonly reported conditions. Despite the natural history of these complex chronic diseases and their tendency to reflect a pattern of deterioration over time, 7 participants reported improvements in their own perceived health status after the intervention. Five of those participants specifically attributed this improvement to the intervention. “They make you feel like you’re not alone, and they understand you and the things you’re going through. And they actually help explain why you’re going through these things…you don’t feel like just a patient.” - 24-year-old African American woman with depression and Type 1 diabetes.
CMO 2.7. When intervention care providers build trusting relationships with patients [C], patients have confidence in their providers' desire to help [M] resulting in patients seeking advice from their intervention care provider before going to the ED/hospital [O].

Relevant data extracts from included literature
During the early months of CLM's [Care Level Management's] program implementation, nurse care managers focused on building relationships with the patients during telephone contact between PVP visits, so that patients would be comfortable calling the nurses if health problems arose. Patients at highest risk were to receive calls on a weekly basis, whereas those at moderate and low risk were to receive calls on a monthly or bimonthly basis....Over the course of the first year of operations, CLM reported ...that they reorganized their patient care teams to include more nursing support. CLM believed that this arrangement would allow patients to bond with the nurse care manager over time, whereas CLM had observed that the clinical specialists were not able to forge a sufficient bond as evidenced by the fact that some of their participants were going to the hospital rather than calling the clinical specialists when problems arose.34

In addition to connecting clients to health and social resources in their community, the community navigators focus on building trust between the client and navigator and subsequently with other healthcare entities and social systems in the community.42

The care manager is an experienced, calm, trusted professional patients can call when they are frightened or in crisis between groups visits, which is often the difference between going to the ED to seek immediate care or waiting a day or 2 until the next group visit.10

These participants articulated an appreciation for continuity in relationships with providers, including members of the Care Management Team. A majority of respondents (n = 14) described their preference for office-based primary care with their usual providers, reserving the ED for emergent medical necessity or after-hours needs.29
Individualized care for HNHC patients

CMO 2.8. Designing flexible interventions that could be tailored and individualized to specific HNHC patient's needs and circumstances [C] empowers providers [M] to be responsive to each patient's needs and circumstances.

Relevant data extracts from included literature

Care transitions are normally linear and finite (e.g., from Provider A to Provider B), but in our care coordination programs, the number and nature of care transitions are circular, overlapping, and continual. They involve cross-sectoral care givers including social services, government workers, and church and community members—in addition to medical, social work, and behavioral health providers in one or more health systems—and they take place at multiple locations. Because the interventions need to be tailored to each patient individually, based on their medical and life situations, they are not predictable at the outset, and “model fidelity,” as required by most care transition models, is not feasible.38

Specific interventions were tailored to each patient in collaboration with the patients and their family, reflecting the patient’s unique needs.52

Patient intake at IOC included an in-depth patient assessment to determine non-medical barriers to improved health. Care plans and activity to address needs were individualized.13 14

The ability to tailor care to patients’ individual needs was another ingredient staff members felt they provided to complex patients. A SUMMIT care coordinator described a strategy to assist patients with attending specialty appointments:

“I’ll have appointments with patients just with myself if patients need help with scheduling outside the clinic and scheduling transportation…. If a patient chronically no-shows to a (specialty) appointment…I’ll make an appointment for them to come [see] me and we'll schedule together and…give them an appointment planner or write up all their appointments for them.58

Each enrollee gets a tailored 60 day care plan and associated patient services they might need including assistance obtaining housing resources, insurance, disability benefits, refugee services, transportation, coordinating primary and specialty care; and filling prescriptions.7

The housing patterns we found, however, suggest the need for flexibility. Consistent with the experience of many Housing First programs, over two-thirds of the housed intervention participants required rehousing after their first placement did not succeed. The ability to offer a new housing placement is a key component of successful Housing First strategies when working with high complexity populations. With the widespread use of Coordinated Entry that will require that counties place individuals with similar risk profiles into PSH, our findings provide support for the need for flexibility, including the ability to rehouse individuals, in order to serve those at highest risk. Our results offer a measured sense of expected changes in their use of other services.37

Another feature of our program was the flexibility in the range and intensity of services we offered to patients. Some patients required infrequent contact to assist with scheduling and attending primary care appointments. Other patients benefited from more intensive contact, including multiple accompanied clinic visits or home visits.27

Supplemental material

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CMO 2.9. Having interventions address underlying mental health conditions concurrently or before managing other health conditions [C] helps patients’ ability to cope with their health conditions [M] and allows them to benefit from interventions addressing their chronic conditions [O].

Relevant data extracts from included literature

Theme 3: Addressing Both Psychosocial and Clinical Needs Participants noted that it wasn’t possible to separate provision of psychosocial support from traditional medical care. This can run counter to what occurs in usual care. “I spent an hour with a patient last week and we didn’t talk about medical problems…. It was a therapeutic session. I’m not a trained therapist, but [that’s] what it was. We didn’t talk about diabetes. We didn’t talk about her foot ulcers….A lot of times we end up doing the work of social workers, but when you do primary care, you have to do that. It’s not ‘oh hold on,… I’m not getting into that. I’m only here for the medical stuff.’ It all wraps up into one.” (SUMMIT Physician)

But the extraordinarily high levels of substance abuse among high-risk patients and the history of mental illness even among the population without serious and persistent mental illness make clear that any intervention will have to take these factors into account.

In the early stages of the CMHCB [Care Management for High Cost Beneficiaries] demonstration, CMP [Care Management Program] leadership learned that many high-cost, complex patients have mental health issues that were not effectively addressed by the current model of health care delivery or its pilot program. As a result, the program allocated greater resources to support mental health, hiring a social worker to assess the mental health needs of CMP participants and support them in accessing psychiatric care as needed or provide treatment if appropriate.

Many participants faced a variety of barriers to appropriate care, including lack of stable income, health insurance, legal residency, English language proficiency, knowledge of the health system and chronic disease management, stable housing, social support, and transportation. Many also had issues with cultural barriers, mental illness and substance abuse (despite informal program eligibility criteria that excluded some patients with these conditions), and traumatic experiences that made stabilizing their chronic conditions more difficult.

...the program is unique in having a behavioral health provider screen every enrollee for mental health disorders—and then address those conditions as appropriate.

We found a significant reduction in use of psychiatric emergency services and a concomitant increase in scheduled mental health visits. Project Welcome Home included Intensive Case Management with a low client-staff ratio led by licensed staff with behavioral health training. Research has shown that experiencing homelessness is one factor that leads to ED visits among psychiatric patients, suggesting an unmet need for mental health care. Our findings suggest that these visits are amenable to prevention by providing housing with associated low-barriers mental health services.
CMO 2.10. Connecting patients and supporting them in navigating services that cross medical sectors (e.g., geriatrics, substance disorder treatment) and non-medical sectors (e.g., employment, housing, transportation) [C] help patients gain the confidence [M] to learn how to navigate multiple systems for themselves [O].
Relevant data extracts from included literature

Through the CMP, patients are assigned to a personal care manager who assists with access to social and medical resources, helps patients schedule PCP appointments, and helps bridge barriers between patients and the healthcare system. Enrolled patients are assigned to 1 of 3 outpatient primary care clinics. Components of the CMP include: goal creation/assistance in reaching goals, ranging from applying for benefits and receiving stable housing to losing weight and receiving specialty care appointments; assistance with care navigation (schedule appts, follow-up on referrals, and help refill medications); arranging for social services (make personal connections with staff at various agencies in the community and refer patients to appropriate services, including transportation resources, Legal Aid, homeless shelters, faith-based services, and substance abuse resources); care transitions (meet with patients daily while they are admitted and work with discharge planners to assist patients in receiving recommended follow-up care and understanding discharge instructions); and communication with providers (accompanying them to appointments, creating and prioritizing problems lists, coaching patients about questions to ask, and sitting with patients after their visit to explain follow-up instructions).38

After the visit, the patient navigator and patient created a task list based on the provider’s recommendations. For example, if the PCP ordered additional tests or specialist referrals, the navigators assisted in scheduling these additional appointments, phoned patients to remind them, identified and addressed any barriers such as transportation, and encouraged patients to follow PCP recommendations. When needed, navigators helped patients to access medical transportation assistance through the state Medicaid system. If the patient identified social needs such as precarious housing, food insecurity, or insurance questions, they were provided with information to connect with local resources.25

The team (1) conducted home visits, (2) scheduled and accompanied patients to initial primary and specialty care visits to ensure that such appointments are kept and that the patient understands any instructions given during the appointment, (3) coordinated follow-up care and medication management (medication reconciliations), (4) measured blood pressure and blood sugar levels when appropriate, (5) coached patients in disease-specific self care, (6) helped patients apply for social services (e.g. housing support, Social Security (including SSI), Supplemental Nutrition Assistance Program (SNAP), Temporary Aid for Needy Families (TANF), and General Assistance (GA)) and appropriate behavioral health programs, provides disease specific education, coaches the patient in self-care, and works to empower patients to manage their health issues. During subsequent home visits, the team evaluates the patient and team’s progress. The care team works to connect the patient with stable, continuing, and appropriate primary and specialty care. Coalition staff may help schedule further medical appointments as necessary, continue to help organize transportation, and encourage patients to follow PCP recommendations. After the visit, the patient navigator and patient created a task list based on the provider’s recommendations. For example, if the PCP ordered additional tests or specialist referrals, the navigators assisted in scheduling these additional appointments, phoned patients to remind them, identified and addressed any barriers such as transportation, and encouraged patients to follow PCP recommendations. When needed, navigators helped patients to access medical transportation assistance through the state Medicaid system. If the patient identified social needs such as precarious housing, food insecurity, or insurance questions, they were provided with information to connect with local resources.25

The most frequently used intensive management services were social work and mental health care, highlighting the importance intensive management teams placed on these services on the basis of their comprehensive assessments of patients' needs. The intensity of services varied greatly among patients assigned to the intervention group; patients who used more services tended to be older and to have more comorbid conditions, higher rates of baseline primary care utilization, and lower rates of substance use disorders and serious mental illnesses. These findings suggest that other models of intensive management may be more appropriate for patients whose mental health and substance use conditions are severe and are likely to prevent effective engagement with the intensive management team. By design, the intensive management programs seem to have facilitated referrals to home-based primary, palliative or hospice, geriatrics telephone, specialty mental health, and telehealth care. Because sites performed comprehensive assessment of patients' social issues, treatment plans, and care goals, our results suggest that the intensive management programs could identify unmet needs and connect patients to important resources. Home visits seemed to play a key role in patient assessments, because patients with more intensive services had an average of 1.5 home visits.43

• Some patients with experience in residential or other intensive management programs need support when trying to complete programs, and need housing/support once programs end

• Patients desire support when trying to return to school, find employment, or find housing: “I wish someone would help me navigate the system. I don’t know what resources or programs are available to me.”56

Successful case management also includes assisting with teaching some of these patients basic life skills, for example, not to find housing for them, but rather direct them where to go to get housing assistance.10
CMO 2.11. Because patients’ burden of coexisting chronic diseases and social and behavioral issues are heterogeneous, allowing the length of the intervention to vary across participants [C] helps patients feel supported [M] by providing them with sufficient time to demonstrate intervention goals (e.g., self-management behaviors) [O].

Relevant data extracts from included literature
Patients are continually enrolled at different times, resulting in different lengths in the post-enrollment time frame. Patient diagnoses that are driving admissions, and their burden of coexisting chronic diseases, are heterogeneous. The natural history of these common chronic diseases is such that the patients have ever evolving health conditions intermixed with periods of disease decompensation. Length of time in the intensive intervention period is variable and determined by demonstrated need and functionality: socially, medically, and behaviorally. Our intervention is not administered by number of days exposed but instead is administered until the patient demonstrates the behavior criteria we have defined (“graduates”), the patient expires, or transitions. Because the patients are graduated according to demonstration of objective self-management behaviors (Figure 2), the resultant postgraduation time frames are also variable.30

Participants’ issues often took longer to resolve than the intervention’s time line typically allowed.14

Barriers to HNHC patient change through interventions

CMO 2.12. Despite successful engagement with the intervention and relationships between members of the care team and HNHC patients [C], HNHC patients may continue to prefer seeking primary care at the hospital or ED [M]. Therefore, interventions may not be able to achieve goals such as reducing use of potentially preventable or modifiable healthcare services [O].

Relevant data extracts/summary information from included literature
One challenge for the demonstration was that a sizable minority of beneficiaries and caregivers would prefer to visit the ED [emergency department]—instead of contacting the IAH [Independence at Home] practice—if they were unsure whether symptoms required emergency care (Table III.3). Beneficiaries provided a number of reasons for preferring to go to the ED, including that they or their caregivers thought it was the best place to receive care. Even though three-quarters of beneficiaries reported that the IAH practice visited about as often as the patient wanted them to visit (Appendix C, Table C.8), some beneficiaries’ preference for the ED in uncertain situations might contribute to the demonstration’s lack of an effect on outpatient ED visits.26

Engagement with the program was high (95% of patients had at least three encounters with program staff), and patients received an intensive intervention (averaging 7.6 home visits), but two program goals related to the timing of services — a home visit within 5 days after hospital discharge and a visit to a provider’s office within 7 days after discharge — were achieved less than 30% of the time. Challenges in reaching these goals included patients’ lack of stable housing or a telephone and their behavioral health complexities and providers’ few available appointments. The difficulties that this pioneering, data-driven organization had in achieving rapid assistance for patients may portend difficulties in achieving it at scale.15

Patients randomized to PIM were more likely than patients in PACT to strongly agree that they have a VA healthcare provider whom they trust...Survey findings suggest that the program may have influenced some patients’ experiences with patient-centered care and chronic illness care, and increased the number of patients who reported having a trusted provider, but did not influence satisfaction, perceived access, or most measures of care coordination.40

Though the SUMMIT intervention was developed as a way to address high ED and hospital utilization, staff members did not mention reduced utilization as a marker of success. “We are dealing with a pretty sick population...These are patients that maybe do need to be in the hospital…. A hospitalization is not necessarily a bad outcome for a lot of these patients.” (SUMMIT Physician)9

40
CMO 2.13. Improvements in patients' experiences with their care providers through participation in HNHC patient interventions [C] gradually rebuilds patients' trust in the health care system [M] that may lead to long-term benefits in health behaviors and clinical outcomes [O]

Relevant data extracts from included literature
Furthermore, relationships are at the core of primary care, so this finding suggests that augmenting a medical home with an intensive management program may help fulfill the promise of primary care. In fact, analyses of satisfaction suggest that the program improved patients' experiences with primary care, but not with other services. Improving primary care processes could potentially have positive long term consequences, including changes in health behaviors and clinical outcomes.50
Program Theory 3: CMO configurations with supporting data for care provider engagement in interventions for HNHC patients

Gaining and maintaining support from physicians and other care providers

CMO 3.1. Strong leadership support that facilitates systemic coordination of the intervention and its components smooth the entry of care managers into practices [C] provides credibility of their services to existing practice staff [M], so care managers are more easily incorporated into primary care teams [O].

Relevant data extracts from included literature

Once MGH [Massachusetts General Physicians Organization] had generated lists of CMP [Care Management Program]-eligible beneficiaries receiving care from each physician, the CMP medical director met with each practice to introduce the program and discuss which patients were at highest risk for acute events and should receive priority for enrollment. The medical director also met with specialty practices such as the oncology, cardiology, emergency, and orthopedics departments to explain the resources available through the program, because case managers would likely interact with these providers as they facilitated patient access to these services.30

At the time of the program launch, strong integration support from MGH leadership afforded the case managers physical entry into the primary care practice settings whereby the case managers were co-located with the primary care physicians ultimately becoming a part of the beneficiaries' primary health care teams.30

CMO 3.2. Program leaders' use of tailored strategies and physician champions to explain intervention services [C] helps endorse the intervention [M] and results in physicians participating in the intervention [O].

Relevant data extracts from included literature

A second round of focus groups was conducted with physician groups to specifically discuss how the CMP could add value to their practices.

In addition to providing input about the design of the CMP, the capstone groups provided an opportunity to obtain physician buy-in to the PBCM [practice-based care management] program. Despite the fact that some physician practices already had case managers, CMP management observed that most physician practices were apprehensive about changes such as the introduction of new staff into their practice. CMP leadership used a tailored approach to discuss the project with each practice, offering positive anecdotes from the PBCM pilot project as appropriate. In addition, CMP leadership identified a physician champion for the CMP within each physician practice that had at least 25 or more CMP patients at the start if the project to further ease the transitions involved in the introduction of a case manager into the practice. During program implementation physician champions provided insight about the best way to incorporate case managers into the practice and encourage colleagues to take advantage of services available from the case managers.30

Dr. Fishbane underscored the importance of establishing effective partnerships with the partner nephrologists during [Village Health’s] Phase II and was optimistic about the efforts to secure physician champions, garner enthusiasm and support, and improve physician engagement at the first Medical Advisory Board meeting.30
CMO 3.3. Face-to-face outreach to physicians and their staff by program leaders and/or nurse care managers [C] effectively garners support of the intervention from existing care providers [O] by helping existing care providers understand the value of the intervention [M].

Relevant data extracts from included literature

Case managers assigned to each practice met with physicians at the practices to describe the program, the skills that they bring to the physician practice, and their interest in collaborating to support patients in their efforts to manage their medical conditions. Case managers collected information from providers about how they could add value to the medical practice.30

Acquiring buy-in from participating physician practices was viewed as very important. However, it was recognized early on that buy-in was needed on all levels. There was some concern among practice-based nurses, particularly at smaller practices, that there would be a duplication of effort. To obtain buy-in from the nurses, the CMP case managers spent time working with the practice-based nurses to educate them that the goal of the program was to augment and not to replicate their efforts.30

In addition to distributing marketing materials and conducting group presentations, a TST [Texas Senior Trails] nurse with utilization management and provider relations experience visited the offices of the 250 doctors in the Lubbock and Amarillo areas with the highest numbers of CMHCB [Care Management for High Cost Beneficiaries] demonstration-eligible patients. This nurse was largely successful in gaining physician support for the program, often as a result of spending time with physician office staff and administrators who conveyed information about the program to the physicians...Similarly, the TST medical director in Amarillo had so much difficulty obtaining physician support via phone calls to these individuals that he ceased conducting these outreach calls. At the time of our site visit, the TST medical director and managing director were continuing to look for ways to market the program to providers who were not supportive initially. In particular, they were developing messages that conveyed the fact that the program can serve as a resource for physicians, by providing support for patients who are hard to manage because of mental health and/or social issues.32

CMO 3.4. Using a multi-pronged approach to provide physicians with information about intervention services [C] made it more likely to reach doctors to get their support and engagement [M] in the intervention necessary for the program to succeed [O].

Relevant data extracts from included literature

The program only works well when physicians are highly engaged.30

MGH enlisted physician support to help ensure the success of its CMP in providing high-quality care to patients. Physicians were asked to conduct the following activities: encourage beneficiaries to participate in the program and enroll them in the program when possible; collaborate with case managers to review initial assessment findings and develop care plans for each patient; inform case managers about patient events and refinements to patient care plans during the demonstration period; and discuss advance directives with enrolled patients...MGH physicians received information about the CMP from a variety of sources, including the program’s medical director, the MGH electronic newsletter, and case managers assigned to each practice.30
CMO 3.5. When an intervention includes an insufficient number of patients the physicians [C], physicians do not fully engage and participate in the program [O] because they feel the intervention is not a good investment in time and resources [M].

Relevant data extracts from included literature

The staff also suggested implementing a physician referral model to gain physician buy-in and to identify sufficient numbers of patients to make a financially viable care management program. A physician referral model could increase enrollment by more than 10 times, according to one physician’s estimate, with which others agreed. Interviewed physicians and care managers felt that a physician referral model would increase the appropriateness of patients referred for care management services. It was recommended that patient-specific clinical or educational goals accompany an open physician referral model in order to ensure that participants have clearly identified goals against which to measure their progress.33

Although most physicians were supportive of the outreach efforts, they generally only had one or two patients participating in the program. The program had greatest success with offices that had approximately 30 patients participating in the program...To the extent that patients were concentrated with providers, program staff felt that the physicians were better allies and facilitated the clinical interventions.

“A couple things we’ve gotten a little bit smarter about—one is the alignment to the provider. . . One of the things I would definitely do differently is for ESRD [end-stage renal disease] patients, I would do DaVita only and see what kind of change we could drive there. Then if we had a great solution, we could think about how we could scale it. That was probably 70% of the operational hassle that didn’t actually do anything for patients but took a lot of time and energy. The same is true on the CKD [chronic kidney disease] side with the nephrologists.”43

Although the nephrologists were very engaged initially, the program had less of a renal focus than anticipated given that the beneficiary population did not have the extent of CKD that was originally projected. As a result, the program did not maintain as high visibility among physicians during Phase I as the KTBH [Village Health’s Key to Better Health] program leadership would have liked.

During the first site visit, physicians at both sites reported that they were initially very enthusiastic about the Health Buddy® program, because it offered a promising way to effectively support patients with chronic disease. The Health Buddy® technology coupled with telephonic care management support was viewed as an effective way to maintain and improve patient health and identify symptoms of complications early, so that timely medical intervention could be used to prevent serious problems requiring hospitalization. Once the physicians received the list of patients who were eligible for the Health Buddy® program, they reported that they became frustrated with the project because they felt that many of the patients selected would not benefit from participating. Further, physicians reported disappointment that many of the patients they believed could be helped by the program were not eligible to participate in the program because they had not been identified through the claims based algorithm developed by HHN [Health Hero Network]…Using information gleaned from its early experience with the program, the HBC [Health Buddy Consortium] made a series of changes and enhancements to its operations and as reported to us at our second site visit.43
CMO 3.6. Developing and implementing a financially supportive system or model for physicians and their practice [C] encourages and motivates physicians and other care providers [M] to spend time with their patients and to continue supporting innovative intervention activities [O].

Relevant data extracts from included literature

The Care One program provides incentives to primary care providers by valuing a Care One patient as equal to 5 normal primary care patients when adjusting panel size.\(^\text{22}\)

MGH provided physicians with a $150 financial incentive per patient in Year 1 and $50 in Years 2 and 3 to help cover the cost of physician time for these activities.\(^\text{30}\)

Thus, for such team care to be sustainable, time needs to be carved out for the work involved and systems need to support the follow through.\(^\text{1}\)

The staff also suggested implementing a physician referral model to gain physician buy-in and to identify sufficient numbers of patients to make a financially viable care management program. A physician referral model could increase enrollment by more than 10 times, according to one physician’s estimate, with which others agreed.\(^\text{33}\)

Physician: ‘When your hospital is basically saying... ‘Here is 15 minutes for a repeat visit for another patient’, I mean how are you gonna be able to actually provide the kind of care they need?’\(^\text{12}\)

Recent changes in the Medicare Advantage program (nearly all of ChenMed’s patients are enrolled in Medicare Advantage) have created a favorable environment for delivery system innovation. In particular, the 2004 introduction of the Hierarchal Condition Categories risk adjustment model created a mechanism that reduced the financial risk of taking care of high cost patients with multiple chronic conditions. Patients with multiple chronic conditions have higher risk scores and, accordingly, higher reimbursement. Although not perfect, risk adjustment has alleviated participating payers’ and providers’ concerns about attracting sicker and costly patients without receiving commensurate reimbursement.\(^\text{41}\)

In addition, Medicare Advantage’s capitation model is more favorable to delivery system innovation than traditional fee-for-service Medicare because it eliminates the process of negotiating reimbursement for cost-reducing delivery system innovations. Because providers are paid according to the size of their patient panel in a capitated system, they have an incentive to develop and test innovations to determine which ones lower the cost of care without compromising quality—and, ideally, increase it. For those innovations judged to be cost reducing without compromising quality, providers in a capitated system have the flexibility to deploy the innovations across their network. Providers in the fee-for-service system do not have such flexibility because they must negotiate with payers for the reimbursement of care delivery innovations—a step that can delay or even block such efforts.\(^\text{41}\)

Administrative pressures in health care delivery systems. Physicians and health system leaders felt existing payment structures and administrative pressures (such as the impetus to maximize the number of patients seen while minimizing visit time) negatively impacted the way they could interact with patients. Many agreed that when such a limited time frame is allotted for each patient, it barely gives providers time to think, resulting in the delivery of ‘bad care’. This also affected the way physicians communicate with their patients in key situations including discussions of illness, treatment options and care plans. Finally, stakeholders felt that the current care delivery model significantly dis-incentivized physicians from going into primary care, leading to a primary care physician shortage. The underlying sentiment was that if there are fewer primary care doctors overall, then HNHC patients will be at a greater disadvantage to have continuity of care at a primary care site, their diseases will not be well-controlled, leading to more ED visits and inpatient admissions.\(^\text{12}\)
Staffing arrangements in care management interventions

CMO 3.7. Reducing providers’ workload and responsibilities associated with the implementation of complex intervention activities [C] will reduce provider stress [M] so providers are more satisfied [O1] and more willing and able to engage with their patients and in participate intervention activities [O2] such as attending care team meetings, and carrying out care plans.

Relevant data extracts from included literature

At baseline, members were divided in the anticipated effect of team care on their workload and stress levels. At 3 months, one member noted a decrease in workload, and three perceived an increase. Two indicated that the intervention “increased my stress by adding to my many responsibilities.” Getting to Care Team meetings on time was difficult for about half of the team members.¹

Some team members felt their work increased by participating in the team.¹

Early on, we determined that certain tasks the HC RNs [Health Coach Registered Nurses] and LCSWs [Licensed Clinical Social Workers] were performing could be offloaded as these did not require their level of licensure, training, and skill. By doing so, we could free up the HC RNs and LCSWs to serve more patients and increase their job satisfaction.³⁸

Respondents from both independent and system-owned practices described turnover that occurred because care managers felt overwhelmed with numerous responsibilities.³⁵

Patient And Physician Time We also emphasize physician and patient time. Our primary care physicians, all internists, have a panel of 350–450 patients. By comparison, physicians at many commercial “concierge” practices, where patients pay sizable out-of-pocket retainers for the additional physician time, have larger panels. Small panel sizes allow our physicians to spend more time with their patients. Our physicians average fewer than eighteen visits a day; in contrast, primary care physicians average nearly thirty.⁴¹

Physician: ‘Need more primary care physicians who can manage outpatient things… And so you end up not being able to fill the need, and then we see them in the emergency department.’¹²
CMO 3.8. Case managers, social workers, and high functioning administrative assistants in turn take on many time-consuming tasks (e.g., medication management, identifying community services, outreach, engagement) to help engage and manage HNHC patients and their paperwork [C] so that providers can focus their efforts [M] on providing continuous, comprehensive care to patients [O].

Relevant data extracts from included literature

Early on, we determined that certain tasks the HC RNs and LCSWs were performing could be offloaded as these did not require their level of licensure, training, and skill. To address this, we worked with the teams to identify tasks that could be done by high functioning Administrative Assistants (AAs) and we now use AAs for tasks such as maintaining telephone contact with patients to remind them of appointments, check up on them when they have not been heard from, and assist the team members in entering and retrieving data related to the patients they serve. This is effective as long as there are intermittent face to face opportunities for the patients with the HC RNs, LCSWs, and CCLs [Client-Community Liaison].

...Case managers take care of things like preauthorization, gathering documentation, medication tracking and other time-consuming issues, allowing PCPs [primary care providers] to focus on the relationship with patients and provide real continuity of care. ...The program does what every PCP needs to be doing but cannot do anymore because of the medicine practice and reimbursement realities and primary care provider shortages. ...Both patients and physicians love the program as case managers take a lot of burden off both sides. ...Key value of the program is in the help they provide PCPs with medication review and management, the most difficult to resolve issue when PCPs do not have any help,...” [Summary from a focus group of multiple physicians]

The care manager served primarily as an adjunct to the patients' primary physicians.

As in 2015, deep-dive practice respondents described approaches to improving support for care managers, to clarify their roles and enhance staffing resources to help them feel less overwhelmed. A few practices were monitoring care managers' caseloads to determine whether they needed more staff to support high-risk patients, or to reduce (or even eliminate) activities focused on lower-risk patients. These practices brought in social workers to help meet patients' social needs and medical assistants to assume logistical or administrative tasks.

Navigators shared information about individual patients utilizing a team-based navigation model that provided flexibility in dividing the workload and providing cross coverage.

The program was staffed by a multidisciplinary care team consisting of a community health worker (CHW), a social worker (SW), and a PCP [primary care provider]. With guidance and support from the SW and the PCP, the CHW was responsible for patient outreach, engagement, activation, and accompaniment. The SW was responsible for counseling and brief interventions for patients with behavioral health needs and for coordinating referrals to social service agencies and other medical providers. The PCP was responsible for providing comprehensive care for acute and chronic conditions and for coordinating with specialists and inpatient providers.

The CHW was able to identify unmet social needs contributing to acute care utilization that may not be apparent to busy clinicians and are not readily addressed during a single ED or clinic visit. For example, one patient with chronic restrictive lung disease who was dependent on home oxygen experienced financial insecurity and anxiety related to his inability to make on-time utility payments. The CHW was able to enroll him in a financial assistance program to prevent utility shutoffs, provide a list of local food pantries, and accompany him to primary care appointments where he was connected with the pulmonology clinic social worker who assisted with ongoing needs.

CMO 3.9. Providing training for staff members [C] gives them the confidence and skills [M] to function effectively as a care team [O1] and to understand and work with HNHC patients [O2].

Relevant data extracts from included literature

"...The program has done a remarkable job in training and cultivating case managers who are very good at breaking barriers and making it work for the most difficult patients;...” [Summary from a focus group of multiple physicians]

...our team members received minimal training in ways to decrease frequent attendance and did not follow a systematic approach in assessing the patient. A more systematic approach, however, would have improved the function of our team.

Both navigators completed training at the Harold Freeman Institute for Patient Navigation, a 2-day intensive training program that teaches navigators to identify and eliminate barriers to care and serve as a support hub for patients moving through the health care system. The PN also completed local training at Gateway Community College, which emphasized needs and resources within the local community.
CMO 3.10. When care managers have regular opportunities to talk across offices and health care systems [C], they are more emotionally and technically prepared [M] to work with HNHC patients [O].

Relevant data extracts from included literature
As in 2015, deep-dive practice respondents described approaches to improving support for care managers, to clarify their roles and enhance staffing resources to help them feel less overwhelmed. In some practices affiliated with health systems, respondents described providing opportunities for care managers embedded in practices across the health system to meet regularly, share best practices, and offer one another support.10

CMO leadership also emphasized team support and peer counseling by developing infrastructure that provided opportunities for mutual support among CMP case managers and peer counseling from the members of the mental health team as the emotional toll on staff working with a highly frail and sick population are substantial.30

CMO 3.11. Having small care teams [C] helps teams members develop awareness of each HNHC patient's entire complex care [M] which can improve the coordination of patient care [O].

Relevant data extracts from included literature
In addition, the ability for a team to be small and nimble was seen as a strength as it allowed for increased cohesion. "One of the issues with complex care is [it's] spread out amongst a bunch of different people…. There's a learning curve each time the patient meets with a different provider…. With SUMMIT [Streamlined Unified Meaningfully Managed Interdisciplinary Team], it's a small team…. Everybody knows what's going on with the patients in terms of their conditions and it really cuts through the confusion." (Usual Care LCSW)8

Communication across the care team

CMO 3.12. Leadership-supported, regular communication across all staff [C] builds collaborative feelings among teams [M] that results in job satisfaction for care team members [O], and facilitates implementation success [O].

Relevant data extracts from included literature
Team communication was important for program implementation, although sites had different levels of success in this area over time. Care teams with a solid supervisory structure and frequent collaboration across all levels of staff experienced greater implementation success and staff satisfaction.14

Due to the complexity of the CMP demonstration population, CMP leadership felt that constant and good communication between all staff within the program was essential.30

CMO 3.13. Having transparent and supportive communication among care team members [C] fosters shared values and commitment [M] that results in stronger, more cohesive care team [O].

Relevant data extracts from included literature
Team members caring for HNHC patients noted the importance of shared values and commitment, citing mutual respect for other disciplines and appreciation of the need for teamwork. "We respect one another’s clinical view…. We come at this from different backgrounds and feel like we get more out of our patient care experience if we hear what everyone else has to say…. We have a very supportive and inclusive team environment" (SUMMIT Physician) The importance of the team comes through particularly when patients aren't faring as well as hoped: "They [other team members] really listen and they really care and we all really feel it when someone does fail…or something bad happens. It's a very empathetic group of people...." (SUMMIT Nurse)8

Our finding that staff members value a sense of unity and esprit de corps speaks to the value of cohesive multidisciplinary teams doing this work. As prior studies have shown, individual members of multidisciplinary teams may have different conceptualizations of which disciplines are part of a care team—often these are only a team in name.8
CMO 3.14. Regular, multidisciplinary care team meetings that include physicians and staff [C] gave care team members the openness [M] to discuss patient cases [O1] and the practices' performance on quality metrics, outcomes, and other performance goals [O2].

Relevant data extracts from included literature

Our CHAs [Community Health Advocates] provide perspectives in huddles that often enlighten licensed staff and offer a better understanding for the team regarding the unique needs of the patients we serve.38

VPA [Visiting Physicians Association] corporate medical directors conducted weekly company-wide, web-based meetings with all clinicians, and regional managers conducted individual meetings with IAH practices, to review clinicians’ performance on IAH [Independence at Home] quality metrics and outcomes and consider broader implications for all of their patients.26

Common themes and issues from the Virtual Rounds were also presented at bimonthly management meetings. The bi-monthly management meetings were used to review protocols, present resources, provide training, and identify issues and brainstorm solutions.30

In addition to tracking metrics, most practices reported conducting care team meetings. Care team meetings provided a forum for clinical teams and staff to review quality metrics and progress toward performance goals, discuss an individual beneficiary’s case, and receive information on clinical topics.26

We have designed processes and structures that promote a physician culture of collaboration, transparency, and accountability for high-quality care. For example, our primary care physicians meet three times a week to review hospitalized patients and discuss complex cases practice approaches. Specialists and hospitalists join these meetings as well. We use these sessions to conduct traditional morbidity and mortality review as well as to review each hospitalization and ask, “Could this hospitalization have been prevented?” Physicians are prepared to discuss each hospitalized case and explain to their peers the circumstances involved and their clinical thinking.41

The team met weekly throughout the course of the intervention. One- or two-page patient summaries were prepared by the navigators, including a detailed, written summary of the patient’s medical history, prior ED use, barriers to accessing primary care services, life stressors that could be impacting their health, and type of help the patient wished to receive from the program. Each new patient was discussed by the team after the initial enrollment and on an as-needed basis (e.g., emergence of a new or challenging need or a repeat ED visit). The team discussed ways to support the patient’s clinical and social needs, brainstormed specific resources that might be helpful for the patient, and provided guidance to the patient navigators (24).26

We held multidisciplinary team meetings weekly to develop care plans to support patients’ clinical and social needs.25

CMO 3.15. Having regular care team meetings to discuss HNHC patients [C] may increase provider workloads [M] causing providers’ to be arrive late for meetings [O1] and to not carry out care plans [O2].

Relevant data extracts from included literature

The primary barriers to conducting regular Care Team meetings were the lack of time to meet and carry out the Care Plan and the difficulty of involving the patient...The team met for 40 min on a weekly basis to discuss one or two of the cases. The physicians were the most likely to arrive late and as noted by the chart review, were at times unable to follow through on the Care Plans.1
CMO 3.16. When providers are given practical, constructive feedback about patient care approaches [C], providers are provided with the clinical knowledge or resources they need [M] to improve the care they provide to their patients [O].

Relevant data extracts from included literature

"[Care team meetings] give us an opportunity to look back upon our encounter with the patient and really be able to gauge, 'Was there a reason why the hospitalization happened, could it have been prevented, is there something that I missed?' … It can be a little bit unnerving … but it [has] actually … strengthened my practice quite a bit. Because you learn a lot from that feedback." 26

Clinicians valued receiving performance feedback and appreciated the opportunity to discuss cases with other clinicians and share ideas to improve care. 26

The CMP leadership implemented Virtual Rounds, regular e-mail reports that went to all staff, as a mechanism of providing feedback on a weekly basis. Case managers used Virtual Rounds to report on difficult patients and unnecessary admissions, and to describe both positive and negative events. Virtual Rounds were also used for case reviews with forms that staff filled out at the end of the week. These case reviews were then discussed with physicians in weekly face-to-face meetings. 30

Physicians in our study acknowledged their frustration in caring for frequent attenders, but also received specific, practical suggestions for changing their approach to care. 1

Peer consultation provides much needed perspective, more objective assessment and support for the difficulties of the case. 1

CMO 3.17. Having patients who received care from providers in other healthcare systems or locations [C] creates challenges for care teams [M] to be able to effectively and efficiently communicate with the patient’s providers [O].

Relevant data extracts from included literature

TST staff reported that most participants had a primary provider that was associated with TTUHSC [Texas Tech University Health Sciences Center]; however, many patients, particularly in Amarillo, received care from additional providers that were not associated with the university. These providers typically operated independent practices, so TST care managers had to establish relationships with a number of different practices. 32

The second proposed improvement had to do with excluding beneficiaries from practices outside the care management organizations, if a systematic means of communicating with clinicians from these practices is not established. 31

Further, not all intervention beneficiaries had primary care physicians in the two study sites, therefore the care managers had to interact with community-based providers with whom they had little or no prior relationship. During our site visits, the care managers cited several challenges working with these physicians, in particular, because of communication barriers. 33
CMO 3.18. Providing opportunities for face-to-face conversations among care team members (e.g., being co-located, creating spaces that allow for provider conversations) [C] helps build strong working relationships [M] that improve team communication in support of coordination of patient care [O].

Relevant data extracts from included literature

Our findings speak to the importance of co-located, embedded teams that “hear what everyone else has to say.”

The Health Buddy® nurse care managers often were not in direct proximity to their beneficiaries’ primary care physicians, thereby potentially affecting their interactions with the beneficiaries’ primary providers, changing medical care plans, or mitigating deterioration in health status...Interviewed physicians felt that care management would be more effective and efficient if care managers were colocated with primary care physicians.33

Later, they returned patient care coordinators to local practice sites after clinicians and patients expressed dissatisfaction with the centralized system. According to one respondent, locating at the practice enables patient care coordinators to have more in-person contact with clinicians and to build relationships with patients. This change promoted strong working relationships among teams of clinicians, medical assistants, and care coordinators. Those strong working relationships help to address patients’ needs and avoid unnecessary readmissions and hospital and ED (emergency department) visits. Another practice changed where the physicians and other staff on the care team sat in the office. This practice clustered the care team together so they could discuss patients’ concerns and care delivery more easily.26

We have also designed our centers to promote physician collaboration and conversation. They look more like an inpatient setting or intensive care unit than a traditional physician office. There is a large nurses’ station in the middle of the center where specialists do their paperwork, which is a sufficient distance from the patient exam rooms to allow for spontaneous discussions between specialists and primary care physicians after the specialist has seen the patient. In addition, there is a cluster of four to six individual primary care physician workstations away from direct patient view, where private conversations among physicians can readily happen. In the vast majority of cases, a specialist is able to have a brief face-to-face conversation with the patient’s primary care physician after she or he sees the patient. The face-to-face conversation allows for more rapid alignment between primary care physician and specialist than the traditional faxed consult and voice mail.41


Relevant data extracts from included literature

One improvement proposed was featuring a care management structure that pairs care managers and participants’ primary care physicians in the same physical location.33

CPC (Comprehensive Primary Care) practices greatly increased their use of dedicated care managers who were members of the primary care practice team over time. The number of practice survey respondents from CPC practices who reported that “care managers who were members of the practice team systematically provided care management services to high-risk patients” increased from 20 percent in 2012 to 88 percent in 2014 and 2015, and 89 percent in 2016. In comparison, fewer than half of comparison practices reported in 2016 that care managers who were practice care team members systematically provided these services to high-risk patients.35

Most physicians supported the general concept and potential benefits of the program but also expressed frustration with several aspects of the current demonstration design...care managers were not embedded in their physical practice locations.33

At the time of the program launch, strong integration support from MGH leadership afforded the care managers physical entry into the primary care practice settings whereby the case managers were co-located with the primary care physicians ultimately becoming a part of the beneficiaries’ primary health care teams.30
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