

# Identifying and Coordinating Care for Complex Patients

Findings from the Leading Edge of Analytics and  
Health Information Technology

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## Preface

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Complex patients—defined as having multiple comorbidities, high risk for poor outcomes, and high cost—incur most of the health care costs in the United States and yet their care is poorly coordinated, with few interventions having been shown to be effective in addressing their needs and reducing costs. This report summarizes findings from a literature review and a qualitative analysis of expert discussions that explore how advances in analytics and health information technology (HIT) are being used identify complex patients and coordinate their care. We synthesize findings to describe the state of the art of these technologies and summarize emerging evidence and best practices. We also describe the various types of data, analytics, and care coordination functionalities; identify key barriers to progress; and propose solutions to address the barriers.

This report should be of interest to policymakers, including those in both federal agencies and nongovernmental entities involved in improving care for complex patients or promoting the use of HIT, as well as to public and private purchasers, clinicians, and analytics and HIT companies.

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# Summary

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## Background

In the United States, a relatively small proportion of complex patients—defined as having multiple comorbidities, high risk for poor outcomes, and high cost—incur most of the nation’s health care costs. For these patients especially, fragmentation and poor coordination of care across settings and providers can lead to unnecessary spending on redundant laboratory testing, repeated imaging, and avoidable emergency department (ED) visits and hospitalizations. Improved care coordination and management of complex patients could reduce costs while increasing quality of care. However, care coordination efforts face multiple challenges, such as segmenting populations of complex patients to better match their needs with the design of specific interventions, understanding how to reduce spending, and integrating care coordination programs into providers’ care delivery processes.

Innovative uses of analytics and health information technology (HIT) may address these challenges. Analytics are predictive algorithms that use various types of data and may help create better risk stratification approaches that more effectively target patients for interventions. HIT includes tools that may facilitate communication and improve timely decisionmaking, particularly because patients with complex needs tend to have large care teams and generate substantial volumes of data during their care. As new payment models spread, there is increasing interest in predicting and managing care and its costs, for complex patients in particular.

This project reviewed the literature and held discussions with subject matter experts (SMEs) to understand how analytics and HIT are being used to identify and support the coordination of care for complex patients. Our goal was to summarize emerging evidence and best practices that can inform the development and dissemination of more-effective analytics, HIT functionalities, and care models to meet the needs of complex patients.

## Methods

To better understand the state of knowledge and to inform the SME discussions, we conducted a targeted literature review with the goal of identifying analytics projects that use data and algorithms to find complex patients as part of an intervention and HIT functionalities designed to facilitate care coordination and communication among providers caring for the same patient. We developed a conceptual framework to guide this search: We searched multiple research databases, including PubMed, Web of Science, and SCOPUS, and limited the search to articles published from 2008 to the present. In total, 122 articles were selected for abstraction. One reviewer captured information from the articles using a literature abstraction form based on our conceptual framework, and the research team reviewed that information.

We identified SMEs through the literature review, recommendations from colleagues, and snowball sampling. From this initial list, we selected 35 SMEs to represent a wide range of stakeholder perspectives from the private sector, academic institutions, and federal agencies. We conducted in-depth discussions ranging from 30 to 60 minutes using a discussion guide that identified key topics to be covered. Midway through conducting these discussions (in January 2015), we convened a technical expert panel to discuss the results of the SME discussions to date and of the literature review. Based on feedback from the panel, we further refined our plans for the next phase of SME discussions.

Based on the SME discussions, we identified key themes, including technology goals and barriers and opportunities for progress, and formulated recommendations for how to advance analytic and care coordination functionalities further to better meet the needs of complex patients and their care teams.

## Results

Because our review of the peer-reviewed literature used restrictive criteria, we found few papers that addressed analytics and HIT functionalities for complex patients, a result consistent with a previous review on complex patients.

Based on discussions with SMEs, we characterized the purpose of the analytics focused on complex patients into three distinct goals: (1) identify complex patients; (2) identify the subset of complex patients who could be helped by an intervention; and (3) match the subgroups of complex patients to specific interventions. We also identified an additional crosscutting goal to improve the ability to predict the onset of complexity earlier in time so the health care system can intervene preemptively in disease progression.

We found that most efforts sought to address the first goal and (to some extent) the crosscutting goal, while few attempted to address the second and third goals. While SMEs suggested that a growing number of organizations are prioritizing and investing in analytics to identify complex patients, models have limited effectiveness and lack evidence of impact.

SMEs described numerous barriers to progress in analytics, with the foremost among them being those related to data—particularly poor data quality and lack of data related to social determinants of health. SMEs also cited lack of experience using analytics as a challenge for both providers and care coordinators. A third barrier related to financial incentives: While reimbursements are shifting slowly and beginning to reward providers and organizations that identify and treat complex patients, even emerging payment models might not create the right incentives to prioritize devoting resources to the sickest patients, because the return on investment is unclear.

We identified five key HIT functionalities in current use or being piloted for care coordination: dashboards, patient relationship managers, event alerts, referral tracking, and care plans. *Dashboards* support ad hoc searches and prompt discussions among care team members.

*Patient relationship managers* allow care coordinators to manually track interactions with the patient and manage the patient's to-do list. *Event alerts* are triggered by the ED visit, hospitalization, or other events and sent to members of a care team. *Referral tracking* helps to ensure referrals happen and that the summary reports are returned to the referring provider. SMEs suggested that the development and use of referral-tracking functionality was increasing and that the referral-tracking requirement for patient-centered medical homes could be driving the development of this functionality.

Functionalities for *care plans*—which are designed to communicate instructions for a patient's care—varied widely. Some care plans offered task-tracking capabilities and various kinds of communication, such as one that allowed ad hoc communication similar to social media. We did not identify consistent definitions of care plan contents, which ranged from static text describing physician instructions to highly structured content accessed by multiple users based on a set of discretely coded problems. Most care plan functionality targeted care coordinators as the primary users; few efforts engaged physicians as users. Such responsibilities as updating the care plan varied from giving the care coordinator exclusive control to allowing for broader permission that included others on the care team, including patients.

Barriers to further developing care coordination functionality, especially care plans, were substantial and included: unclear definitions of what it means to be a member of a care team; lack of concepts, frameworks, or understanding of what activities are involved in care coordination and should be best facilitated using HIT; and lack of interoperability between care coordination products and electronic health records. SMEs also discussed the challenge of establishing a sustainable business model for developing and using these functionalities, because the move toward accountable care is proceeding slowly.

## Conclusions

We summarize challenges that must be addressed for the success of future work in both analytics to identify complex patients and HIT functionalities to coordinate care. For analytic models to be useful, issues of poor data quality and lack of use of novel data types must be addressed. Making better use of model outputs by integrating predictive model output into clinical workflows is also needed. For work on HIT functionalities for care coordination, existing functionality that supports care plans and communication among care teams has important limitations, and interoperability between care coordination systems and other HIT software is lacking. Also, the lack of evaluative studies suggests that best practices for using any of these functionalities are unknown.

Based on the findings from this work, we propose research options to consider when addressing these challenges as part of a five-part framework: (1) understand the problem and barriers to progress; (2) develop technology and related process and workflow changes; (3) evaluate and generate evidence of impact; (4) implement and disseminate technology and related



process and workflow changes; and (5) create incentives that promote the use of technology and related process and workflow changes. In the near term, there is a need for more knowledge about best practices and the need for a convener to bring together and align key stakeholders to accelerate innovation. Longer-term efforts will need to focus on training providers and integrating these technical advances into clinical practice.

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## Abbreviations

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ACOs	accountable care organizations
ADT	admit, discharge, and transfer
APIs	application programmer interfaces
ASPE	Assistant Secretary for Planning and Evaluation
CMS	Centers for Medicare and Medicaid Services
ED	emergency department
EHR	electronic health record
HIE	health information exchange
HIPAA	Health Insurance Portability and Accountability Act
HIT	health information technology
ICD-9	International Classification of Diseases version 9
PCMH	patient-centered medical home
SMEs	subject matter experts
TEP	technical expert panel
VA	Department of Veterans Affairs

# 1. Introduction

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## Background

In the United States, a relatively small proportion of complex patients—defined as those patients having multiple comorbidities, high risk for poor outcomes, and high cost—incur most of the nation’s health care costs.<sup>1</sup> For these patients especially, fragmentation and poor coordination of care across settings and providers can lead to unnecessary spending on redundant laboratory testing, repeated imaging, and avoidable emergency department (ED) visits and hospitalizations.<sup>2</sup> Examples of care coordination failures include the lack of needed clinical information at the point of care,<sup>3</sup> failure to notify members of a care team when a patient is hospitalized,<sup>4</sup> and poor communication between primary and specialty care.<sup>5,6</sup>

Improved care coordination of complex patients could reduce costs while increasing quality of care. However, care coordination efforts face multiple challenges. First, it will be challenging to define complex patients in a way that enables the design of specific interventions: A recent study of chronic conditions among approximately 32 million Medicare beneficiaries found more than 2 million unique combinations of conditions, reflecting a very “long tail” that changes nationally over time.<sup>7-9</sup> This distribution suggests that developing interventions tailored to each combination of disease is infeasible.

Second, it is difficult to understand how to reduce spending through care coordination. According to an analysis released by the Congressional Budget Office in 2012, 34 demonstrations that included many care coordination programs funded by the Centers for Medicare and Medicaid Services (CMS) implemented from 2000 to 2006 did not reduce spending on average.<sup>10</sup> In the few demonstration programs that have reduced hospitalizations, net costs still were not decreased after accounting for the amounts spent on interventions,<sup>11</sup> or they decreased by less than 10 percent.<sup>12</sup> Savings from reduced hospitalizations may be offset by the cost of coordinating the care of the patients.<sup>10</sup>

Third, care coordination programs frequently are not well integrated into providers’ care delivery processes and can create additional redundancies if designed badly—especially if care coordinators from hospitals, insurers, and clinics are tasked with coordinating a patient’s care after discharge.

To address these challenges, analytics and health information technology (HIT) may be helpful. Analytics are predictive algorithms that could be used with various types of data to help identify patients who can benefit most from care coordination interventions and match them to interventions. HIT functionalities are tools, such as care-planning modules of electronic health records (EHRs), that could improve care coordination by facilitating communication among

members of a care team. Together, analytics and HIT functionalities may facilitate improved care coordination and decreased costs for complex patients.

To be effective, these technologies may need to: (1) allow the timely, interoperable exchange of high-quality patient data; (2) implement analytic algorithms that can identify complex patients—and patients at risk for becoming complex—and match them to appropriate and cost-effective care coordination interventions; (3) facilitate efficient and effective communication among the patient and his/her providers; and (4) facilitate monitoring of data that shows effective care coordination interventions so such interventions can be improved systematically.

While technology ultimately may prove to facilitate effective interventions for complex patients, its impact will be moderated by many other health system factors, including financial incentives, organizational strategies and culture, and the preferences and habits of individual users. To succeed, the technology must be designed with these other factors in mind.

Demonstration programs that attempt to identify complex patients and coordinate and manage their care have proliferated because of federal programs and changes in payment policy, such as CMS Innovation Grants, accountable care organizations (ACOs), and the patient-centered medical home (PCMH). As new payment models spread, there is increasing interest in predicting and managing care and its costs, particularly for complex patients. However, lessons from such programs are only beginning to be gathered and synthesized. Many organizations are using suboptimal methods of providing care coordination and are learning (as others did before them) that care coordination programs are not inevitably effective. Without systematic learning, the development and dissemination of effective models of care for complex patients will be slow.

## Objectives and Approach

This project reviewed the literature and held discussions with subject matter experts (SMEs) to understand how analytics and HIT are being used to identify and support the coordination of care for complex patients, identify key barriers to progress, and determine what is needed to overcome the barriers. We summarized emerging evidence and best practices that can inform the development and dissemination of more-effective analytics, HIT functionalities, and care models to meet the needs of complex patients.

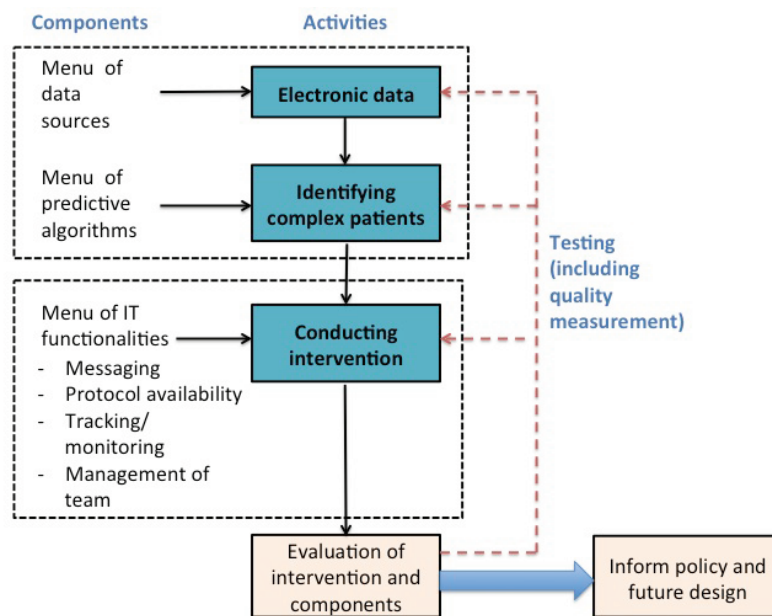
### *Literature Review*

To better understand the state of knowledge and to inform the SME discussions, we conducted a targeted literature review to identify both analytics projects used as part of an intervention and HIT functionalities designed to facilitate care coordination and communication among providers caring for the same patient. To inform the literature search, we developed a conceptual framework that characterized our key areas of interest (Figure 1.1). We searched multiple research databases including PubMed, Web of Science, and SCOPUS. Given the

project’s emphasis on the current state of technology for care coordination, we limited the search to articles published in 2008 or later. The full search terms we used can be found in Appendix A.

Only human-based topics and articles written in English and based in the United States were considered for review, because U.S. health care is a unique environment and innovations here do not necessarily succeed elsewhere and vice versa. We also only included articles related to complex patients, defined as having multiple comorbidities, high risk, and high cost. We excluded articles on analytics that applied only to a single disease or morbidity (e.g., an analytic algorithm that only identified patients with diabetes). Articles that described the development of an analytic method and its validity were excluded if the method was not also used as part of an intervention that affected the care of complex patients. For example, a study on a pediatric medical complexity algorithm<sup>13</sup> would qualify as analytics to identify complex patients, but was excluded from our review because it was not applied as part of an intervention for real patients. For HIT functionalities, we included articles that described the development or application of functionalities that facilitated coordination of care among multiple providers, including care coordinators for complex patients. (Various articles referred to “case managers,” “care managers,” and “care coordinators” interchangeably to describe individuals who actively help complex patients coordinate care with multiple providers. We use the term “care coordinator” throughout for consistency.) Functionalities that were limited to facilitating interactions between patients and providers (e.g., patient portals or home monitoring tools) were excluded, unless they also involved interactions among multiple providers.

**Figure 1.1. Conceptual Framework**



A total of 1,779 articles were identified from the search. Overall, 1,657 of the 1,779 articles were deemed irrelevant and removed. Thus, in total, 122 articles were selected for abstraction. Information from the articles was captured using a literature abstraction form that was based on the conceptual framework (Figure 1.1). One coder performed the initial round of screening and coding, and the others on the research team reviewed the results and selected articles by consensus.

### *SME Discussions and Technical Expert Panel*

SMEs were selected to represent a wide range of stakeholder perspectives from the private sector, academic institutions, and federal agencies. We identified an initial list of SMEs from seminal publications in the field, coupled with professional contacts of the research team. We then used snowball sampling to identify additional expertise and ensure that a broad array of experiences and expertise were represented.

To help focus our study initially, we conducted in-depth discussions, ranging from 30 to 60 minutes, with an initial group of 13 SMEs. We used a discussion guide that identified key topics to be covered (as appropriate to the informant) and a set of probes that could be used as appropriate. The research team recorded all SME discussions, and a team member took notes.

A technical expert panel (TEP) was convened to discuss the results of the 13 SME discussions and the results of the literature review in January 2015. Panelists were selected based on their reputations as leaders in the field. They were selected with the intention of representing academic institutions, federal agencies (e.g., Office of the National Coordinator for Health Information Technology, Center for Medicare and Medicaid Innovation), and health care delivery organizations. Nine panelists were in attendance, along with project team members and representatives from the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services. As a result of the feedback we received from the panel, we further refined our plans for the second phase of SME discussions by focusing on several areas of the field. Using the same approach described for the first phase of SME discussions, we recruited an additional 22 SMEs for discussions.

In total, we held discussions with 35 SMEs between November 21, 2014, and June 30, 2015, representing providers, payers, employers, federal funders, academics, and the private sector.

Based on the SME discussions, we identified key themes, including goals of the technology and barriers and opportunities to progress. We also formulated recommendations for how to further advance analytic and care coordination IT solutions to better meet the needs of complex patients and their care teams. These findings were presented to the TEP, which was convened for a second time in July 2015. Six panelists were in attendance, along with project team members and representatives from ASPE. We incorporated their feedback into the results.

## Study Limitations

This work had several limitations. First, the literature review was deliberately constrained given the scope of the project, and may have omitted some initiatives. However, our findings were fairly consistent with a Department of Veterans Affairs (VA) report with broader inclusion criteria that identified only nine studies of care coordination programs<sup>24</sup> and with a recent national assessment of care coordination functionalities.<sup>25</sup> Our TEP and discussions with SMEs decreases the likelihood that we would miss landmark or seminal projects. Second, we limited both the literature review and SME discussions to the United States. It is possible that we would have uncovered other innovations had we expanded to other countries, but this was beyond the scope of this project. However, it may be fruitful to explore international efforts in future work that would further bolster our understanding of this field. Third, to balance depth of content and breadth of inclusion, our sample of SMEs was limited. A larger sample of SMEs from diverse stakeholders may have identified additional innovative efforts. Fourth, as our focus was on care coordination, we did not include other types of health delivery interventions to which analytics may help match patients, such as home monitoring or behavioral change programs. However, our findings related to analytics apply to these other types of interventions. Fifth, given the time constraints, we chose not to use a formal qualitative research methodology that included the coding of themes with the use of specialized analytic software. Biased interpretations of the data were mitigated by requiring a minimum of two project team members to be present for each discussion and by following up with email when areas needed clarification. Finally, our findings are representative of the efforts that we could identify at the time of the project; given the nature of this topic, innovations occur continuously and rapidly.

## Organization of This Report

Section 2 presents the results of the literature review and of the discussions with SMEs, while the last section provides some conclusions—including challenges and solutions—and implications from the study. The Appendix lists search terms used for the literature review and example interventions identified by literature review and/or SME discussions.





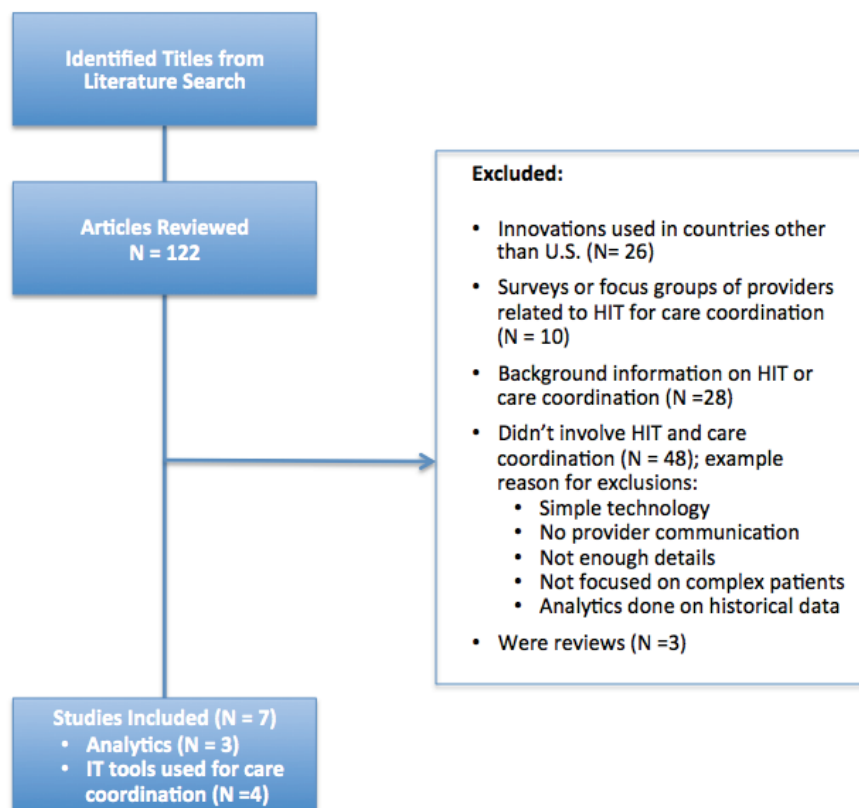
## 2. Results

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### Literature Review Results

As noted in Section 1, searching on innovative uses of analytics and HIT for care coordination of complex patients (Figure 2.1) produced 122 articles for full text screening. Of those 122, 26 were excluded because they described innovations used in countries other than the United States, ten were excluded because they reported on surveys or focus groups of providers only, and 28 were excluded because they provided background information. Of the remaining articles, 48 did not involve our relatively narrowly defined topic of interest. These articles fell into several large categories: Some reported on simple technology, such as text messages to patients;<sup>14</sup> others did not involve provider-to-provider communication;<sup>15</sup> and many described general care coordination interventions that were not focused on complex patients.<sup>16</sup> Once these were removed, ten articles remained: Three were relevant reviews, three focused on analytics, and four described HIT functionalities used for care coordination (None of the articles described both.) Of the seven studies that were not reviews, intervention groups existed for one study of analytics and one of an HIT tool. Table A.1 in Appendix A provides an evidence table detailing these studies. Ultimately, given the limited scope of the literature review and the specific topic it addressed, the number of articles included in the final review was small (N =7).

**Figure 2.1. Literature Review Article Flow**



### ***Results of Three Analytics Articles***

We found three articles that applied analytics to identify complex patients (see Table A.1 in the Appendix). One article used algorithms based on codes from the International Classification of Diseases version 9 (ICD-9) and hierarchical disease stratifications to classify patients into risk group based on comorbidity and complexity.<sup>17</sup> Those analytics were used to inform which patients received phone calls by nurse care coordinators. The study found a drop in the rate of hospitalizations of individuals with chronic disease but did not include levels of statistical significance. A second study consisting of a feasibility pilot used the most recent year of inpatient, ED, and office visits for five diagnosis codes in an algorithm to compute complex chronic disease complexity, which informed nurse telephone outreach.<sup>18</sup> The third analytics-based study used Medicaid enrollment data, claims, notices generated by the decision support system, care manager activity logs, and regional health information exchange (HIE) records to identify triggers for care coordinators to contact patients.<sup>19</sup> That study (which was the only one with a control) found fewer low-severity ED encounters when the system was used (8.1 vs. 10.6/100 enrollees;  $p < 0.001$ ).

## *Results of Four HIT Functionality Articles*

We identified four studies involving HIT functionalities that were used for care coordination (see Table A.1). In one qualitative study, a tool aggregated tasks, reminders, and other communications for care coordinators into a list of planned tasks, which were integrated into the EHRs for review by clinicians.<sup>20</sup> An earlier controlled study of the same tool found that use of the tool by care coordinators using structured protocols for certain conditions resulted in a reduced death rate at one year from 9.2 percent to 6.5 percent ( $p < 0.05$ ).<sup>21</sup> A third study described how care coordinators specializing in depression could add patients to a homegrown software tool and assign them to a primary care physician.<sup>22</sup> However, the study did not describe the primary care physician's use of the tool after being assigned a patient. Finally, a fourth study described the development of a tool that allows a patient's providers to interact through a social media-style user interface in which members of a care team can communicate with each other and with a patient using a shared care plan.<sup>23</sup>

## *Summary*

In summary, we found few papers in the peer-reviewed literature that addressed analytics and HIT functionalities for complex patients, although we used restrictive criteria to ensure the specificity required to address this topic. The two articles that included control groups described initiatives in 2006 or before. Results showed a reduction in low-severity ED utilization<sup>19</sup> and a reduction in the death rate.<sup>21</sup> As a comparison, a review done by the VA in 2012 identified nine papers evaluating the impact for programs designed to address the needs of complex patients and little evidence of benefit.<sup>24</sup> This review focused on intensive primary care programs for high-risk patients, and the papers identified did not all necessarily contain HIT components. A recent study about whether HIT functionalities support care transitions also identified little innovation occurring for patient-centered care coordination.<sup>25</sup>

## **SME Results**

We present our findings separately for data/analytics and for HIT functionalities for care coordination.

### *Analytics*

SMEs suggested that a growing number of organizations—health plans, providers, and employers—are prioritizing and investing in data analytics to identify complex patients and patients at risk for becoming complex. Several SMEs from provider organizations attributed this change to the move toward accountable care, where it is more profitable to focus on keeping patients well to prevent expensive services. SMEs believed that identifying these patients was important for effectively using limited resources to target the patients who would most benefit from care coordination. SMEs also mentioned several vendors that offered analytic services for

identifying complex and high-risk patients, which suggests that many organizations are willing to pay for these services.

Based on these discussions, we characterized the purpose of the analytics focused on complex patients into three goals, with an additional crosscutting goal:

- Goal 1: Identify complex patients and patients at risk for becoming complex.
- Goal 2: Identify subset of complex patients who could be helped by an intervention.
- Goal 3: Match the subgroups of complex patients to specific interventions.
- Crosscutting Goal: Improve ability to predict the onset of complexity earlier, so that the health care system can intervene preemptively in disease progression.

Within each goal, SMEs discussed efforts related to data (using data from various sources and collecting novel forms of data) and efforts to improve predictive capabilities (improving analytics methods and finding the appropriate balance between machine prediction and clinical intuition). Many of these efforts apply to more than one goal; we present them in the context of the goals in which the SMEs discussed them and then discuss barriers to improving analytics.

#### Goal 1: Identify Complex Patients and Patients at Risk for Becoming Complex

Identifying and predicting complexity is the primary goal of analytics used in most care management programs today. We defined complex patients as those having multiple comorbidities and those who were high need and high cost. However, for the SME discussions, we asked SMEs about complex patients and allowed each SME to describe what kinds of patients they were targeting for analytics to better understand how complexity was being defined. SMEs were typically targeting patients at high risk for an expensive event, such as a hospitalization, ED visit, or patients otherwise at high risk for imminent high costs or death. Therefore, most programs were attempting to delay or prevent patients from becoming high cost but not necessarily identifying high-need patients (although the two are likely correlated in many cases). It was clear that while many programs use these types of predictive tools, most have not been rigorously evaluated, making it difficult to determine if these programs were effective. One SME pointed out his organization did not have a way to determine how well they were treating complex patients, regardless of the use of analytic tools, much less attribute specific benefits brought about by using analytics.

SMEs described various forms of data they are using in predictive models (Table 2.1).

**Table 2.1. Advantages and Disadvantages of Using Different Data Sources for Predictive Analytics**

<b>Data Sources</b>	<b>Advantages</b>	<b>Disadvantages</b>
Administrative claims	Longitudinal, standardized, audited	Incomplete picture of clinical happenings, delays in data availability
EHRs	Rich clinical data (e.g., smoking, weight); some EHRs have capability to incorporate social data	Variable and often poor data quality (e.g., problem list), gaps for visits to other providers, predictive algorithms aren't portable because of variability in documentation practices across provider organizations, lots of data are uncoded free text, social data often absent or not standardized
Patient surveys	Ability to gather social and other idiosyncratic data	Requires additional resources, limited but improving integration with EHRs, data standards are still evolving, burden to patient

*Administrative Data.* Most predictive models still rely solely on administrative claims data. Many SMEs said they believed that such models were of limited utility because claims data often have a time lag, show an incomplete picture of a patient’s clinical care, and do not capture social and psychological elements that greatly affect health care needs. Additionally, several SMEs expressed concern that while claims could predict hospitalization within the next year reasonably well, those models depended on prior hospitalization as a key predictor variable. SMEs believed that for the predictive models to be useful in substantially reducing costs, they would need to identify patients *before* a hospitalization. Nevertheless, timely availability of claims was noted as having immense potential value by alerting providers when their patients visit hospitals, EDs, or other external locations and by improving the care team’s awareness when care is sought outside the system.

*EHR Data.* Several SMEs had experience using EHR data to identify complex patients for interventions. While EHR data contains substantially more clinically relevant information than administrative claims data, SMEs highlighted that much of it was in free text format, making it much harder to use for analytics. Even data in coded fields was of poor quality. For example, one SME pointed out that many studies have shown that the problem list often contains omissions or otherwise inaccurate data. Furthermore, given current limitations in HIE, data from patient encounters that occur at external provider organizations are often not available for predictive models. However, one SME mentioned an increase in the availability of hospital admit, discharge, and transfer (ADT) information among unaffiliated providers and the use of those data in predicting readmission.

*Patient-Derived Data.* Many SMEs said they believed that the most promising types of data to help with predictive modeling could be collected directly from the patient. This was particularly noted for data related to social determinants of health because a growing body of research supports the idea that many health issues have their roots in social issues, such as housing stability, food security, and access to public transportation. Some SMEs were using surveys to attempt to gather these types of data. The surveys would also ask about clinical information that might be available from claims or EHRs (e.g., number of medications).

However, the SMEs said a patient's perception of their clinical issues was often more predictive of potential problems than the objective data. Several SMEs emphasized the potential predictive value of seemingly idiosyncratic data (e.g., use of a wood-burning stove as a predictor of respiratory illness and related complications), but they also mentioned that systematically collecting these data so that they could be included in predictive models was challenging. Novel patient-derived data types identified by SMEs included:

- patient perceptions of healthiness relative to others
- number of providers/number of separate organizations
- number of medications
- social isolation
- social supports
- caregiver taking care of only that patient
- hearing status
- mobility
- number of people in household/marriage status
- exercise
- social needs (e.g., transportation, housing status)
- nutrition
- no-show rate
- ability to bathe self
- believe will go to hospital in next 12 months
- income levels by census tract
- device/sensor data
- idiosyncratic data: wood burning stove, time watching home shopping channel, pet ownership
- health literacy.

#### Goal 2: Identify Subset of Complex Patients Who Could Be Helped by an Intervention

SMEs pointed out that simply identifying complex or high-risk patients was not enough because some of the identified patients are more amenable to intervention than others. For example, patients with a strong support network may already have well-coordinated care; thus, the additional work performed by a care coordinator may yield minimal marginal benefit. Also, certain diseases or disease combinations may be associated with greater care coordination needs than others, and, thus, such patients may derive greater benefits from such efforts. The SMEs identified two efforts related to the goal of identifying patients amenable to intervention. One effort developed a “propensity score” for patients enrolled in a Medicare Supplemental health plan to respond to an intervention. The other effort created a modified risk score reflecting

potential for health outcome modification, based on the Archimedes model.<sup>26</sup> Neither effort has yet been formally evaluated.

In the absence of available analytic capabilities to achieve this goal, SMEs described the role of provider judgment in identifying complex patients and referring them for interventions. Some efforts tasked physicians with selecting the patients they believed would be most treatable with an intervention. In other cases, care coordinators were also involved in selecting patients. For example, if a care coordinator did a home visit and found that the patient had supportive caregivers, she or he might decide that the patient has the potential to benefit only minimally from the additional services of a care coordinator.

### Goal 3: Match the Subgroups of Complex Patients to Specific Interventions

The third goal of analytics is to match subgroups of complex patients to the specific interventions that might lead to reductions in cost and utilization or to improvements in health and quality of life. Some of the dimensions of the interventions that SMEs described for complex patients are listed below:

- members of a care team (e.g., medical specialties, social services, care coordinator)
- social needs (e.g., sanitation, housing, transportation, legal issues) versus clinical needs
- structure of care delivery (e.g., use of a medical group dedicated to complex patients)
- use of monitoring devices
- idiosyncratic interventions personalized to patient
- patient advocacy programs.

One SME articulated a vision in which care coordinators would receive “Amazon-like suggestions” of types of interventions that have worked with similar patients in the past. For example, suggestions might include which types of clinical and social expertise members of their care team should have, what types of monitoring devices might be useful, and whether a patient would benefit from a patient advocate.

Despite the above vision, the information currently available to care coordinators to support their decisionmaking is far from such an ideal. We did not find any examples of analytics that help a clinician or care coordinator decide which specific intervention is optimal for particular complex patients that were mature enough to scale-up nationally. Many care coordinators tailor interventions to specific patients using only their clinical judgment without the assistance of analytics. Some clinicians and care coordinators spend considerable time developing their care plans, which suggests the complexity of the task. One SME described using analytics to prioritize gaps in care that a care coordinator should address based on cost implications but did not suggest specific interventions beyond addressing those gaps. Some SMEs described models that predict a disease-specific outcome (e.g., asthma-related hospitalization) and provide a narrower set of interventions related to the specific diseases. However, no models indicated



which disease-specific interventions would work best based on individual patient characteristics and situations.

#### Crosscutting Goal: Improve Ability to Predict Onset of Complexity Earlier So Health Care System Can Intervene Preemptively in Disease Progression

SMEs described numerous barriers to progress in addressing these three goals and the crosscutting goal of predicting the onset of complexity earlier so that the health care system can intervene preemptively in disease progression:

1. *Limited capabilities of predictive models.* Many SMEs described the challenges of producing predictive models with adequate accuracy. Existing models are thought either to suggest too many patients compared with available resources or to fail to identify patients until it is too late to change their disease trajectory, thus making for suboptimal use of resources. Additionally, developing models with EHR data can be very resource-intensive. Moreover, once completed, such models would be tethered to a specific provider organization's data and present a challenge to wider adoption.
2. *Data issues.* There are two data issues: data quality and data related to the social determinants of health. As for data quality, while it is likely possible to improve the predictive accuracy of the models with improved algorithms, SMEs believed that the quality of data is a larger barrier to improving the models. EHRs in particular suffer from major data quality issues. One SME said there are several additional uses for higher quality, standardized data beyond risk prediction, including comparative effectiveness research and disease surveillance. However, that SME said data quality would only improve substantially if there were economic incentives promoting improvement, such as requirements for administrative claims that must be met for reimbursement. The SME claims that the lack of such incentives could explain the inaccuracies found in EHR data, such as problem lists. SMEs also stressed the importance of having the data available in a timely fashion. In particular, delays in procuring claims hampered predictive effectiveness.

The use of data related to social determinants of health was frequently cited as an important factor in improving predictive models. When such data exist, they often lack standardization and are thus difficult to include in models. However, we found evidence this may be changing: SMEs believed the recent IOM report on social determinants of health is an important milestone.<sup>27</sup> SMEs indicated at least some EHR products have recently added the capability to include data on social determinants.

3. *Lack of experience using analytics.* SMEs said that few providers or care coordinators are accustomed to using analytics, and some SMEs believed that many providers would not trust the data at first, preferring to rely on their own experience. To make effective use of analytics requires incorporating the analytic outputs into work processes, perhaps through training programs.

4. *Lack of evidence that analytics results in reduced costs and improved outcomes.* SMEs from provider organizations said they do not know what interventions work, or even the impact of their existing efforts beyond anecdotes. For example, they lack information on how much can be saved by using care coordinators. While analytics could inform resource allocation decisions, such as whether to focus on a narrow group of patients with intensive care needs or a broader group with less-intensive needs, few data or evaluations exist to help provider organizations make these decisions. This view is consistent with the findings from our literature review, in which we found little evidence on the effectiveness of programs that use analytics applied to real-world patients as part of an intervention.
5. *Financial incentives.* This barrier was mentioned most frequently by SMEs. While reimbursements are shifting slowly and beginning to reward providers and organizations that identify and treat complex patients, even emerging payment models in which the providers assume financial risk may not create the right incentives to prioritize devoting resources to the sickest patients, because there is an unclear return on investment.

The above barriers contributed to the opinion that one SME had about the current state of analytics for identifying complex patients: “No one is doing it well.”

### *HIT Functionalities for Care Coordination*

SMEs described several distinct HIT functionalities currently used or piloted by care coordinators, providers, and patients for coordinating care (Table 2.2). These functionalities addressed various care coordination activities. Most HIT functionalities were designed to be used primarily by care coordinators, who operated either within health plans or large providers such as ACOs. The HIT functionalities included dashboards, patient relationship managers, event alerts, referral tracking, and care plans.

#### **Coordination Among Providers for Treatment**

Several SMEs distinguished functionalities that support care coordination from those that support treatment. Communication among providers for informational purposes to establish the optimal evidence-based care plan was considered to be related to treatment and thus not care coordination. We included functionalities that supported both activities but found little functionality designed primarily to support communication around treatment. While some products did allow multiple providers to discuss treatment plans through a virtual interface, most were designed for use by care coordinators to keep track of tasks within a care plan.

**Table 2.2. HIT Functionalities for Care Coordination**

Functionality	Description
Dashboards	Dashboards support ad hoc patient searches and can serve as prompts for discussions among members of a care team. They are populated by clinical data from an EHR that displays the performance on quality indicators for a panel of patients. They may also provide administrative functionality for scheduling patients and monitoring their status.
Patient relationship managers	These can be commercial or homegrown, may be hosted by a payer or a provider, and can be integrated with an EHR or exist as a stand-alone system. Used primarily by care coordinators, they allow users to manually track interactions between care coordinators and patients and help to manage a care coordinator’s to-do list. Generally, only the care coordinator uses them, but some products are designed for use by all members of a care team, including primary care physicians, specialists, patients, and proxies.
Event alerts	Event alerts are sent automatically to members of the care team and triggered by ED and hospitalization events (admissions, discharges, and transfers) or by the lack of follow up post-discharge. They can be generated within a provider organization or through an arrangement with a different provider organization, sometimes through HIE. In some cases, providers can “subscribe” to alerts for their patients.
Referral tracking	Once a provider refers a patient to a specialist, referral tracking helps providers or their staff follow up on those referrals and ensure they are completed in a timely fashion. It allows providers to “close the loop” to ensure patients see the appropriate specialists and that summary reports are received by the referring provider.
Care plans	Care plan definitions vary widely, though most are designed primarily for care coordinators. Typical care plan functionality allows care coordinators or other care team members to select care goals and interventions and track progress. Care goals may be prepopulated based on a patient’s diagnoses or physician orders. Some care plans may be used by the patient, the patient’s multiple providers, or by patient surrogates.

### Dashboards

SMEs described dashboards that care coordinators used to both monitor individual patients and keep track of an entire panel of patients. Individual patient-level dashboards typically involved an assortment of modules, each displaying different pieces of information about the patient, such as vitals, medications, or clinical notes. This information was typically pulled from the EHR, although the amount of EHR information in stand-alone care coordination systems varied with the degree of interoperability achieved. Other dashboards were designed to show the health status of a panel of patients. These dashboards reported aggregate metrics showing the quality of care that panel members were receiving, often using “stop light” functionality to show if patients in care coordination programs were doing well (“green”), at risk (“yellow”), or in need of intervention (“red”).

### Patient Relationship Managers

Several SMEs referred to products that tracked contact between care coordinators and patients. These tools were usually set up as either part of an EHR or as a stand-alone tool that care coordinators used to record their daily interactions with patients. One SME commented on a commercial patient relationship manager that allowed care coordinators to automatically create and assign tasks to other members of the care team based on documented patient interactions.

## Event Alerts

Many of the care coordination tools were able to alert care team members when something happened to one of their patients. These alerts were most often triggered by admissions, discharges, or visits to EDs, but some systems alerted care team members when laboratory tests results were abnormal or if patients did not report their vitals with a home monitoring device. Because of the potentially large volume of alerts, providers were often able to unsubscribe from these alerts for specific patients. Additionally, one SME discussed a system where providers could send each other patient-specific alerts.

## Referral Tracking

Several SMEs described referral-tracking functionality that was recently developed and allows for “closing the loop” to ensure referrals happen and that summary reports are received by the referring provider. Referring providers either make the referrals themselves or, more frequently, have a staff member at the front desk complete the referral request, which is ordered like a laboratory test. The status of the referral is tracked and the provider or staff member can follow up on incomplete referrals. SMEs described referral-tracking products that were part of an HIE and those supplied by vendors to large community provider organizations. SMEs suggested that the recent interest in referral tracking might be motivated by the PCMH requirement to perform referral tracking. One SME noted a benefit of automating the referral process was that the referring provider would be educated by the feedback obtained by the specialists’ reports and could make more informed referrals in the future.

## Care Plans

Care plans were the most sophisticated care coordination functionality described by SMEs. SMEs described several products developed by companies, including several startups, and as part of research projects. Other SMEs described the desired functionality based on their experience as leaders in large provider organizations. Below, we summarize the SMEs’ input on the following aspects of care plans related to HIT: (1) the definition of care plan and its varying content, (2) types of users involved, (3) definitions of user role and responsibilities, (4) methods for tracking members of a care team, (5) task tracking, and (6) support for communication among the care team.

*Definition of Care Plan.* We found the term “care plan” was poorly defined and meant different things to different SMEs. SMEs described different approaches about how they understood the content of the care plans to be structured within a HIT system, as shown below:

- static text that described brief action steps: “annual ophthalmology visit and foot exam; reach a target weight; take BP every day”
- ability to track gaps in care (such as overdue screening tests) and issue reminders to patient, clinicians, or care coordinator

- care plan structured around a list of problems, each with an associated goal and its assigned intervention
- “dynamic” care plans that are accessible between visits and can be updated (SMEs did not provide any more detailed specifications.)

*Types of Users.* Care plan functionalities mentioned by several SMEs were accessible to members of a care team and facilitated interactions among them. These users included clinicians, the patient, patient surrogates (e.g., parents or children), care coordinators, and staff from social services. Typically, the care plan functionality was designed primarily for use by care coordinators who would work with other supporting services, such as social workers, diabetic coaches, or fitness coaches. Although physicians usually had access to the functionality, they were rarely actively involved in using it, and when they did, the degree of use varied. For example, one startup company found that some physicians wanted to be fully engaged, overseeing the whole process surrounding a surgical episode of care. Others wanted to create the postsurgical care plan, hand it off to the rest of the care team, and not be involved further.

*Definitions of User Role and Responsibilities.* Patients used the care plan functionalities to varying degrees. In some cases, patients were not actively using or not offered access to their care plan, partly because SMEs stated that older, sicker patients often were not interested in using the software to actively manage their care. In other cases, the patient was allowed control of many aspects of the care plan, such as the ability to selectively share specific types of data only with specific team members (e.g., patients may not want to share psychological issues with fitness coaches). Some care plans allowed for structured interactions with patients, such as the use of patient assessment surveys that ask patients about their available resources, goals, and symptoms. These assessments are used in some products to automatically produce or update tasks within the care plan. For example, they may trigger the care coordinator to give patients self-management education materials or send alerts to the care team. SMEs also described how the care plan functionality defined control and ownership. In one project that used a care plan functionality, only the care coordinator was allowed to edit the care plan: Other team members could make suggestions but could not make official changes. Other care plans are more flexible and allow multiple users to change the care plan.

*Methods for Tracking Members of a Care Team.* Implementing care plan functionality requires identifying and tracking the current members of the care team, a task one SME who was an executive from a large provider organization described as nontrivial. This same SME said that having clinical logic that would suggest or automatically add or remove providers to the team for a specific patient would facilitate use of care plans. Several SMEs described products that allowed the patient to specify members of their care team. Other products were more provider-focused and required the provider or care coordinator to “invite” providers, who might practice in the same organization or a different one. We found no widely agreed-upon definition of a care

team member, and care team membership changes over time, complicating the efforts of those developing these functionalities.

*Task Tracking.* Some care plan functionalities support task tracking, allowing users (most frequently the care coordinator) to create customizable tasks that can be assigned to and viewed by other members of the care team. The SMEs said most tasks are highly customizable and can be entered as free text; there is no predetermined workflow for how to use them. One product allows for a wiki-style interface for editing a care plan. One SME described care plan software that supported some coded fields with logic (e.g., for a scheduled appointment). Another product allows certain tasks, such as those related to Healthcare Effectiveness Data and Information Set measures, vital signs, blood pressure, and patient-reported values, to be tracked as coded fields. Tasks may have due dates and generate alerts to the care coordinator if a task is overdue. Some care plans allow users to customize which kinds of alerts or messages they will receive (e.g., completed lab result, completed visit). Users may be able to view the care plan and tasks differently depending on their role.

*Support for Communication.* Care plans can support communication among members of the care team in different ways. Several SMEs described a goal of social media-like flexibility so that any member of the care team could engage in “ad hoc, timely communication.” Other SMEs described communication involving structured notes or secure messaging similar to email.

#### Barriers to Care Coordination HIT Functionalities

SMEs pointed to several barriers to developing and implementing care coordination functionalities, mostly related to the care plan. We discovered some barriers from users’ direct experiences, and thought leaders suggested others hypothetically.

1. *Establishing current members of a care team and their role over time is challenging,* especially given the lack of a standardized shared definition of what it means to be a member of a care team or a method for recording changes in team membership over time. Despite this uncertainty, one SME emphasized the importance of integrating all members of a care team, including patients and their families, as users of care coordination software.
2. *Engaging in care planning and IT-enabled coordination changes the work performed by providers.* Working as a team on an ongoing basis outside of a visit may be a cultural change for some providers, and including the patient in those communications is also new and unfamiliar. One SME mentioned that incorporating this kind of work into routine clinical practice would require substantial training. Additionally, rules and guidelines may need to be established, such as how to handle possible conflicts between providers. When asked about these conflicts, one SME representing a private company said that none had been reported but that such conflicts may become a problem as use of care coordination tools increased. The challenge is exacerbated when the providers are part of different organizations. One SME described the difficulty of having providers at different



organizations agree to use a common system for basic data exchange functionality. The technology was not the challenge; rather, it was getting multiple organizations using different EHRs to work together, adopt a common workflow, and train all providers to use a new system that was time-consuming and required considerable expense. These challenges may be even greater for more-advanced care coordination functionalities.

3. *Care coordination is complex and multifaceted, and the needs of the users are poorly understood.* We identified seven dimensions of delivering coordinated care from the SME discussion (Table 2.3). There is substantial variability and uncertainty in the context in which care coordination functionality would be used, rendering product design a formidable challenge. One SME emphasized the importance of a detailed requirements analysis to define essential features of the product. Given the variability and complexity of the tasks that care management systems must facilitate, such an analysis would be a significant undertaking.

SMEs elaborated further on some of the dimensions described in Table 2.3. For example, there is no established common practice for determining which member of a care team should manage the problem list or task list. One SME from a provider organization found that providers tend to be reluctant to modify problems added to the problem list by other providers. SMEs discussed challenges simply in creating names for roles like a care coordinator, because they lack universal meaning. As a result, products are designed to be maximally flexible and allow the users to define their own roles. Given the challenges with defining roles and responsibilities, one SME warned of potentially overburdening certain members of the care team, especially patients or their caregivers. The ideal method of developing a product would be “participatory design” involving all the users, particularly because of the diversity of roles involved. However, with so many users and so much variation among them, such design is dauntingly complex, and there is little knowledge of each role’s core activities. SMEs urged that user needs and how they vary need to be better understood to help translate users’ needs into technical design specifications. SMEs believed this requires more scientific study and does not fit into the fast turnaround of most existing funding sources.

4. *Vendors may claim to offer advanced care coordination software to explore a market even if their products are not fully developed or tested.* One SME said there was a lot of “smoke and mirrors” in the industry and that some vendors were marketing simple functionality, such as secure messaging, as revolutionary care coordination innovations. This made it difficult for SMEs to find products that were actually helpful.
5. *Care coordination products are often not easily integrated into EHRs and require an interruption in workflow.* Some SMEs emphasized integration issues as a major barrier and said it is difficult to engage physicians unless the coordination functionality integrates directly with their EHRs. Other SMEs downplayed the need for EHR integration by describing conceptual differences between their functionalities and the

purpose of EHRs. A representative of one vendor said EHRs are for documenting what happened in the past, whereas care plan functionality plans for the future. Another SME who was the leader of a research project made a different distinction: EHRs are for clinical treatment, whereas their care coordination functionality was for care coordination services, defined as all the activities that support treatment. A third SME described their product as not requiring intensive involvement of the patient's physicians, unlike an EHR. Some SMEs said that care coordination functionalities served as a kind of bridge between different EHRs, because they would contain data from multiple systems. However, in these cases, care coordinators were often, for example, required to manually translate some information (e.g., physician orders) from the EHRs into the separate care plan software. Providers also needed to log in to an application separate from their EHRs, a substantial workflow barrier. SMEs said that addressing interoperability barriers, perhaps by using application programmer interfaces (APIs), would be critical to scaling solutions. EHR integration challenges were less of a problem when the care plan functionality was offered as part of an EHR vendor's integrated solution, as one SME described. In that case, certain data elements were populated automatically from the patients' medical record, facilitating the generation of the care plan.

6. *Difficulty interpreting the Health Insurance Portability and Accountability Act (HIPAA) and regulations is an impediment to developing compliant software.* For example, one SME described the implementation of care coordination software that was part of their EHR. This provider organization had an affiliated health plan, which hoped to use the same care coordination software for its care management program. Doing so would require adding all patients under the health plan's care management program to the provider's EHR, but because of HIPAA, the legal team advised them against adding any patient to an EHR who did not have a direct relationship with that provider, even if those patients' data were not accessible to anyone other than the health plan's care managers. This restriction was a substantial barrier.
7. *Incentives—such as the move toward accountable care—make a better business case for providers investing in care coordination software, but they are shifting slowly.* It is challenging to figure out a business model with so many different types of users who often span different organizations. One SME suggested that the reason its product had so few physician users was because they had not found a satisfactory value proposition for this important stakeholder.



**Table 2.3. Dimensions of Care Coordination Identified by SMEs**

<b>Dimension</b>	<b>Example</b>
Variability in types of care team roles, which change over time	For cancer patients, primary care responsibility is often handled by the oncologist during active treatment and then handed off back to the primary care provider
Variability in patient goals, which change over time	Patient's clinical goals and priorities change along with social changes (e.g., loss of job, move to nursing home)
Variability in user preferences	Some physicians prefer to be actively involved in monitoring the care plan, while others prefer to develop it once and hand it off.
Simultaneous occurrence of multiple events	A patient's symptoms may change during the time between when a referral is made and an appointment with a specialist
Changes in data over time	Headache diagnoses may change, resolve, and reappear
Potential for disagreement of the care plan	Team members may disagree on whether a problem has completely resolved and should be removed from the list
Aversion to information overload (especially physicians)	The potential for receiving too many notifications from a care plan may prompt some users to turn off the notifications altogether

### 3. Conclusions

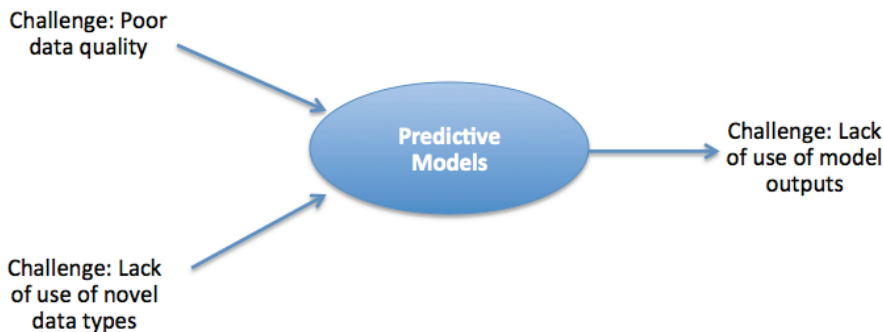
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Our review of the literature and discussions with a diverse range of SMEs shows that analytics and HIT are being used in innovative ways to coordinate care for complex patients. Analytics are being used to identify complex patients who may benefit from care coordination and other interventions, and HIT functionalities are being used to improve communication among patients and their providers. However, the functionalities have limited capabilities, evidence of their effectiveness is lacking, and challenges are substantial. Important foundational work is still needed. We describe the key challenges and potential solutions, and practical implications.

#### Data and Analytics: Challenges and Solutions

We identified three key challenges to improving use of analytics to identify complex patients for care coordination: poor data quality, lack of use of novel data types, and integrating model outputs into clinical practice. As shown in Figure 3.1, these challenges are related to acquiring high-quality data as inputs to a predictive model and using predictive models' outputs by providers. No SMEs suggested that the major challenge was developing the predictive models themselves. While there will be room for innovation in developing novel predictive algorithms and improving model performance, model effectiveness will always be limited by the data on which it is based and by the ability of individuals and institutions to apply them. Our findings suggest that future work should address the challenges related to improving model inputs and applying the outputs in real settings.

**Figure 3.1. Key Challenges to Improving Analytics and Identifying Complex Patients for Care Coordination**



We suggest solutions to address each key challenge (Table 3.1). These suggestions are not meant to be exhaustive. Rather they show the range of options for interventions that might be useful. We discuss implications and the role of incentives below.

Substantively addressing these challenges will likely require diverse approaches. To improve data quality, we suggest solutions that involve technology, education, administrative process changes, and expanded patient engagement. To further increase use of novel data types, we suggest further development of concepts and frameworks, and experimentation in data collection and evaluation. To improve use of model outputs, we suggest solutions that involve technology, changes in clinical processes, and education.

**Table 3.1. Challenges and Solutions to Improving Data Inputs and Outputs of Predictive Modeling**

Challenge	Solutions
Poor data quality	<ul style="list-style-type: none"> <li>• Develop tools to facilitate EHR documentation in standardized formats</li> <li>• Develop methods to assess and report data quality</li> <li>• Educate and train providers to standardize EHR documentation processes</li> <li>• Make administrative claims data available in a timely manner</li> <li>• Further involve patients in reviewing the accuracy of their medical records (e.g., expanding on the Open Notes project<sup>28</sup>)</li> </ul>
Lack of use of novel data types	<ul style="list-style-type: none"> <li>• Increase routine collection data related to social determinants of health through diverse collection modes<sup>27</sup></li> <li>• Explore value of idiosyncratic data elements and data from novel sources (e.g., credit card purchases, social media)</li> <li>• Improve documentation of care coordination events</li> <li>• Take advantage of data from devices (e.g., smartphones, fitness trackers, biosensors)</li> <li>• Develop, expand, or integrate data and logic models to guide the collection of novel data types</li> <li>• Create constructs for salient concepts related to complex patients (e.g., resilience of a patient's support network)</li> </ul>
Lack of use of model outputs	<ul style="list-style-type: none"> <li>• Develop decision support tools that incorporate model outputs</li> <li>• Integrate model outputs into clinical workflows (e.g., embedded predictions in EHRs)</li> <li>• Educate and train medical groups and individual providers to appropriately use model outputs</li> </ul>

## Care Coordination Functionalities: Challenges and Solutions

While there are companies and research projects developing care coordination functionalities, many are in early stages of development, and there are important limitations to many products, such as the lack of engagement by physicians and limited existence of standardized concepts and frameworks. We identify three key challenges to improving care coordination functionalities and suggest solutions (Table 3.2). While issues related to interoperability are already recognized by policymakers and many other stakeholders, the limitations in care coordination functionalities and how they should best be used have not received sustained attention and will require more fundamental knowledge. In particular, we believe the most important challenge is that neither developers nor users have a clear understanding of the key problems related to care coordination and what kinds of functionality can best address them. Solutions will require an understanding of how members of care teams can interact through an electronic communication medium in a way that improves care

coordination, while also being sustainable for each individual. Mechanisms to facilitate closer collaborations among users and developers are needed to accelerate knowledge and the discovery of innovative solutions.

**Table 3.2. Challenges and Solutions to Improving Care Coordination Functionalities**

Challenge	Solutions
Existing functionality that supports care plans and communication among care teams has important limitations	<ul style="list-style-type: none"> <li>• Better understand design space by developing concepts and frameworks that characterize the needs of diverse users, especially physicians</li> <li>• Develop and test prototypes using principles of user-centered and participatory design</li> <li>• Develop formal models that characterize team interactions</li> <li>• Foster collaborations between developers and users</li> </ul>
Interoperability is lacking	<ul style="list-style-type: none"> <li>• Improve the ability for care coordination functionalities to integrate across diverse EHRs through APIs</li> </ul>
How to best use the tools are unknown	<ul style="list-style-type: none"> <li>• Establish rules of engagement and user roles/responsibilities</li> <li>• Create standard cross-organizational best practices for implementation and coordinating among all stakeholders</li> </ul>

## Implications for Future Studies

The challenges described above are substantial, and most stakeholders lack a business case for addressing them. Emerging payment models such as ACOs and PCMHs may help, but even health systems under capitated models (such as the VA) struggle to care for these patients and might not have the resources needed to address the challenges. The resources required to develop analytics and HIT functionalities with proven effectiveness may be out of reach for any individual organization.<sup>29</sup> Therefore, there may be a role for government involvement to accelerate innovation.

We propose several solutions in Table 3.3 using the following framework. Within this framework, we propose options in each category for both analytics and for care coordination functionalities.

- *Understand the problem and barriers to progress.* For analytics, a better understanding is particularly important for identifying novel data elements that could improve predictive algorithms and ensure synergy with ongoing data collection efforts. For HIT functionalities, convening relevant stakeholders and coming to agreement on concepts and frameworks could accelerate understanding of the needs of complex patients. The federal government could facilitate such an effort.
- *Develop technology and related process and workflow changes.* For both analytics and HIT functionalities, standards, tools, and methods will be needed and may involve research projects, private companies or collaborations between research and companies. Such efforts would likely benefit from strong patient involvement.

- *Evaluate and generate evidence of impact.* Evaluating the impact of both predictive models and new functionalities is critical to provide feedback on the development cycle. Such evaluations may also lead to identifying best processes for both data collection and use of functionalities.
- *Implement and disseminate technology and related process and workflow changes.* Education and training will help ensure that useful data are collected and functionalities are effectively implemented.
- *Create incentives that promote use of technology and related process and workflow changes.* Existing incentives have not adequately promoted development of the types of technologies we evaluated in this report for addressing the needs complex patients. New kinds of incentives will be needed.

Two key themes emerge. First, there is a clear need for knowledge, particularly in understanding the problems that complex patients and their providers face in using these technologies and in evaluating impact. Second, there may be a role for the federal government to convene the many stakeholders to define the key problems and galvanize the industry toward addressing them.

**Table 3.3. Options to Accelerate the Development of Analytics and HIT Functionalities for Care Coordination of Complex Patients**

Category	Data and Analytics	Care Coordination Functionalities
Improve understanding of the problem and barriers to progress	<ul style="list-style-type: none"> <li>Identify key novel data elements with predictive potential (e.g., social determinants of health, data from biosensors, smartphones) and develop frameworks to characterize their relationships</li> <li>Identify synergies with data collection efforts for other purposes (e.g., clinical research, quality measurement)</li> <li>Convene a forum to facilitate collaborations between analytic modelers and all stakeholders involved in collecting and using data</li> </ul>	<ul style="list-style-type: none"> <li>Identify the key types of care coordination needs of complex patients and their care teams</li> <li>Convene a forum to facilitate collaborations among developers, information technology vendors, and end users</li> </ul>
Develop technology and related process and workflow changes	<ul style="list-style-type: none"> <li>Standardize formats for data elements identified as relevant to identifying complex patients, including care coordination events.</li> <li>Develop tools and processes that facilitate EHR documentation in standardized formats</li> <li>Develop or improve on existing methods for the routine collection of novel data types, especially related to social determinants of health</li> <li>Further engage patients in supplying, annotating and correcting inaccuracies in their data</li> <li>Develop workflow models and clinical decision support tools for integrating predictive model outputs into routine care</li> <li>Improve availability of administrative claims data</li> </ul>	<ul style="list-style-type: none"> <li>Develop methods for how to effectively apply user-centered and participatory design principles to develop functionalities for complex patients</li> <li>Develop prototypes of novel functionalities that address identified needs</li> <li>Develop standard processes for care team interactions (e.g., how to handle conflicts) and documentation</li> <li>Develop standards for the contents and capabilities of shared care plan functionality</li> <li>Develop standards for integrating care coordination functionalities with EHRs.</li> </ul>
Evaluate and generate evidence of impact	<ul style="list-style-type: none"> <li>Evaluate impact of predictive models applied to real complex patients</li> <li>Identify best practices for high-quality data collection of data types relevant to complex patient.</li> </ul>	<ul style="list-style-type: none"> <li>Evaluate the impact of care coordination functionalities applied to real complex patients</li> <li>Identify best practices for implementing and using care coordination functionalities.</li> </ul>
Implement and disseminate technology and related process and workflow changes	<ul style="list-style-type: none"> <li>Develop education and training programs to help with improving data quality, collecting novel forms of data, and using data in clinical practice.</li> </ul>	<ul style="list-style-type: none"> <li>Develop education and training programs to help implement best practices for most effectively using care coordination functionalities.</li> </ul>
Create incentives that promote use of technology and related process and workflow changes	<ul style="list-style-type: none"> <li>Create a market for high-quality data production by identifying combinations of use cases, payment models and other contextual factors in which the individual and/or organization collecting the data used in predictive models has an incentive to make it of high data quality.</li> <li>Incorporate use of predictive models into standard care models (e.g., PCMHs)</li> </ul>	<ul style="list-style-type: none"> <li>Identify combinations of payment models, organizational types, and other contextual factors in which individuals and/or organizations have incentives to effectively use care coordination functionalities.</li> <li>Incorporate use of care coordination functionalities into standard care models (e.g., PCMHs)</li> </ul>

In the near term, the most important efforts likely will involve understanding problems related to improved data for predictive analytics and the user needs for care coordination

functionalities. Focused research efforts, as well as convening all stakeholders to create a shared understanding and focus on this topic, may be helpful. In the medium term, it will be important to develop the technology in concert with care delivery models and workflows and gather evidence of what does and does not work. In the long term, after evidence is established, emerging payment models may promote implementation. However, additional dissemination efforts will likely be needed, which may include convening stakeholders to establish a common understanding of expectations, direct incentives for adoption and use of certain technologies, or incorporation into existing payment models.

This paper adds to the literature by describing current thinking about the use of analytics and HIT functionalities to coordinate care for complex patients. The literature described a modest number of projects and evaluations, but our search was constrained and we specifically excluded interventions for the care of single-disease patients. Our discussions with a diverse range of SMEs revealed many innovative projects and products. Together, our findings identified a number of innovations in which analytics are used to identify specific complex patients who may benefit from interventions and HIT functionalities that improve coordination among patients and their providers. However, there are a number of key challenges around analytics related to data quality and social determinants of health and around care coordination functionalities related to understanding the key coordination problems. Options that could accelerate innovation include producing better knowledge of the key problems and convening the diverse stakeholders to align around potential consensus solutions.

## Appendix A: Details of the Literature Review

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We conducted a targeted literature review to identify both analytics projects used as part of an intervention and HIT functionalities designed to facilitate care coordination and communication among providers caring for the same patient. We searched multiple research databases including PubMed, Web of Science, and SCOPUS. The full search terms we used are listed here.

### PubMed

- ((“health IT” OR “informatics” OR “analytics” ) OR (medical records systems, computerized[MeSH Terms] OR electronic health records[MeSH Terms] OR personal electronic health records[MeSH Terms] OR decision support systems, clinical[MeSH Terms]), AND
- (“complex patients” OR “care coordination” OR “coordination of care” OR “coordinated care” OR “coordinating care” OR “health information exchange” OR “disease management” OR “case management” OR “self-management support” OR “chronic disease” OR “chronic disease”[MeSH Terms] OR “risk stratification”), AND
- (humans[mh] OR premedline OR inprocess[sb] OR publisher[sb]))

### Web of Science

- TS=“health IT” OR TS=“informatics” OR TS=“analytics” OR TS=“computerized medical records systems” OR TS=“electronic health records” OR TS=“clinical decision support systems”, AND
- TS=“complex patients” OR TS=“care coordination” OR TS=“coordination of care” OR TS=“coordinated care” OR TS=“health information exchange” OR TS=“disease management” OR TS=“case management” OR TS=“self-management support” OR TS=“chronic disease” OR TS=“risk stratification”

### Scopus

- TITLE-ABS-KEY (“health IT”) OR TITLE-ABS-KEY (“informatics”) OR TITLE-ABS-KEY (“analytics”) OR TITLE-ABS-KEY (“computerized medical records systems”) OR TITLE-ABS-KEY (“electronic health records”) OR TITLE-ABS-KEY (“clinical decision support systems”) AND
- TITLE-ABS-KEY (“complex patients”) OR TITLE-ABS-KEY (“care coordination”) OR TITLE-ABS-KEY (“coordination of care”) OR TITLE-ABS-KEY (“coordinated care”)



OR TITLE-ABS-KEY (“health information exchange”) OR TITLE-ABS-KEY (“disease management”) OR TITLE-ABS-KEY (“case management”) OR TITLE-ABS-KEY (“self-management support”) OR TITLE-ABS-KEY (“chronic disease”) OR TITLE-ABS-KEY (“risk stratification”)

Of the ten articles used in our literature review, three were relevant reviews, three focused on analytics, and four described HIT functionalities used for care coordination (None of the articles described both.) Of the seven studies that were not reviews, intervention groups existed for one study of analytics and one of an HIT tool. Table A.1 provides an evidence table detailing these studies.

**Table A.1. Example Interventions Identified by Literature Review**

<b>Study, Year; Study design</b>	<b>Time Period</b>	<b>N (patients)</b>	<b>N (providers)</b>	<b>Outcomes</b>	<b>Analytics</b>	<b>HIT Functionalities</b>
Dale et al., 2012 <sup>20</sup> Semistructured interviews	n/a	4,043	47	Qualitative findings related to access, best practices, and communication. Clinicians found value in care coordination functionalities, but lack of integration with EHR made system difficult to use.	n/a	Tasks, reminders, and communication for case manager aggregated on a "tickler" (list of planned but incomplete tasks). Providers and clinics have access to a dashboard with 27 quality measures. Patient summaries are then integrated into the EHR.
Dorr et al., 2008 <sup>21</sup> Controlled trial	2002–2005	3,432	122	Death rate among care managed patients at one year reduced from 9.2 percent to 6.5 percent (p<0.05). Care managed patients were more likely than controls to have had an ED visit at two years (49.9 percent vs 43.8 percent; p<0.05)	n/a	Care coordination done by a case manager using structured protocols for certain conditions and a care management tracking database. Primary care clinics have access to the information and reviewed it regularly.
Fortney et al., 2010 <sup>22</sup> Description of tool development	n/a	n/a	n/a	n/a	n/a	Depression care coordinators add patients to a homegrown software tool and assign them to a primary care provider.
Hewner et al, 2014 <sup>17</sup> Pre-post	2008–2009	88,615	n/a	Rate of hospitalization dropped from 497 to 449 per 1,000 individuals with chronic disease in Medicare, from 303 to 279 in Medicaid, and from 177 to 152 in those with private insurance (no significance data)	Algorithms use ICD-9 codes and hierarchical disease stratifications to classify patients into risk group based on comorbidity and complexity for targeting with phone calls by nurse care coordinator	n/a
Hewner, 2014 <sup>18</sup> Feasibility pilot	2004–2009	n/a	n/a	n/a	Most recent year of inpatient, emergency room, and office visits for five diagnosis codes was used in an algorithm to compute complex chronic disease complexity to inform nurse telephone outreach	n/a

<b>Study, Year; Study design</b>	<b>Time Period</b>	<b>N (patients)</b>	<b>N (providers)</b>	<b>Outcomes</b>	<b>Analytics</b>	<b>HIT Functionalities</b>
Kim et al., 2014 <sup>23</sup> Description of tool development	n/a	n/a	n/a	n/a	n/a	Care team has access to a centralized care plan. Patient can decide which care plan members are included and enter self-report assessments. Activities are scheduled and assigned to different care team members. Care coordinator monitors the tool for these patients.
Lobach et al., 2013 <sup>19</sup> Randomized controlled trial	2005– 2006	20,180	n/a	Patients in intervention group had fewer low-severity emergency department encounters vs. controls (8.1 vs. 10.6/100 enrollees, p<0.001) with no increase in outpatient encounters or medical costs	Used Medicaid enrollment, claims, notices generated by the decision support system, care manager activity logs, and regional HIE to identify triggers for care coordinators to contact patients	n/a

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