

# Knowledge Gaps Inhibit Health IT Development for Coordinating Complex Patients' Care

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**A**rguably, the greatest opportunity to save on healthcare spending in the United States is through more effective care of complex patients—defined as those with multiple comorbidities, high risk for poor outcomes, and high cost.<sup>1,2</sup> Given that such patients typically visit multiple providers, improved care coordination is one important means of improving the effectiveness of their care.<sup>3-5</sup> Despite this need, the care of complex patients is generally poorly coordinated.<sup>6-9</sup> Few interventions have been shown to be effective in addressing the care coordination needs of these patients, and thus, reducing costs.<sup>10</sup>

Information technology (IT) has been widely adopted outside of healthcare to support coordination among individuals. For example, project management technology coordinates workplace tasks, and configuration management programs help coordinate the work of software developers. However, recent studies have found a relative lack of such technical capabilities in healthcare, despite the existence of many of the components required for such capabilities (eg, cloud computing platforms, widespread use of smartphones, internet connectivity).<sup>11,12</sup>

Although spending on health IT has increased, little effort has been devoted to developing care coordination technologies for complex patients. In addition, little is known about the latest generation of technologies.<sup>13</sup> We sought to understand the key barriers to progress and the technical capabilities (ie, functionalities) at the leading edge of innovation. Building on our findings, we provide suggestions for how to better harness health IT to coordinate care for complex patients.

## METHODS

We conducted a series of discussions with experts from a variety of stakeholder perspectives, identifying them through a targeted literature review, recommendations from other experts, and snowball sampling. We selected 35 experts to represent a wide range of stakeholder perspectives from the private sector, academic institutions, and federal agencies. We conducted 2

## ABSTRACT

**OBJECTIVES:** Complex patients incur a majority of healthcare costs in the United States, in part, because their care is poorly coordinated. We sought to determine the leading edge of health information technology (IT) tools for care coordination of complex patients.

**STUDY DESIGN:** Qualitative discussions and technical expert panels.

**METHODS:** We conducted 35 discussions with clinical leaders, technology and startup executives, government officials, academic researchers, and 2 technical expert panels.

**RESULTS:** Although health IT has the potential to improve care coordination, the types of IT tools available to clinicians and patients are currently limited. We found substantial barriers to developing technical capabilities for improving care coordination, including lack of knowledge of users' needs; lack of standardized roles, responsibilities, and protocols; required changes in providers' work activities to achieve coordination; and an unclear value proposition.

**CONCLUSIONS:** We found several innovative tools, but existing efforts suffer from important limitations, including minimal engagement by physicians, lack of standardized definitions of what the tools do, and challenges integrating with clinical workflows. For health IT to facilitate coordination of care for complex patients, user needs and workflows must be better understood and used to guide the development of technology and policy.

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### TAKE-AWAY POINTS

Coordination of complex patients' care has great potential for producing savings. Although health information technology (IT) has the potential to help achieve this goal, the types of IT tools available to coordinate care for complex patients are currently limited. Specific study findings include:

- ▶ Substantial barriers to developing technical capabilities exist and include a lack of knowledge of users' needs and a lack of standardized roles and responsibilities.
- ▶ Current tools engage physicians minimally and have challenges integrating with clinical workflows.
- ▶ For health IT to facilitate coordination of care for complex patients, user needs and workflows must be better understood and used to guide the development of technology and policy.

phases of in-depth discussions, ranging from 45 to 90 minutes, using a guide that identified key topics to be covered, including IT capabilities for care coordination. After the first phase, we convened a technical expert panel to discuss the preliminary results and refine a second phase of expert discussions. The second phase focused on IT capabilities designed to facilitate care coordination through communication among providers caring for the same patient.

From the expert discussions, we identified key themes, including barriers to progress and types of technical capabilities that overcome these barriers. We then identified potential opportunities for further advancing care coordination IT tools to better meet the needs of complex patients and their care teams.

This study was approved by the RAND Institutional Review Board and all discussion subjects gave informed consent.

### Barriers to Innovation

Experts identified 4 key barriers to the development of new IT tools for care coordination.

**1. Defining coordination.** The types of coordination needs, and activities that address them, are poorly understood, which makes it difficult for IT designers to create solutions. Even members of our technical expert panel disagreed about what activities should be called coordination. Some experts drew a sharp distinction between activities related to coordination versus treatment; in their view, physicians were not a necessary part of coordination. Others believed that such a distinction was unhelpful because many coordination activities are also related to treatment and involve physicians (eg, developing care plans, communicating with other physicians). From their viewpoint, it would be a mistake to not fully engage physicians as users of a functionality that facilitates care team communication.

**2. Standardization.** The users' roles, responsibilities, and protocols are not standardized, except in special circumstances, like postsurgical care within an institution.<sup>14</sup> The lack of standardized shared definitions for care team membership and associated workflows makes it difficult to operationally establish current care team roles. Even creating names for roles, such as "care coordinator,"

is challenging, because they lack universal meaning and the roles change over the course of a patient's care. Experts described challenges defining user roles even for common tasks: the management of a patient's problem list—a list of the most important health problems facing a patient, including current and active diagnoses as well as relevant past diagnoses—does not have agreed-upon protocols defining which member of a care team is responsible for updates or corrections. Providers tend to be reluctant to modify problems added by

other providers.<sup>15,16</sup> Additionally, product design is complicated if users must be able to handle significant diversity, which can include variation among providers' practice patterns and workflows, and patients' needs and preferences.

**3. Forced change.** The use of IT tools for care coordination forces changes in the typical provider workflow. Joint use of a shared platform outside of a patient visit may require a work culture change for providers accustomed to visit-centric care. Including the patient in such communication is also new and unfamiliar.<sup>17</sup> Incorporating this kind of work into routine clinical practice may require substantial training and the development of new work processes, such as establishing dedicated time for using the tools, and protocols for identifying and prioritizing patients' coordination needs.

**4. The business case is unclear.** Changes in incentives—such as accountable care—may make a better business case for providers to purchase and use care coordination IT capabilities, but the shift to newer payment arrangements has been slow. Even under such incentives, there is no evidence that use of IT tools for coordination will result in enough savings to justify purchasing and using the tools. Part of the challenge is the need to provide a compelling value proposition that takes into account the many types of users (eg, patients with varying conditions, patients' families, physicians of all specialties, nurses, social workers, medical assistants) that vary both across and within organizations.

### Technical Capabilities for Care Coordination

Despite the barriers described above, we identified 5 types of IT tools that can facilitate coordination: care plans, dashboards, patient relationship managers, event alerts, and referral tracking (Table). Some products combine and integrate these capabilities and focus on certain types of care coordination activities. We found no efforts that were comprehensive care coordination solutions. For some of these capabilities, basic forms are in more widespread use (eg, dashboards of quality indicators, text-based care plans). More advanced functionalities (eg, a goal-oriented care plan that supports communication among all members of a care team, alerts for a range of event types that can be "subscribed" to) are largely

**TABLE.** Descriptions of Identified Care Coordination Capabilities

Capabilities	Description
Care plans	Care plan definitions vary widely, although most are designed primarily for care coordinators. Typical care plan capabilities allow care coordinators or other care team members to select care goals and interventions and track progress. Care goals may be pre-populated 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	Dashboards are populated by clinical data from an EHR that displays the performance on quality indicators for a panel of patients. They support ad hoc patient searches and can serve as prompts for discussions among members of a care team. They may also provide administrative capabilities for scheduling patients and monitoring their status.
Patient relationship managers	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. 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 standalone system.
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.

ED indicates emergency department; EHR, electronic health record; HIE, health information exchange.

still under development or being tested in pilots. Care plans were the care coordination functionality described by experts as being in use most frequently, as well as being the most complex and varied. Other functionalities included dashboard, patient relationship managers, event alerts, and referral tracking. We describe care plans below and provide additional details on this functionality and others in the [eAppendix](#) (available at [www.ajmc.com](http://www.ajmc.com)).

Experts described several care plan products developed by companies, including several startups, and those as part of research projects. Other experts described the desired functionality based on their experience as leaders in large provider organizations. Below, we summarize the experts' input on the following aspects of care plans related to health IT: the definition of care plan and its varying content, types of users involved, definitions of user roles and responsibilities, and methods for tracking members of a care team. The eAppendix contains a summary of how care plans supported task tracking and communication among the care team.

**Definition of a care plan.** We found that the term "care plan" was poorly defined and meant different things to different experts. Experts differed in their understanding of the content and purpose of the care plans within a health IT system: a) static text that described brief action steps: annual ophthalmology visit and foot exam; reach a target weight; take BP every day; b) ability to track gaps in care, such as overdue screening tests, and issue reminders to patient, clinicians, or care coordinator; c) care plan structured around a list of problems, each with an associated goal and its assigned intervention; and d) "dynamic" care plans that are accessible between visits and can be updated (experts did not provide any more detailed specifications).

**Types of users.** Care plan functionalities mentioned by several experts were accessible to members of a care team and facilitated interactions among them. Users included clinicians, the patient, patient surrogates (eg, parents or children), care coordinators, and 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 roles 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 experts 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 (eg, 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 about patients' available resources, goals, and symptoms. These assessments are used in some products to automatically produce or update tasks within the care plan (eg, triggering a care coordinator to give patients educational materials). Experts also described how the care

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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. One expert said that having clinical logic that would suggest or automatically add or remove providers to the team for a specific patient would facilitate the use of care plans. Several experts 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 given that care team membership changes over time, this complicates the efforts of those developing these functionalities

### Limitations to Existing IT Capabilities

Although the 5 IT capabilities above are clear signs of innovation, we found 3 important limitations. First, few care coordination products are designed for or used by physicians—this is particularly true for care plans. Although there are certainly care coordination activities that may not need to involve physicians, complex patients commonly receive care from multiple physicians,<sup>4</sup> and some coordination-related issues that involve physicians are well-documented (eg, missing or unclear information at the point of care, unclear accountability for next steps, “dropping the baton” on referrals).<sup>6,7,18,19</sup> Yet, few efforts described by discussants engaged physicians to address these issues.

Second, the types of activities that the IT tools support vary widely and lack standardized definitions, which reflects the barriers cited above; ultimately, user roles and responsibilities are poorly understood. For example, “care plans” could mean anything from a simple text box to a structured list of problems with associated goals and assigned interventions. Other ways in which care plans varied included the types of users for whom the capabilities were designed, the ability granted to patients to perform tasks, tracking members of a care team (patient invite vs provider invite), support for tracking tasks as part of the care plan, and lastly, the ability to communicate through messages embedded within the care plan. This variation and lack of standard definitions for describing the technical capability was a source of frustration for executives from provider organizations and made it challenging for them to understand the capabilities or compare products.

Third, care coordination products are often not easily integrated into existing physician workflows. Some experts believed that electronic health record (EHR) integration was required for physicians to agree to use the capabilities. Others said that care

coordination capabilities could serve as a kind of bridge between different EHRs, because they would contain data from multiple systems. However, in order for such capabilities to bridge this EHR gap, care coordinators were often required to manually translate information (eg, physician orders) from the EHRs into separate care plan software. EHR integration challenges were less of a problem when the care plan capability was offered as part of an EHR vendor’s integrated solution, as certain data elements were populated automatically from the patients’ medical record, facilitating the generation of the care plan. Some experts expressed optimism in a “post-EHR” world in which innovative care coordination tools could be more easily integrated into the products used by providers.

Although the potential for IT to improve the coordination of complex processes has been demonstrated in many industries, the use of IT to improve coordination of care for complex patients is less clear. Substantial barriers impede development and the use of these tools in healthcare. Recent efforts are focusing on developing innovative solutions, but are nevertheless struggling with the barriers. Below, we discuss 3 key challenges, as well as policy opportunities to address them.

**Challenge 1: The information and communication needs of users are diverse and poorly understood.** Understanding user needs is a prerequisite for building effective technology. To improve care coordination of complex patients, the needs of every type of user (eg, physicians of every specialty, nurses, social workers, patients, family members) and the types of coordination activities in which they participate must be understood. This knowledge is needed to allow IT tool developers to accommodate different types and levels of engagement by various types of users as they perform a range of coordination activities. Amassing this knowledge is complicated by the wide variation in workflows across the healthcare system, as well as diversity of users’ preferences. For example, one recent study assessed preferences of elderly patients for information sharing with their caregivers and found substantial complexity and diversity.<sup>20</sup> Furthermore, information needs will undoubtedly change; as with other technologies, the roles, responsibilities, and workflows of users will need to be redesigned to make full use of new capabilities.<sup>21</sup>

Two activities could help address this problem. First, conducting an extensive assessment of user needs. This work will require characterizing the workflows and preference of each type of user, establishing standard definitions for user needs, and describing prototypical roles and responsibilities. Second, experimenting with the redesign of both workflows and IT capabilities to address a subset of critical user needs. It will be important to perform rapid cycles of testing, evaluation, and refinement of workflows and IT capabilities, so that care coordination interventions can be improved efficiently.

**Challenge 2: Care coordination capabilities interrupt provider workflows.** To fully engage physicians and other providers in care

## CONCLUSIONS

coordination, the burden of accessing care coordination IT capabilities must be minimized. If EHR vendors developed the capabilities to be well-integrated into existing products, workflow interruptions could easily be reduced for some patients. However, patients are likely to continue to receive care from providers in different organizations given existing patterns of fragmentation.<sup>3-5</sup> Thus, there will be an ongoing need for care coordination IT capabilities to integrate with multiple EHR vendors to avoid workflow interruptions for patients who receive care from provider who use different EHRs.

Improvement in integration could be achieved through novel care coordination capabilities and/or improved interoperability of health IT more generally. Given that EHR vendors have many competing priorities, organizational capacity to focus specifically on developing novel care coordination functionalities may be limited. Therefore, we believe that the most promising path to innovation is through improved interoperability. Ongoing health IT interoperability efforts are attempting to develop standards that would make it easier for healthcare applications to integrate with each other.<sup>22,23</sup> Such standards could facilitate integration of care coordination capabilities and ultimately reduce workflow interruptions.

The challenge to this approach, however, is to develop technical standards for capabilities that have not yet been specified. To better specify care coordination capabilities, particularly care plans, policymakers may consider convening experts to decide on key use cases (specifications of how and by whom the technical capabilities will be used) to guide standards efforts. Such efforts may be informed by the user needs assessments described above.

**Challenge 3: Existing incentives are not sufficient.** The lack of reimbursement for the care coordination supported by IT capabilities means that only risk-sharing or other emerging forms of accountable care provide incentives for adopting these technologies. However, there may be a “chicken and egg” problem: providers may resist taking on risk without proven tools and methods to manage the care of their highest-cost patients. Yet, without a market of providers to drive innovation, such tools may not be developed. Policy makers may overcome this problem by sponsoring research the helps to develop the tools as described above, demonstrate their efficacy, and identify best practices.

### Limitations

This work has several limitations. First, we limited our expert discussions to the United States because the international situation was beyond the scope of this project. Second, this was not a formal qualitative research study and we did not transcribe the discussions. We did conduct the discussions rigorously, requiring at least 2 project team members at each discussion and following up with e-mail for clarifications as needed. Finally, new innovations could have emerged since our discussions given the high level of interest in cost-effective coordination strategies related to payment reform.

Although health IT capabilities are being developed to facilitate coordination of care of complex patients, much is still unknown. Developing successful health IT capabilities should begin with a deep understanding of user needs and will require iterative development in which changes are made to both the technology and workflows. There may be a role for policy to address these critical gaps in knowledge and kick-start the development of better solutions.

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## **eAppendix.** Additional Details on Functionalities

### **Care plans**

**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 experts 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 expert 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 experts described a goal of social media-like flexibility so that any member of the care team could engage in “ad hoc, timely communication.” Other experts described communication involving structured notes or secure messaging similar to email.

### **Dashboards.**

Experts 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 experts 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 expert 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 expert discussed a system where providers could send each other patient-specific alerts.

## **Referral Tracking.**

Several experts 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. Experts described referral-tracking products that were part of an HIE and those supplied by vendors to large community provider organizations. Experts suggested that the recent interest in referral tracking might be motivated by the patient-centered medical home requirement to perform referral tracking.<sup>1</sup> One expert 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.

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