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**Health Information Technology to Support Care Coordination and
Care Transitions:
Data Needs, Capabilities, Technical and Organizational Barriers, and
Approaches to Improvement**

Commissioned Paper

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Introduction

Improving measures of care coordination would allow us to align policies and financial incentives with the provision of coordinated care. The way that we measure healthcare quality is rapidly changing with the adoption and widespread use of clinical information systems and other health information technologies. In addition to information systems within the healthcare system, telemedicine and consumer health informatics offer an unprecedented opportunity to gather data directly from patients. Eventually, we will be able to use all of these data sources to support care, and they will likely be pivotal for care redesign efforts such as patient-centered medical homes and payment reform approaches like accountable care organizations.

In this commissioned paper for the National Quality Forum, we give an overview of health information technology (HIT) to support care coordination and care transitions. We start with background on existing measures and legislation governing health information technology. We describe data needs for care coordination. The next section addresses the current capabilities of clinical information systems to fulfill these data needs. We then outline both organizational and technical barriers to improving the capabilities of health information technology and health information exchange. Finally, we put forth approaches to addressing each barrier.

This information may be useful to organizations as they plan for increased HIT capacity to support care coordination. The paper may also be used by measure developers to identify areas where measures are currently feasible. Lastly, we need technical solutions and organizational solutions to gaps which must be filled in order to harness the potential of HIT to support care coordination.

Background: Measures of Care Coordination and Care Transitions

The National Quality Strategy has identified effective communication and coordination as a high priority area for the nation.¹ In addition, the Office of the National Coordinator has clearly identified care coordination and transitions as high priority domains for which quality measurement built into electronic systems will be required.²

The National Quality Forum (NQF) began to address this complex issue by undertaking several projects over the past few years that intended to provide a framework and guidance for care coordination measurement. In 2006, the NQF endorsed the NQF Care Coordination Framework that identified five domains of care coordination measurement: healthcare home; proactive plan of care and follow-up; communication; information systems; and transitions or hand-offs.³ This project was followed by a Phase I project, which followed the formal Consensus Development Process (CDP), in 2010 that endorsed 25 care coordination Preferred Practices and 10 performance measures.⁴ Three of the Preferred Practices were included within the Information Systems Domain and highlighted the need for “standardized, integrated, interoperable, electronic information systems,” which could “allow patient’s health information to be accessible to all caregivers” and be governed by “regional health information systems, which...enable healthcare home teams to access all patient information.”

More recent work by the NQF has further supported the infrastructure needed for the development of more innovative care coordination measures. Specifically, the NQF has developed the Quality Data Model (QDM), which will develop an information model that

defines clear concepts used to enable the automation of electronic health record use for quality measures. For example, the recently released draft technical specifications provide QDM elements, or standard definitions and expression language, to express a category of information, the context of its use and its relationship to other information to allow for measures of care coordination such as referral loop closure.⁵ In addition to developing measure expression language via the QDM, the NQF has also developed the Measure Authoring Tool (MAT). The MAT is a web-based tool for measure developers to express their measures in HL7 approved format.⁶ The MAT uses the QDM as its core structure and can enable future care coordination measure development by providing a wide variety of measure developers by enabling standardization of measure concepts.

In addition to work by the NQF, the Agency for Healthcare Research and Quality recently completed the AHRQ Care Coordination Measures Atlas, which was intended to comprehensively review existing measures for assessing care coordination interventions in research studies and demonstration projects.⁷ In addition to proposing an enhanced framework for care coordination measurement, this review identified 61 care coordination measures. Most of these measures, however, were written surveys of patient experience and no electronic health records based were identified by this rigorous systematic review.

The evolution of care coordination measures demonstrates progress with limitations due to the nature of data sources. Initial measures of patient-experience, such as the 3-item Care Transitions Measure (CTM-3)⁸ are patient-reported, written surveys that are both costly to administer as well as aggregate. Much of the last decade has evolved from written surveys to measures utilizing

paper charts. The transition record includes specified elements received by discharged patients⁹ and is not only limited by the time-consuming chart abstraction of unclear reliability, but also by the limited utility of medical records to capture many transition data elements. More recent measures, such as the “Patients with a transient ischemic event ER visit who had a follow-up office visit”, attempt to utilize administrative claims data to capture care coordination. These measures however are unable to account for disruption in insurance plans or coverage, the lack of clinically relevant data available in insurance claims¹⁰, and difficulties in attribution created by these measures. Finally, while some eMeasures have been developed to overcome the aforementioned hurdles, the few that have been reported may be condition specific and are not designed to support comprehensive care planning. For example, the Preventable Drug Related Morbidity Indicators can measure coordination for high risk medications such as warfarin, but fail to adequately measure medication management and outcomes in a broad-based manner.¹¹

A recent unstructured review of care coordination measures¹² demonstrated that virtually no reliable, validated eMeasures are available in the public space for organizations or practices interested in care coordination measurement. Recent initiatives, however, may change this trend as the Accountable Care Organization pilot initiatives by Premier Group and the Dartmouth Collaborative are piloting measures such as use of post-discharge care plans with documented follow-up action as well as measures of patient communication for application to high-risk patient portals.

Beyond work conducted by traditional performance measure developers, the Office of the National Coordinator’s (ONC) and the Centers for Medicare and Medicaid have incorporated

care coordination into the Meaningful Use regulatory strategy and this effort has laid the groundwork for Electronic Healthcare Records (EHR) driven care coordination measures. Stage 1 of the Meaningful Use regulation demonstrates the ONC's commitment to care coordination measurement. The Final Rule included Core Objectives with an explicit requirement for key clinical information (problem lists, medication lists, medication allergies, and diagnostic test results) to be available and exchangeable among providers, patients and patient authorized entities electronically in order to be considered for Meaningful Use certification.¹³ In addition to the Core Measures, Stage 1 Menu Measures included measures of medication reconciliation and care transition summary records to support coordination. Stage 2 of Meaningful Use regulations are expected to include an expanded set of measures intended to ensure that EHR development support care coordination. For example, the Stage 2 Proposal by the Health Information Technology Policy Committee includes structural measures for care plan goals, patient instructions and the ability to electronically identify and communicate with healthcare providers including the primary care physician and other healthcare team members.¹⁴

As the Healthcare Information Technology Standards Committee continues to choose standards and measures for Stage 3 of Meaningful Use, there will likely be even greater momentum for EHR integration and information exchange to promote care coordination. (See Approaches section for further information on these efforts) Stage 2 includes many structure or process measures, which makes the measurement of a critical coordination processes such as the development and transfer of effective comprehensive care plans challenging. There is a short-term need for the public evaluation and testing of innovative care coordination eMeasures to

ensure that the Office of the National Coordinator and all relevant committees have sufficient evidence to support the development of more mature standards for care coordination.

In this commissioned paper, we have used a framework proposed by Singer et al.¹⁵ for ‘integrated care measurement’ that considers both care coordination activities as well as the needs for patient centeredness that function as the basis for the need for information technology improvements to serve as an underpinning for the National Quality Strategy. Singer et al. recently proposed a new definition and framework for integrated care with the goal of providing more clarification by defining integrated care as a multidimensional construct rather than unidimensional “organizational” activities. The working definition for integrated care used was “patient care that is coordinated across professionals, facilities, and support systems; continuous over time and between visits; tailored to the patient’s needs and preferences and based on shared responsibility between the patient and caregivers for optimizing health.” For this analysis of the role of HIT in care coordination measurement, we will frame our discussion along the seven constructs proposed by Singer et al: 1) Coordinated within care team; 2) Coordinated across care teams; 3) Coordinated between care teams and community resources, 4) Continuous familiarity with patient over time; 5) Continuous proactive responsive action between visits; 6) Patient centered; and 7) Shared responsibility. (See Glossary for definition of Care Team and Care Plan as used throughout the manuscript.)

Data Needs: Support for Care Coordination and Care Transitions

The data needs to improve patient-centered care at transitions and over the patient's lifetime are expansive. The healthcare system must move toward a multidisciplinary approach to care and this must be supported by clinical information systems designed for use by all members of the care team. Vulnerable patients, such as frail geriatric patients, are the least able to navigate the healthcare system and may be assisted by caregivers or by community-based organizations, which have distinct data needs from an individual. The future success of care coordination efforts depends on fulfilling the data needs in 'the last mile' between the healthcare system and the patient in the community.

As a starting point, this report details data needs for seven domains taken from a framework for measuring integrated patient care:

- 1) Coordinated within care team
- 2) Coordinated across care teams
- 3) Coordinated between care teams and community resources
- 4) Continuous familiarity with patient across time
- 5) Continuous proactive and responsive action between visits
- 6) Patient-centered - the extent to which providers consider the needs, preferences, values, and capabilities of the patient, family members, and other caregivers
- 7) Shared responsibility - based on shared responsibility between patient and caregivers for optimizing health

Domain 1: Coordinated within care team

Documenting information generated within a care team

It is imperative to document accurate and up to date core data elements such as problem, allergy, and medication lists so that all members of a care team can access these data elements which impact diagnostic and therapeutic decisions. It is preferable to use structured searchable data in many instances. Data to support billing is often stored as structured data, but clinical data is not. Structured data fields should be used more widely in order to support research and quality measurement, as well as to drive point-of-care clinical decision support.

Compiling information within a care team

Tools to track patients over time would help members of a care team to quickly assess what has been completed and what is pending for the patient. Quantitative data are best represented using graphs and other temporal data views. An EHR should identify trends in data over time that put the patient at risk of iatrogenic complications or indicate worsening disease.¹⁶ Providers need tools that help them to create a mental timeline of events for a particular problem.

Multidisciplinary care teams need tools to improve communication within the care team. Patients and caregivers need a summary of the role of each provider in the care team.

Comprehensive Care Plans

We should be able to create one care plan for all conditions, including documentation from physicians, nurses and other providers responsible for each condition. (See Glossary for definition of Care Team and Care Plan as used throughout the manuscript.) Within one care team, the plan should state who is responsible for answering questions about each diagnostic test, medication, or procedure.

Domain 2: Coordinated across care teams

Core data elements from multiple sources

Interoperable clinical information systems should be able to incorporate changes to core data such as problem, allergy and medication lists. This activity should not involve double data entry by the receiving care team or scanned documents.

Medication reconciliation

Medication reconciliation tools should include at least four functions:

1. import medication data from other sources
2. display medication lists to allow comparison
3. show new, changed, and discontinued medications
4. support the ability to designate who ordered the medication and who is allowed to refill it

Patient adherence is a major factor in effectiveness of medications, so medication reconciliation should also produce a patient instruction sheet with a patient-appropriate reason for each medication.¹⁷

Laboratory and radiology data

Clinical information systems should track laboratory and radiology tests until full loop closure.

When a provider orders a laboratory or radiology test, the order should be tracked until the result is received. Once the provider acknowledges the result, the system should also track the test until the patient is notified and a follow-up action has been initiated if the test is abnormal.

Referrals and consultations

Just as clinical information systems should track test results, they should ensure full loop closure of referrals.¹⁸ We need secure electronic communication within and across settings so that

generalists and specialists have a dependable mode of communication. In addition to generalist-specialist communication, we need better links to allied healthcare providers, home care, and visiting nurses. Finally, patients need more information on the role of each provider and whether the loop has been closed.

Transitions and emergency care

When a patient is discharged from the hospital, a summary should be generated that is timely, comprehensive, brief, and legible.¹⁹ Discharge summaries should adhere to the Care Transitions Performance Measurement Set.⁸ They should include the reason for admission, procedures and tests performed, devices (e.g., central lines, urinary catheters), wounds, summary of results, principal diagnosis at discharge, prognosis (whether the condition increases the risk of morbidity or mortality, e.g., retinopathy of prematurity increases the risk of low vision), disposition needs, functional status, and outcomes achieved by allied healthcare and entire team. Providers should be aware of other factors known to impact outcomes such as psychosocial complexity and caregiver information (e.g., foster care, joint custody).^{20,21} Ideally, the document should include an assessment of patient preferences, patient values, patient goals, and patient level of understanding. These items are particularly important for patients who are unable to communicate such preferences, such as the frail geriatric patients. The expectations for follow-up should include patient self-management, medication list, and studies pending at discharge (e.g., laboratory). We need to be able to document an Advance Care Plan or reason for omitting this information (e.g., rapid change in end-of-life preferences). Finally, the discharge summary must contain contact information for the ‘attending or record’ and the discharging physician should have the ability to confirm receipt by the physician accepting responsibility for the patient.

Comprehensive Care Plans

The plan should state whether patients have been counseled and have expressed understanding about the reason for each medication, diet and lifestyle changes, and where to learn more about each condition. In addition, behavioral health information should be available to all providers. Providers would be better able to provide patient-centered care and shared decision-making if the plan also included patient preferences about language, family involvement, and end-of-life care.

Domain 3: Coordinated between care teams and community resources

Clinical information systems should contain data on patient use of community resources. Providers should be able to communicate with community organizations. In some cases, the comprehensive care plan should be available to community organizations. When patients give healthcare teams permission to interact with community organizations data must be transferred securely, according to a standard format, and according to a service agreement.²²

Domain 4: Continuous familiarity with patient across time

A data field in the EHR should designate the patient's PCP. If another team member coordinates and triages care, that person's contact information should be stored in the EHR and electronically accessible by patients and their caregivers. Every member of the primary care team should have access to the comprehensive care plan. The patient should have the ability to send new information to everyone on the primary care team. The primary care team should be able to share information electronically with the patient and each other simultaneously.

Domain 5: Continuous proactive and responsive action between visits

We should have systems to both track patients and prompt appropriate action at the appropriate time according to the comprehensive care plan. With the test and referral tracking systems described above, providers would know which patients are in an open test or referral loop. For chronic disease management, population management systems such as registries with functions for tracking patient-entered data help providers to support patient self-management between visits. In addition to producing a list of patients with a condition, these systems should include functionality to schedule future tasks.

Patient-centered care domains

Patients are learning to use the internet across all ages and socio-demographic groups. At the current time, tools have not been customized for differing patient skills for internet use. Therefore, we will address Domains 6 and 7 only briefly in the subsequent sections (Current Capabilities, Barriers and Approaches to Improvement). We list a few points here as future data needs.

Domain 6: Patient-centered

Electronic Health Records

We need a standardized way to record needs, preferences, values, and capabilities of the patient, family members, and other caregivers. EHRs should support structured documentation of preferred language, which would allow automatic output of patient education materials and patient letters in the appropriate language. Similarly, there should be a way to record patient literacy and numeracy levels. Constructs such as patient preference for shared decision-making

should be represented, as well as other constructs which have been proven to impact health outcomes. Patients should be able to view all of this information through patient portals.

Personal Health Records

To the extent that this section addresses health information technology support for care coordination broadly, the concept of using PHRs and interoperability between EHRs and PHRs is important. However, we will not address PHRs in the following sections as explained below.

Patient needs and capabilities may change over time and patients should be able to contribute to our store of information. Patient input of data about activities of daily living and other patient-reported outcomes could help healthcare providers coordinate care. Also, patients should be able to modify contact information, such as cell phone number, because this could impact a number of health outcomes.

In addition to ‘helping us help them’, patients and their caregivers are true care coordinators and may benefit from PHRs and other consumer health informatics applications independent of the healthcare system. Social support has been proven to modify outcomes. Websites like PatientsLikeMe are helping patients with rare conditions to learn about resources that may not be offered in their local community.

Domain 7: Shared responsibility

Electronic Health Records

We should be able to document the roles of providers and patients in EHRs so that they can produce a summary for patients. In chronic disease management, self-management expectations should be documented and patients should have electronic access to this information. With interoperability between EHRs and pharmacy fill data medication adherence may be estimated which may impact shared responsibility. Patients should be able to see whether providers have fulfilled responsibilities such as acknowledgement of receipt of test results or referrals. Patients should have electronic access to patient letters, particularly if management changes are suggested.

Personal Health Records

Patients can take on greater responsibility by updating problem, allergy, and medication lists, as well as mutable history components such as family history and social history.

Current Capabilities: Health Information Technology and Exchange

Information about the existing capabilities of health care delivery organizations to effectively use health information technology (HIT) in support of clinical care coordination is available from surveys of organizational leaders (and end users) and published organizational experience. Evidence about the current use of HIT can be assessed in the first five of seven domains.

Domain 1: Coordinated within care team

There is a scarcity of information on how care teams use HIT to deliver consistent clinical care and administrative services for individual patients. Reliably assigning patients to specific primary care physicians (PCPs) or care teams remains a key challenge in most ambulatory practices. In a semi-structured telephone survey of 60 physicians and ancillary staff with experience using commercial electronic health records systems (EHRs) in 12 randomly selected US communities in 2009, only a few respondents identified capabilities for electronically linking patients with specific PCPs.²³ Whether this capability extends to assigning patients to care teams comprising nurses and support staff in addition to PCPs remains unknown.

Domain 2: Coordinated across care teams

Most of the evidence about HIT support for coordinating care across care teams comes from large integrated delivery systems. Use of ambulatory EHRs that integrated laboratory and radiology test reporting, physician order entry, recording of health care utilization (such as emergency department visits and hospital admissions), and easy searchability for these data elements was adopted early on by Kaiser Permanente resulting in a decrease in overall health care utilization without a significant change in intermediate measures of quality of care.²⁴ Large integrated delivery systems have also developed capabilities for sharing information about patients' allergies across ambulatory and inpatient care settings.²⁵ EHR functionality facilitating post-discharge medication reconciliation was recently implemented by Partners HealthCare, a large integrated delivery system in Massachusetts.²⁶

Unfortunately, such high functionality is not readily available at ambulatory sites outside of large integrated delivery systems. In the survey by O'Malley et al referenced above, only a few respondents reported EHR capabilities for importing information from diagnostic testing facilities and hospitals and this information was often in PDF format and hence not easily searchable.¹ Evidence on the capabilities of US regional health information organizations (RHIOs) reveals substantial heterogeneity in providing ambulatory practices access to inpatient information. In a 2009 national survey, only 14% of US hospitals and 3% of ambulatory practices were covered by the 75 operational RHIOs capable of facilitating clinical data exchange between independent entities.²⁷ However, only 14 of these RHIOs were engaged in exchanging patient demographic characteristics, laboratory and radiology test reports, medication and problem lists, and discharge summaries between hospitals and ambulatory practices – covering only 3% of US hospitals and 0.6% of ambulatory practices. Remaining

RHIOs were capable of exchanging only one or two of the types of information listed above.

This lack of engagement in regional health information exchange (HIE) by ambulatory practices is borne out by more in-depth analyses such as a case study of nine Minnesota primary care practices which found that “no practice was fully involved in a regional HIE, and HIE was not part of most practices’ short-term strategic plans.”²⁸

Domain 3: Coordinated between care teams and community resources

Although promotion of HIT interoperability between ambulatory practices, acute and sub-acute facility providers, community-based providers of services (such as Meals-on-Wheels), and public health agencies has been espoused by the Public Health Data Standards Consortium, evidence of routine electronic data sharing is currently very limited.²⁹ Anecdotal evidence suggests that some publicly-funded hospital systems are making efforts to integrate electronic data with community-based agencies but the extent to which such efforts have succeeded has not been systematically assessed.³⁰ One program to address pediatric asthma developed a secure, web-based registry where asthma-specific information is available to patients, their families, nurses in public schools and community-based health workers.³¹ By and large, community-based agencies are using standalone electronic data systems that are not routinely integrated with private sector organizations thereby limiting opportunities for making and tracking referrals electronically and other data sharing.

Domain 4: Continuous familiarity with patient over time

Although the maintenance of up-to-date problem lists (of current and active diagnoses) and active medication lists are both “meaningful use” criteria and essential for care teams to provide

well coordinated clinical care over time, the extent to which US ambulatory practices qualifying for incentive payments through the HITECH act have adopted use of structured lists in EHRs is not known for certain. In a 2005 Massachusetts mail survey of PCPs only about 18% were using EHRs routinely and among them less than 20% reported capabilities for viewing test results, problem lists, or medication lists.³² This situation has improved somewhat in recent years; in the 2010 *National Center for Health Statistics* survey on EHR use by office-based physicians, about 25% reported having EHRs that met criteria for a “basic system” – assumed to possess capabilities for maintaining current problem lists and active medication lists.³³ Overall, 51% of US office-based physicians reported using all or partial EHR systems in early 2010.

Of particular concern for frail older adults, adoption of EHRs by skilled nursing and rehabilitation facilities has been exceedingly slow thereby limiting the electronic exchange of clinical information with acute care hospitals and ambulatory practices. In a 2003 semi-structured panel discussion among health informatics experts from multiple stakeholder groups, only about 1% of skilled nursing and rehabilitation facilities nationally were thought to have successfully implemented functional EHRs.³⁴ Furthermore, this expert panel estimated that EHR adoption by such facilities would grow to only about 14% nationally over the succeeding five years.³⁵ A 2005 national survey of RHIOs conducted by *Healthcare Informatics* magazine in collaboration with the American Health Information Management Association found that long-term and sub-acute care facilities comprised about 20% of RHIO participants nationally.³⁶ Limited adoption of HIT by sub-acute facilities imposes obvious constraints on sharing clinical information electronically across diverse care settings. Case studies of the functional capabilities of EHRs used by such facilities revealed little evidence for interoperability or auto-population of

data fields for electronic transfer of discharge documents.^{37,38} Site visits confirmed that sending paper documents with patients or faxing relevant documents remained the predominant form of facility-to-facility communication.

Domain 5: Continuous proactive and responsive action between visits

Although the positive impact of HIT in improving care delivery for patients with chronic illnesses is well documented, the extent to which EHR functionalities capable of supporting such improvements are available in ambulatory practices is not well known.³⁹ As can be expected, large integrated delivery systems were among the first to develop capabilities for tracking preventive and chronic care services for select, at-risk patient populations. By 2000, the Department of Veterans Affairs had developed capabilities for accurately and reliably identifying diabetics nationally based on linking inpatient and outpatient ICD-9-CM codes with pharmacy information.⁴⁰ Similar functionality was subsequently developed by Geisinger Health System's network of 38 practice sites and used to improve compliance with recommended diabetes performance measures.⁴¹ Comparable success was demonstrated by Partners HealthCare System in implementing electronic clinical reminders to improve compliance with recommended care for diabetes and coronary artery disease across 20 ambulatory practices.⁴²

In recent years, such capabilities have been adopted by increasing numbers of primary care practices outside of integrated delivery systems. This success is partly due to the efforts of state-level multi-stakeholder consortia such as the Massachusetts eHealth Collaborative. A 2009 Massachusetts survey of 167 ambulatory practices found that 89% were capable of generating diagnosis-based registries, 78% were able to create a laboratory results registry, and 83% could

generate a medication registry – a significant improvement compared with a prior survey conducted in 2005.⁴³

A unique example of a metropolitan public health system leveraging HIT to track and improve the delivery of preventive health services is offered by the New York City Department of Health and Mental Hygiene's Primary Care Information Project (PCIP).⁴⁴ Between 2007 and 2010, PCIP assisted more than 300 small, independent primary care practices with adopting fully functional EHRs capable of generating patient-specific point-of-care primary and secondary prevention reminders and automatically transmitting summarized data from each practice on the monthly delivery of recommended services. This allows PCIP to track provision of preventive health services to large segments of the population in real time instead of relying on random sampling in which each patient represents many times more patients in the target population.

Domains 6 and 7: Patient centered and shared responsibility

Personal health records (PHRs) hold great promise for involving patients and their family caregivers in coordinating care but currently lack widespread use and sufficient capability for delivering on this promise⁴⁵ PHR capabilities are improving with time and it is expected that closer integration into hospital and ambulatory practices' EHRs will increase in future⁴⁶. Large, urban academic medical centers have been early adopters of highly integrated PHRs whereas smaller, non-academic hospitals and ambulatory practices have been slow to follow due to slowness in adopting EHRs⁴⁷. Currently, there are no reliable data on the extent to which PHRs capable of two-way communication (capable of both uploading and receiving information) with hospital and ambulatory practices' EHRs have been adopted nationally or at the state level.

Barriers to Improvement

To address, through the use of health information technology, the capability and data needs for achieving fully integrated patient care as envisioned by Singer, it is important to understand what the organizational and technical barriers are. Only with consideration of these obstacles can solutions be designed to maximize the success of new paradigms of care. The barriers presented below are organized into those affecting all seven constructs of Singer's framework: Barriers to Effective Use of Technology, Barriers to Data Exchange, and Barriers to Availability of Important Information; and those primarily affecting the ability to achieve the shared responsibility and patient-centeredness constructs: Barriers to Sharing Expertise and Care, and Barriers to Patient/Family Involvement, although many of the barriers may also extend to these two constructs as well. (see Table 1)

1. Barriers to Effective Use of HIT

Resistance to New Technology

The healthcare industry has been slow to adopt electronic health records. Despite current national efforts to align incentives and accelerate the implementation and meaningful use of these systems, considerable resistance to integrating these systems into daily clinical care still exists. The primary obstacle continues to be the substantial expense of these systems, particularly for the small physician practices, and the lack of perceived value to justify their investment.⁴⁸⁻⁵⁰ Users find EHR systems take them more time, are hard to learn and disruptive to their workflow, and their implementation require more time and resources than they can manage.²³ They may

also feel the systems are not designed to meet their needs as a care provider; structured data input does not support their clinical decision-making processes, there is too much data and not enough actionable information, the system is hard to use at the point-of-care, there are too many alerts that are not relevant, and multiple systems may be difficult to integrate.^{23,51}

In moving a practice from paper to electronic records, or even in upgrading existing systems, careful consideration to planning, clinician and staff workflow re-design and change management principles are often inadequately applied.⁵² This can result in systems that are not well-integrated into a practice's processes of clinical care severely impeding clinician and staff use. Even those practices that have successfully implemented systems may resist modifying legacy systems or upgrading older versions of commercial EHRs to expand functionality. This is primarily related to cost and resource issues particularly given competing demands (e.g., ICD9 conversion), but may also be related to the difficulty in retooling for changed systems.⁵³

Sub-optimal Design of EHRs

Current capabilities and designs of EHRs and other health IT are variable and often do not adequately support the full range of clinical care data needs and processes.^{23,54} O'Malley et al systematically assessed more than 20 practices with commercial ambulatory care EHRs and identified a number of challenges with current EHR systems in supporting a vision of more comprehensive care coordination. Even for currently agreed upon important elements and functions of an EHR for managing patient information within a primary care practice, EHR designs are sub-optimal. Examples she reports include: summary screens that do not capture assessment and plan, tabs that separate related information so additional searching is required, templates that are too generic or too burdensome for documentation, missing fields to indicate if

a medication was stopped, and clinical decision support not sufficiently personalized to be relevant to individual patients. There has been an increase in the use of EHRs in creating registries to assist in population management within a practice,⁴³ but continued expansion and improvement in these capabilities is warranted.

Current EHR systems are also limited in their ability to support even fundamental components of care transitions between practices such as loop closure in referrals and consultations. Many EHRs lack referral and consultation tracking capabilities or, if electronic referral managers do exist, they often require providers to take on administrative responsibilities rather than creating this tracking as a byproduct of other clinical tasks.^{23,55} If standard email is used in sharing information, these are not integrated into the EHR and do not become part of the medical record.²³

When looking at EHRs' ability to support broader care coordination activities, much needs to be done. Design of the optimum care plan, associated data elements, and the blueprint of how best to synthesize and present all sources of data together have not been established to provide a framework for EHR development.

In addition to EHR content and functionality, the ability for users to intuitively navigate, easily absorb information presented, and not be burdened with excessive cognitive load -- that is, the usability of a system -- varies considerably across available systems. Historically, health IT vendors have not sufficiently involved clinicians, staff, and patients in their system design and development. EHRs designed without adequate attention to the user experience are destined to

meet with resistance, poor use, and unhappy customers. More recognition of the critical importance of optimizing the usability of systems is reflected in the recent release by the National Institutes of Standards and Technology of draft guidance underscoring the importance of evaluating the usability of EHRs,⁵⁴ but until usability evaluation efforts are consistently employed by system developers this will remain a challenge.

Inadequate Training and Support

Also impeding the successful use of health information systems is the lack of sufficient training and support of both physician and non-physician staff to make them competent users of the systems. It is challenging to get future users to participate in training, in part, because there are often no financial incentives or reimbursement for time spent in these activities. The importance of adequate training and support was highlighted by O'Malley's findings that many physicians were using workarounds to accomplish critical tasks even when the functionality existed in the system.²³

Organizational management principles such as change management in which end-users help to guide implementation, training, and support to promote success of system adoption are also not consistently employed by organizations.⁵² Vendor models of providing training and support may not be well-matched to the needs of users, particularly those in ambulatory care settings.⁵⁶

Upfront instruction on the use of a system is helpful for orienting users to the product, but it is the ongoing support in the moment when users are having difficulty accomplishing a task that leads to more effective learning and retention.

2. Barriers to Data Exchange

Lack of Industry-wide Standards

A significant barrier to the exchange of data in support of care coordination is the lack of comprehensive, industry-wide standards specifying the data elements, structure of data, standard models for querying data, and mechanisms for the technical transfer of data. Progress in addressing this issue is apparent with the recent efforts of a number of organizations, such as the Office for the National Coordinator HIT Standards Committee which has developed a Standards and Interoperability framework specifying structured data elements to include in care transitions, such as medications, allergies, problem lists, and patient demographics.⁵⁷ In addition, this group's Query Health initiative is tasked with identifying the clinical information model, standards, and services needed to support querying data sources across widely distributed EHR systems⁵⁸.

However, an extended set of standardized key data elements, structure, and implementation guidelines to support the broader vision of care coordination and patient-centered care, including the co-management of longitudinal care plans, does not yet exist. Work has begun in a number of areas to identify the framework and components required (e.g., patient medical home's whole-patient care plan or the Master Care Plan by ONC's Standards & Interoperability Transitions of Care Work Group), but no organization has yet been tasked with taking the lead on specifying all that is required to operationalize this goal. However, even once standards have been defined, it typically takes several years for them to mature as they are tested, revised, and re-revised to work the bugs out. Only after this crucible are they stable enough to promulgate for system development, exchange, and quality measurement.⁵⁹

Lack of Structured Data

In order for data to be exchanged between transmitting and receiving systems, it needs to be collected, structured, and coded for easiest integration. The consistency with which these requirements exist in practices and systems is extremely variable. Fields that are never filled out, or practices of entering free text in coded fields, restricts the ability to use and send these data. For example, Chan et al reported that none of the varied six practice sites they visited had structured data for all required fields to support referral loop measures.¹⁸ Interfaces in which paper documents, such as consultation letters or diagnostic results, are scanned and uploaded to electronic systems only provide unsearchable and uncoded information unless additional data entry occurs. Over time as systems develop and improve their functionality in support of structured data, practices may still lag behind in their capabilities because of resistance to and/or lack of resources to change or upgrade their EHRs to newer versions.

Lack of Interoperability

A basic, secure communication infrastructure to facilitate the exchange of information among patients/families, primary care and other providers, and the broad set of healthcare and community resources is needed. There is a lack of agreed upon standards to support interoperability between systems but, currently, very little incentive exists for vendors to cooperate with each other to become interoperable. The competitive nature of the EHR and other health information technology markets does not promote working together.²³ In addition, differences in state laws with respect to data access and patient privacy further complicate the landscape. Despite these hurdles, progress has recently been made with the release of a set of

technical specifications to standardize connections by a collaborative of seven states and eight vendors called the EHR/HIE Interoperability Workgroup.⁶⁰

Lack of system interfaces to pharmacies, outside laboratories, and other diagnostic services further complicate the ability to exchange data. With the proliferation of commercial and home-grown systems, often system interfaces must be customized requiring additional costs and putting smaller practices at a disadvantage in influencing vendors' development plans.⁴⁹ This problem will be magnified with the extension of data exchange to patients/families and other healthcare and community resources envisioned as instrumental in comprehensive care coordination and patient centered care. Before interoperability, however, the first challenge will be the availability of electronic systems at all in typically paper-based organizations. The cost and resources required for upgrading systems to those that can better connect to external organizations is also a barrier to interoperability, as it is for adopting standards.

Misaligned Incentives

Another barrier to interoperability is that vendor incentives are not aligned with the goal of exchanging data and, in fact, there are powerful disincentives to interoperability.^{23,61} There is also often a disincentive from the healthcare organizational standpoint to share data which, to change, would require shared accountability for patients' care. This, in turn, would create demand for interoperable systems that vendors and markets would be more eager to meet.

There are also currently no financial incentives to encourage connections between EHR-enabled practices and others who care for patients outside of the hospital that are not using EHRs, such as

home care organizations, long term care facilities, and visiting nurses associations. The cost of interoperability includes the cost of upgrading existing clinical information systems.

3. Barriers to Availability of Important Information

Collecting, maintaining, and being able to access current and accurate information on a patient and their clinical care team is often difficult. Organizational processes, technical characteristics, and inconsistent use of systems all contribute to this issue which may result in unreliable data that may change frequently without adequate mechanisms to update.

Missing or Inaccurate Data

To illustrate the problem of missing or inaccurate data we can look at the availability of information on a patient's primary care provider (PCP) which is important to maintaining patients' care coordination within their own primary care team.²³ Patients may never have a PCP assigned because patient panels are full or patients with frequent insurance changes may be seen only in urgent care. Sometimes a PCP may be assigned by the insurance company but the patient has never seen that physician. When patients have a designated PCP, EHR systems may not have a field to capture this information or, if they do, it is not maintained or presented in the EHR in an easily accessible way. EHR systems may not incorporate a PCP banner when viewing the medical record or have links to a scheduling system whereby it is easy to identify the provider that patients most frequently see. There may be no easy mechanisms by which patients can update this information, such as through a patient portal.

Even when data elements are well defined, structured to capture consistent information, and are easily accessible in an EHR, they may not be used.⁶² Elements may also not be filled in because they require that users do duplicate entry rather than creating the elements as an automatic byproduct of use of the system for clinical care. Inconsistent documentation of required data elements can also be problematic when, for example, coded drop down lists allow free text data entry as well.¹⁸ The fewer incentives for data capture, the lower the quality which is why there is consistently high quality billing data but many other parts of the medical record suffer. Practices may also receive clinical data in paper documents that are scanned in as ‘.pdfs’ and are, therefore, not searchable or able to integrate into the record in any structured way.

Information Overload

With the proliferation of data and data sources, there are considerable challenges in distilling and presenting the information most relevant to a patient’s clinical care. As an example, problem lists may grow exponentially with new tests and encounters and may become cluttered with redundant and often irrelevant information that can render them difficult to use.^{23,63}

Documentation that is typically done to support billing and point-in-time encounters does not support the planning and medical decision-making process and, as O’Malley notes, the “need for concise and clinically relevant information is made difficult because of repetition and automated guidance around E&M billing.” When generated through EHR systems, information, such as referrals and consultation letters, may be less concise and clinically relevant than what may have occurred through paper-based processes.²³ Unless carefully designed, longitudinal care plans incorporating information from an even broader range of clinical and community inputs needed for integrated care are at risk of being unusable.

Just as information overload can be a challenge for physicians, patients will also find it difficult to sort through extensive information generated from the EHR. The patient's need to be able to understand and engage with their comprehensive care plan will require careful attention to the selection of information and design of presentation.

4. Barriers to Sharing Expertise and Care

Lack of Shared Vision of Roles and Accountability

Sharing clinician and patient/family knowledge, expertise and care across providers, settings and with patients/families is important to creating patient-centered care.¹⁵ The barriers to effective collaboration across all participants begin with organizational issues. A shared vision of care management that is cross-setting, cross a patient's lifetime, and that incorporates the broader participation of patients/families and social services and community resources is still evolving. Clear delineation of the roles and accountability of all participants does not yet exist, but is critical to mediating responsibilities between disciplines for co-management, involving the patient as an active participant in their care, creating longitudinal care plans, and defining needed information exchange.^{15,18,23} Agreement on roles and accountability for appropriate communication is needed to meet even basic expectations, for example, of post-hospital discharge summaries being available to primary care providers at a patient's first follow-up visit, or of patients that have self-referred for specialty care reporting back to their primary care providers.^{18,55,64}

Misaligned Incentives

Often there are disincentives for organizations to share data and financial incentives are not aligned with inter-specialty coordination. For example, there are no incentives for loop closure in referrals and consultations. Reporting back to referring clinicians takes time and reimbursement is not structured to support these tasks, particularly for specialists.⁶⁵ Because of the time required in clinicians' busy practices, workflow challenges, and cost, the value proposition of bi-directional communication does not support closing the loop. Also, for population management, tools may provide risk stratification of patients but there are no incentives to manage patients this way. It is only with changes in reimbursement that care processes and EHR products will begin to prioritize care coordination.²³

Difficulty in Creating the Longitudinal Care Plan

Once there is a shared vision, definition, and aligned incentives that reward time spent in these activities, technical challenges in creating and communicating a functional longitudinal care plan still exist. Current EHR documentation has been optimized for encounter-based billing and is not structured or supported in ways that promote collaborative clinical decision-making or present a concise view of patients' goals, health, social factors, and progress overtime. Many challenges exist in being able to compile the information needed to construct a care plan and evaluate the patient/family factors important to successful care coordination. Data fields may not be completed or data may reside in a variety of paper and electronic systems. New data concepts to support care coordination and patient-centeredness, such as what a patient may be at risk for, patient level of health understanding and activation, have not yet been built into systems in a structured way. Designing a care plan that can concisely present the clinically relevant data

extracted from the extensive amount of available information will be critical to avoiding data overload.

Privacy and Security Concerns Persist

Even if the technical challenge of creating secure communication channels within and across settings is met, patient concerns about privacy and security of their sensitive health care information and with electronic data exchange remain an obstacle. Most patients understand the value of their health data being shared between those involved in their care.^{57,66,67} However, some patients are also interested in having control over which providers can see what information, especially with respect to behavioral health.⁶⁸ Some behavioral health providers themselves have expressed serious reservations about exchanging this type of information given privacy considerations.⁶⁹ The ability to capture patient preferences for data sharing (that may change over time) and parse specific data for exchange present difficult technical challenges. Expanding the exchange of information to include other social services and community resources will compound this issue.

Patients who may embrace comprehensive sharing of their data may still worry about the proliferation of data breaches reported in the popular media. Once longitudinal care plans that reflect comprehensive information across life and multiple healthcare and community resources are compiled and exchanged, patients may feel even more at risk.

5. Barriers to Patient/Family Involvement

For successful patient-centered care and care coordination, involving patients and their families is essential, but they are often excluded. Patients and their families frequently do not get the information they need, their preferences and abilities to understand and manage their responsibilities are not assessed, and the tools that could assist communication between patients and their care providers in a continuously proactive and responsive way between visits do not exist or are inadequately designed. Patient concerns about the privacy and security of sensitive data also persist limiting their willingness to fully support the range of communication desired for successful care coordination.

Needed Information is Lacking

The healthcare system is not providing the information it needs to share to help patients and their families be successful at home. When a patient leaves the hospital or their outpatient visit, they may not understand what they need to manage their care including their care plan, medications and care instructions, who to call with questions, follow-up visits required within what timeframe, and the contact information needed to arrange for this care. No national provider directory exists for providers or patients to assist in making these connections.

Healthcare organizations are also not collecting information that is important to providing comprehensive and appropriate care to their patients, such as: overall patient goals and preferences, how well patients understand their care instructions, their ability for self-care, care-giver abilities, health-related quality of life, patient activation level, social factors, and end-of-life planning. Something as seemingly simple as patient educational level may not be collected within an EHR or, if it is, may be buried in other sources of data such as nursing notes, and not

readily accessible. Processes and tools for sharing data relating to between visit health status and activities, such as whether prescriptions have been filled or follow-up visits kept, are also limited in their availability and scope.

Tools to Facilitate Patient/Family Involvement are Limited

Given the right tools, patients and families can be more actively involved in their care.

Healthcare information technology tools beyond the EHR, such as patient health records (PHRs) and telehealth applications, have the potential to be very useful in supporting patient-centered care and care coordination activities. PHRs tethered to EHRs have the potential for two-way communication with practices outside of office visits and can provide visit summaries and care plans, and can capture and communicate data from patients' efforts to track goals, health, and clinical care. As discussed in the National Priorities Partnership Care Coordination Meeting Report, "advances in telehealth have pushed its use beyond basic remote monitoring and communication to more complex patient management functions, including alerts and decision support for providers, patients and caregivers" and "has the potential to address unreliable information transfer and aid in patient engagement and activation."⁷⁰

Implementation and use of these applications are growing, but their reach is still limited on both the patient and provider sides. Adoption of PHRs continues to increase, but the digital divide continues as these tools are still less frequently adopted by racial and ethnic minority patients and those with lower annual incomes.^{71,72} Ease of use of these systems varies and may limit their

utility. More patients have cellular phones than computers⁷² which would argue for expansion of efforts to incorporate mobile applications in the suite of care coordination tools. Designs of these applications, along with EHRs, do not yet include the components needed to support provider and patient management of longitudinal care plans, such as the ability to update PCP information or mechanisms for routine collection of patient-reported data (e.g., functional status, quality of life assessments, and clinical data) between visits. Longitudinal data would also need to be displayed in ways that are helpful for patients to understand their self management.

Although the organizational and technical barriers to fully integrated patient care are not insignificant, there are approaches that can be taken in the short term to make progress towards this important goal.

Approaches to Improvement

There are numerous barriers to improving current capabilities of clinical information systems to match data needs for care coordination. There is a need for further research, including surveys of EHR and PHR users, as well as usability testing to determine the ease of use, efficiency and effectiveness of existing tools. The approaches presented below are organized the same way as barriers: Approaches to Effective Use of Technology, Approaches to Data Exchange, and Approaches to Availability of Important Information, Approaches to Sharing Expertise and Care, and Approaches to Patient/Family Involvement.

1. Approaches to Effective Use of HIT

Resistance to New Technology

One of the major reasons for resistance to adopting EHRs is uncertain return on investment. Federal health policy has begun to address this issue. However, continuous assessment is needed to ensure that incentives are matched to true costs.

Organizations should make an effort to integrate HIT into existing workflows within healthcare settings, but organizations should also work toward improving and changing workflows. If we are to pursue new goals of care coordination which have not been a major focus for many practices it would be helpful to consciously build workflows that incorporate HIT, rather than designing HIT tools that largely go unused.

Sub-optimal Design of EHRs

The current system of reimbursement based on inclusion of the review of systems and physical exam should be changed to encourage documentation that supports high quality coordination of care. Some of this can be accomplished under the current health care reform process, but this has not yet been done. In order to reduce the time burden of documentation on providers, EHRs should track clinical care as a byproduct of clinical actions.

Usability is another important issue. The informatics literature on the human computer interface and usability is extensive. Researchers must test approaches that have been established in the laboratory setting in real-world settings. Commercial systems should incorporate new interface designs to improve usability for documentation and results review.

Finally, clinical decision support should be improved. Errors may be prevented by using all data in a patient's chart, for example by noting that a medication which requires laboratory monitoring is on the medication list but no monitoring tests are in the laboratory results.⁷³ Medication, laboratory, and billing data can also be used to infer diagnoses that are not listed on a patient's problem list.⁷⁴ Patients at high risk of a poor outcome due to psychosocial factors may be identified using structured and unstructured data.^{20,21}

Inadequate Training and Support

In order to achieve documentation within primary care practices which fulfills the data needs of care coordination it will be important to address low competency in using EHRs. A novice user may not immediately learn to use EHR features that support care coordination. Users must have an incentive to learn how to use all of the functionality which exists in an EHR.

Though there are federal incentives for implementation and other financial incentives to reach full productivity in an EHR environment, there is no financial incentive for the ongoing training and support that is crucial to reaching competency. Tools that allowed assessment of how users were using such functions, which might also allow triage of resources to improve their use to those who would benefit most, would be helpful.

2. Approaches to Data Exchange

Lack of Industry-wide Standards

To compile information generated in different healthcare settings or outside of the healthcare system, the lack of industry-wide standards and interoperability must be addressed as is the case

with current federal efforts. Major efforts are already underway to choose standards and mandate one standard at a national level rather than depending on state level regulation or local markets.

Lack of Structured Data

Certain data should be structured for clinical, research, and quality measurement. Currently, data which has low value from a clinical or research perspective is structured (e.g., physical exam findings). Instead, data which will have high clinical value in the future (e.g., the reason that a medication was stopped) should be structured. Data for evidence-based quality measures should be structured. Data that may be used secondarily for research should be structured. In each case, aligning the options for each data field to a standard taxonomy is preferable to each product using its own data dictionary.

Lack of Interoperability

The federal government has already provided some incentives for interoperability for Stage 1 and has demanded upgrades to existing systems, but there are issues with the current business models for data exchange.²⁷ Primary care providers particularly need electronic interfaces from all laboratory and radiology providers to all existing EHRs. In the short-term, it will be possible to pull in data from insurance data warehouses such as the All Payer Claims Databases.⁷⁵ Some patients will become PHR users and the healthcare system should pursue the same level of interoperability with those tools as with EHRs.

The Standards and Interoperability Framework Transitions of Care community is working on “translation” of this information by software services that address health literacy and preferred language requirements⁵⁸.

Misaligned Incentives

Addressing disincentives for healthcare organizations to share information will incentivize vendors to pursue interoperability. One approach would be to pursue accountable care organizations (ACOs), so that interoperability from community-based settings through referral centers would be encouraged. However, interoperability between ACOs and between insurance plans may require completely new incentives so information may follow patients who move or change insurance plans.

3. Approaches to Availability of Important Information

Missing or Inaccurate Data

Inaccurate or absent PCP information is an example. An organizational approach to this problem is to agree upon a standard for PCP attribution (e.g., patient has seen that PCP twice) rather than being assigned a PCP upon enrollment with an insurer. A longer-term technical approach is to include structured fields in EHRs that automatically populate using billing data and logic (e.g., the EHR might suggest filling in a blank PCP field after two notes are written or two visits are billed by a PCP).

In order to improve the information exchange during transitions, condition-specific rules are appropriate. A standard, such as Care Transitions Measure, would help, but any standard that is adopted will need to be adopted and refined.⁸ A technical approach is to build interoperability and secure communication to allow confirmation of receipt.

Medication reconciliation represents an especially acute issue in this area.²⁶ An approach to improving medication reconciliation is to establish a standard procedure (e.g., listing new medications, changes, and discontinuations) and to build interfaces between systems so that the prescriber can incorporate information from multiple settings and pharmacies at the point-of-care.

Information Overload

In general, EHRs should include tools for summarizing information and searching for specific types of information within and across electronic health records. It will be essential to build tools to help providers sort through the vast quantities of data that are available in electronic health records, which are likely to include new search capabilities. In addition, tools to help reconcile, sift through and handle data coming from data exchanges will be pivotal. Support for research in these areas is needed.

4. Approaches to Sharing Expertise and Care

Lack of Shared Vision of Roles and Accountability

Better registry functions will be centrally important to improving care, and in particular registries should be interoperable so that they do not compound the problem of separate datasets for each healthcare setting.⁷⁶ Such tools should offer different views to members of the care team in different roles.

Today, many organizations struggle with referrals in ensuring that good communication occurs and that loops are closed. An organizational approach to improving referrals is to develop tools that ensure that full loop closure has occurred. Just as current electronic documentation has evolved around the need to support billing, the referral process today has been designed to fulfill utilization management and not clinical needs. It will be helpful in the future to design in tools that ensure inclusion of key data in both directions and confirmation of receipt. Also, much of the communication regarding informal consults or questions about a completed consult occur through phone calls or email. A blog or chat function would incorporate this information into the medical record. Some have suggested incentivizing defined responsibility of each member of the care team with a service agreement,⁷⁷ although this would likely not be necessary under prospective reimbursement.

The American College of Physicians has endorsed the following definitions:

- Preconsultation exchange—intended to expedite/prioritize care, or clarify need for a referral
- Formal consultation—to deal with a discrete question/procedure
- Co-management – either with Shared Management for the disease, Co-management with Principal care for the disease, or Co-management with Principal care of the patient for a consuming illness for a limited period
- Transfer of patient to specialty PCMH for the entirety of care.

One of the keys to improving care coordination will be to make it easier for providers to collaborate with each other even if they do not need to do so frequently. One example of a useful tool would be to build directories of providers across settings that would allow providers to communicate securely for provider communication outside of systems. The “Direct” project is one such example. Needs around this are particularly acute for some conditions such as mental health issues and HIV.

In addition, there are major needs with respect to sharing care with non-clinicians, including patients, families, caregivers, and community organizations. Many patients prefer email, but all communications should be secure and part of the medical record.

Misaligned Incentives

If providers are to fully engage in care coordination for individual patients, it will be essential to give providers financial incentives for this activity. This would best be done by moving to prospective reimbursement of some type, since by its nature it would be very difficult to determine what is or isn’t reimbursable under fee-for-service. Reimbursement should be sufficient to decrease productivity requirements imposed upon practices. There is also the need for appropriate staffing across disciplines and shared responsibility in order to manage the increasing workload which will result from improved care coordination processes.⁷⁸

Difficulty in Creating the Longitudinal Care Plan

Documentation that stresses issues around care coordination including in particular a longitudinal comprehensive care plan is likely to be far more effective in improving efficiency and quality than the current approach. The 2013 meaningful use criteria call for inclusion of a care plan, but further work is needed to determine what will be most effective to include in it. In the short run, merely having a placeholder for it which is easy to locate will be an improvement. Taking a technical approach, such plans might be built from free text notes and should link encounters to a longitudinal views.¹⁶ Innovative interfaces are also needed to display longitudinal data to providers and patients.

Privacy and Security

Patients and providers are both concerned about privacy and security. Both patients and providers must trust the system, and that there are ways to achieve that, including by following patient preferences and using role-based access. For sensitive health information, such as mental health information, different views of data should exist so that the information may be hidden from some members of the care team. Patients should be able to grant and revoke access to this information.

Security issues are evolving. Healthcare should generally follow the standards and protocols that are successfully being used in other industries, such as banking. However, there are some unique aspects of healthcare that will require a different approach.

5. Approaches to Patient/Family Involvement

Needed Information is Lacking

Patients need electronic access to each type of data that we have discussed in the section on data needs because patients and their caregivers are care coordinators. They need access to core data elements such as problem, allergy and medication lists. They should have electronic access to PCP contact information and a list of everyone on the care team along with their role. The same information should be provided to the patient upon leaving any healthcare setting including the Emergency Department and long term care. Patient involvement is emphasized in standards for discharge, such as the Care Transitions Measure. Improvement depends on the ability to assess patient-centeredness both for transitions and for longitudinal care.

Tools to Facilitate Patient/Family Involvement

Tools to compile information from patients, community resources, and others outside of the healthcare system will improve care coordination. In the short-term reimbursement for care coordination should incentivize incorporation of patient-generated data and community-generated data into the medical record in a standardized way, even if it means using paper forms, fax and downstream optical character recognition to input data into electronic systems.⁷⁹ Finally, due to the rise in mobile phone use by patients from all sociodemographic groups, tools for coordination with patients and family members should be optimized for use on cellular phones via SMS, websites designed for mobile phones, and mobile apps.⁸⁰

Conclusions

We have presented a variety of approaches to fulfilling the pressing data needs for care coordination. These approaches are both organizational and technical and are intended to help

address the gaps in current capabilities of health information technology for care coordination. Clinical information systems must support care coordination better. The most pressing activities are developing standards which will be core for care coordination, incentivizing their use of these industry-wide standard, supporting the development of new tools and views which can be used within electronic health records for care coordination purposes, and encouraging organizations to participate in data exchange efforts, which will be very important for both care coordination broadly and especially in transitions. Researchers, those who fund research, and vendors might contribute significantly. For those who measure quality in particular, it will be important to develop new measures which allow better assessment of care coordination functions. Organizations that endorse measures must help promote measure development create a clearinghouse for the multiple efforts which are likely to ensue in this area. Such efforts will ensure progress in the area of HIT-enabled care coordination.

Glossary

Care Team - While Singer et al. frame “care teams” as the group of practioners who “routinely” work together to provide care for a specified group of patients, we consider care teams as groups of practitioners who are responsible for a specific patient’s comprehensive care plan across an integrated health delivery system and often are connected by an electronic health record when separated by geographic setting.

Care Plan – We use the terms “comprehensive care plan”, “shared care plan”, and “plan of care” throughout. A “comprehensive care plan” implies a care plan that crosses diseases and conditions. A “shared care plan” implies a care plan that crosses geographic settings. “Plan of

care” indicates a document that outlines the future care for the patient, as in “Assessment and Plan”. Rather than limiting the consideration and assessment of the comprehensive care plan to a single Singer domain, we will consider comprehensive care planning to be a core activity that crosses multiple domains as a fundamental tool for care coordination.

Table 1. Relationship between Singer integrated care constructs and barriers to care coordination and patient centeredness

Barriers to Care Coordination and Patient Centeredness	Singer Constructs of Integrated Care						
	Care Coordination				Patient Centeredness		
	Coordinated within care team	Coordinated across care teams	Coordinated between care teams and community resources	Continuous familiarity with patient over time	Continuous proactive and responsive action between visits	Patient-centered	Shared responsibility
Barriers to Effective Use of HIT							
Resistance to new technology	X	X	X	X	X		
Sub-optimal design of EHRs	X	X	X	X	X		
Inadequate training & support	X	X	X	X	X		
Barriers to Data Exchange							
Lack of industry-wide standards		X	X				
Lack of structured data	X	X	X	X	X	X	
Lack of interoperability		X	X				
Misaligned incentives		X	X		X		
Barriers to Availability of Information							
Missing or inaccurate data	X	X	X	X		X	
Information Overload		X	X	X	X	X	
Barriers to Sharing Expertise & Care							
Lack of shared vision re: roles & accountability		X	X		X	X	X
Misaligned incentives		X	X		X		X
Difficulty in creating the longitudinal care plan	X	X	X	X		X	
Privacy and security concerns persist		X	X		X		
Barriers to Patient/Family Involvement							
Needed information is lacking	X	X	X	X	X	X	X
Tools to facilitate involvement are limited	X	X	X		X	X	X

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