



TECHNICAL REPORT

Care partners and consumer health information technology: A framework to guide systems-level initiatives in support of digital health equity

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Abstract

Introduction: Consumer-oriented health information technologies (CHIT) such as the patient portal have a growing role in care delivery redesign initiatives such as the Learning Health System. Care partners commonly navigate CHIT demands alongside persons with complex health and social needs, but their role is not well specified.

Methods: We assemble evidence and concepts from the literature describing interpersonal communication, relational coordination theory, and systems-thinking to develop an integrative framework describing the care partner's role in applied CHIT innovations. Our framework describes pathways through which systematic engagement of the care partner affects longitudinal work processes and multi-level outcomes relevant to Learning Health Systems.

Results: Our framework is grounded in relational coordination, an emerging theory for understanding the dynamics of coordinating work that emphasizes role-based relationships and communication, and the Systems Engineering Initiative for Patient

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Safety (SEIPS) model. Cross-cutting work systems geared toward explicit and purposeful support of the care partner role through CHIT may advance work processes by promoting frequent, timely, accurate, problem-solving communication, reinforced by shared goals, shared knowledge, and mutual respect between patients, care partners, and care team. We further contend that systematic engagement of the care partner in longitudinal work processes exerts beneficial effects on care delivery experiences and efficiencies at both individual and organizational levels. We discuss the utility of our framework through the lens of an illustrative case study involving patient portal-mediated pre-visit agenda setting.

Conclusions: Our framework can be used to guide applied embedded CHIT interventions that support the care partner role and bring value to Learning Health Systems through advancing digital health equity, improving user experiences, and driving efficiencies through improved coordination within complex work systems.

KEYWORDS

health equity, learning health system, patient portal

1 | INTRODUCTION

Person- and family-centered care has been described as the “true north” in care quality¹ and is the foundation of wide-ranging policy, payment, and care delivery initiatives, including the Learning Health System.^{2,3} Defined as “an approach to the planning and delivery of care across settings and time that is centered around collaborative partnerships [...that...] supports health and well-being by being consistent with, respectful of, and responsive to individual priorities, goals, needs, and values”,⁴ this construct is fundamentally interpersonal in nature. A limitation of our current understanding of the domains, drivers, and outcomes of high-quality interpersonal communication is that it has primarily focused on in-person medical encounters, while the care delivery landscape has evolved to include consumer-oriented health information technologies (CHIT), such as the patient portal. The gap between the scientific evidence base and the reality of care delivery has practical importance for Learning Health System applications involving CHIT and vulnerable subpopulations. In this context, vulnerable subpopulations include persons who lack access or capacity to navigate electronic care delivery demands themselves, and who commonly rely on care partners to facilitate electronic care management tasks.⁵⁻⁷

Recently, our group identified opportunities to improve care quality and value through engagement of care partners in CHIT within the context of a Learning Health System specific to persons living with dementia.⁸ We now set forth an integrative framework that articulates pathways by which applied CHIT innovations affect work processes and outcomes, drawing on relational coordination theory.^{9,10} We first describe the rationale for our framework—including interpersonal challenges and the prominent role assumed by care partners in the care of persons with complex health and social needs, such as dementia. We then provide an overview of the theoretical basis and

building blocks of our framework, emphasizing interpersonal processes that are situated between cross-cutting work systems and outcomes. Finally, we discuss the utility of our framework through the lens of an illustrative case study, focusing on pre-visit agenda-setting through the patient portal. The purpose of our commentary is to lay the foundation for conceptualizing scalable systems-level CHIT interventions that are relevant to subpopulations with complex health and social needs (eg, with dementia, sensory loss, language barriers, and low health literacy) while supporting care partner's need for accurate and timely information about the patient.

1.1 | Background and significance: importance of interpersonal communication

Interpersonal communication is the foundation of person- and family-centered care. It is through longitudinal interactions in trusted relationships that tailored care plans are co-produced and executed.^{11,12} Relational rapport—trust, empathy, respect, genuineness, and mutuality—facilitates honest dialog and patient sharing of personal information about health symptoms and concerns, priorities, values, beliefs, and goals. Through the giving and receiving of information, *clinicians* make accurate diagnoses and identify and administer treatments while *patients* gain an understanding of the nature and expected course of their condition as well as related treatment options, benefits, side effects, and uncertainty. Recognizing that patients vary in their preferences and capacity for sharing decision-making responsibilities^{13,14} the “shared” medical decision-making paradigm implies that clinical issues and options are defined and explained in an understandable manner and with sufficient detail (relative merits, drawbacks, and uncertainties) that the patient may assess them within the context of their own preferences and values.^{15,16} In the context of complex health and social

needs, care partners often have an important role in facilitating interpersonal communication and information exchange, coordinating treatments, and participating in routine and high-stakes decisions.

Systems-level factors are generally misaligned with achieving high-quality interpersonal communication in the care of persons with complex health and social needs. Constrained time in face-to-face visits limits opportunities to comprehensively disclose and discuss health-related concerns,^{17,18} that are often treated in siloes of specialty care.^{19,20} At an individual level, persons with greater health and social needs tend to ask fewer questions, express fewer concerns, and are less apt to request clarification during medical encounters,^{21,22} which clinicians may interpret as disinterest or lack of engagement.²³⁻²⁵ Patients with complex health and social needs are also less likely to have the requisite access, experience, or capability to navigate CHIT, thereby exacerbating communication challenges and related inequities.^{26,27}

The prevailing bioethical and legal/regulatory frameworks around health data prioritize patient privacy and the protection of personal health information. These frameworks can create barriers for care partners by impeding access to information that is needed to coordinate care, make medical decisions, or advocate on behalf of patients who are unable to do so themselves.^{28,29} Clinical assessments that are used to formulate patient's treatments may ask about the availability of help to bridge deficits in physical or cognitive function to enact the treatment plan. However, as these assessments do not typically involve direct communication with care partners,³⁰ information regarding the care partner's ability or knowledge to provide care are either not asked or are of questionable veracity.

CHIT interventions to overcome digital health inequities have to date primarily been directed at overcoming patient-level accessibility barriers.^{6,7,27} However, there is growing appreciation that care partners use CHIT to attend medical visits (eg, telehealth), facilitate shared decision-making, and navigate care coordination demands. Engaging care partners through CHIT is therefore an important strategy for bridging gaps between patient capabilities and electronic-based care coordination demands, while also supporting care partners' need for accurate and timely information.^{6,27} However, few systems-level initiatives build on the reality that persons with more limited capacity often navigate care delivery with the help of a care partner; a recent scoping review identified **no** CHIT interventions were directed at care partner engagement.⁷

1.2 | Question of interest

Given this background, our working group sought to develop a framework to guide the design and evaluation of applied CHIT interventions (eg, through the patient portal) directed at supporting care partner engagement for persons with complex health and social needs. To guide framework development, our working group asked: What are the pathways and mechanisms through which CHIT may facilitate care partner identification, role clarification, and support? How would expanding the role of care partners through CHIT affect care delivery processes and outcomes important to individuals and organizations,

including Learning Health Systems? To the best of our knowledge, no existing framework provides a structured and cohesive framework of potential effects of care partner engagement in CHIT and approaches to maximize associated benefits and minimize challenges. This article proposes a framework to fill this gap.

2 | METHODS

2.1 | Working group

The framework was iteratively developed by an interdisciplinary team of researchers and practicing clinicians from schools of public health, nursing, social work, and medicine. A subset of members developed the initial draft of the framework, incorporating revisions based on feedback provided by the larger working group during team meetings.

2.2 | Theoretical basis

Our framework is grounded in relational coordination, an emerging theory for understanding the relational dynamics of coordinating work. "Work" refers to the tasks, effort, and time to manage, plan, and enact behaviors to address health needs. Relational coordination proposes that frequent, timely, accurate, problem-solving communication, reinforced by relationships that are built upon shared goals, shared knowledge, and mutual respect can best support task integration and performance outcomes.⁹ Relational coordination is systems-oriented and explicitly recognizes the importance of cross-cutting work structures (eg, shared protocols and routines, information systems, accountability systems, and rewards) in overcoming siloed thinking and coordinating work across boundaries. Evidence from diverse sectors (eg, the airline industry, criminal justice system, and health care) find that relational coordination positively affects quality and efficiency outcomes.¹⁰ Relational coordination is especially salient when work involves high interdependencies, conditions of uncertainty, and constrained time,¹⁰ all of which describe care delivery for persons with complex care and social needs, such as dementia.

A unique feature of relational coordination that is especially pertinent to our framework is its emphasis on role-based relationships (as distinct from personal connections between individual people) in the coordination of work. This focus on roles rather than individuals underscores a key challenge of the current care delivery paradigm in which the care partner role is diffuse and poorly defined, and in which care partner presence and capacity are not systematically assessed or documented. A second feature of relational coordination is its acknowledgment of the greater relational challenges of achieving shared goals, shared knowledge, and mutual respect for work processes being undertaken when individual actors lack common training, socialization, and expertise (when individual actors are from different "thought worlds"), which is often the case for patients and care partners when interacting with clinicians and navigating care processes.^{31,32}

Care partner circumstances are heterogeneous, as are their needs, skills, and values. As a result, care partners may facilitate or exacerbate communication and care quality.^{33,34} Although care partners have firsthand knowledge of the patient, the absence of a defined role may lead clinicians and other members of the care team to be uncertain about whether to rely on the patient or care partner as the true or sole source of information,^{35,36} and hesitant to engage the care partner for fear of jeopardizing patient autonomy.³⁷⁻³⁹ Patients and care partners commonly diverge in their assessments of patient health and symptoms—concordance tends to be higher when reporting on physical symptoms that are objective, observable, and more severe, and lower for more subjective or private symptoms, such as emotional distress.⁴⁰⁻⁴³ Care partner presence may affect the types of issues that are discussed in a visit by inadvertently suppressing conversation about non-physical concerns. For example, care partner efforts to support, protect, and respect the patient may unintentionally mask the clinician's understanding of stigmatizing symptoms and challenges.⁴⁴

Within this context, the concept of family caregiver assessment is especially relevant. Here we note the term “family caregiver” is complementary to “care partner” but differentiated by a focus on assisting with daily activities for health and functioning reasons rather than navigating care delivery and health care tasks—and we refer to “family caregiver assessment” in deference to the scientific and practice base from which the concept originated. Family caregiver assessment refers to the systematic process of gathering information from the caregiver's perspective about role-related problems, needs, strengths, and resources, including their ability to contribute to addressing the needs and enacting the care plan of the person they assist.^{45,46} Family caregiver assessment is motivated by an appreciation of the diversity of caregiving circumstances, and understanding a caregiver needs and capacity is a prerequisite to tailoring service interventions or direct service programs that rely on their involvement. Such assessments are a best practice in dementia care and support,⁴⁷ including CMS dementia care planning reimbursement codes.⁴⁸

We contend that CHIT applications represent work system components that have the potential to improve relational coordination through (1) more explicitly defining the care partner role, including the promulgation of system-level CHIT efforts to document the presence and identity of involved care partners, (2) integrating tools to elicit the direct input of care partners regarding the patient's health and treatments (eg, with respect to monitoring and reporting on symptoms and adherence), and (3) integrating tools to elicit information about care partner needs, including the deployment of tailored resources to address identified gaps in capacity, as we further elaborate in the following text.

2.3 | Building blocks of integrative framework

Our framework (Exhibit 1) builds on the Systems Engineering Initiative for Patient Safety (SEIPS)^{49,50} model domains of work systems, work processes, and work outcomes. Work systems

encompass people performing tasks by interacting with tools and technologies (eg, care delivery system websites, patient portals, and chatbots) within the context of organizational environments (eg, policies around registration and functionalities that are afforded to a care partner within the patient portal). Work system features (people, tasks, tools and technology, and environment) interrelate with each other to drive work processes. Work systems and work processes collectively drive key outcomes at the levels of the person (eg, patient, care partner, and members of the care team) and organizations. Our adaptation depicts reinforcing feedback loops whereby work outcomes may affect work systems and processes (eg, improved efficiency drives further enhancements to related work systems).

3 | RESULTS

In the following text, we elaborate on each of the SEIPS domains with attention to the potential of care partner engagement with CHIT as a mechanism for enhancing work processes and promoting person- and family-centered care and performance outcomes.

3.1 | Work systems

SEIPS prioritizes human factors, as reflected by the central location of people within work systems. We explicitly name care partners and refer to the “care team” to acknowledge the wide range of disciplines and care settings (eg, direct care workers and community health workers) involved in the care of persons with complex health and social needs.⁵¹ Patients, care partners, and care team members are each depicted as having unique needs (eg, physiological and emotional), skills (eg, technical, social, and critical thinking), and values (eg, beliefs and preferences), which individually and collectively inform work processes.

People within work systems take specific actions when seeking to access, support, or provide care, captured under the “tasks” element of the work system. Here, we specifically call out CHIT modalities, such as the patient portal, that are used to perform tasks such as scheduling medical appointments, viewing laboratory test results, reading clinician visit notes, filling prescriptions, and sending secure messages to the care team. Within this context, interactions of people, tasks, and tools and technology are recognized as being shaped by internal and external environments. Internal environments reflect factors such as physical space and the socio-organizational environment of settings (eg, the presence of a computer, broadband access, and ease of portal registration and use). External environments reflect legal, political, and societal level factors (availability of paid caregivers; generosity of home and community benefits, and policies that guide patient privacy, such as HIPAA). We recognize that CHIT and tools of work systems are highly variable and continually changing through new or modified electronic functions and services.

3.2 | Work processes

Work processes encompass physical, cognitive, and social-behavioral processes situated between work systems and outcomes. Here we distinguish opportunities to systematically engage care partners through CHIT and tools in longitudinal work processes that span time, setting, and space. We recognize that care partner involvement is often triggered by the health and function needs of the person being assisted.³³ A key challenge is that the role of care partners is not well-specified or supported in face-to-face visits^{52,53} or digital health strategies.^{28,54,55} When care partners do engage in CHIT, such as the patient portal, they most often use patient identity credentials.^{55,56}

We contend that care partners are already present and seek to engage in frequent, timely, accurate, and problem-solving communication—but that role ambiguity undermines effective partnerships and the formulation of shared goals, knowledge, and mutual respect. Cross-cutting work systems geared toward explicit and purposeful support of the care partner role would advance these important work processes. For example, shared protocols and routines that proactively differentiate care partners' individual identity credentials to access the patient portal overcome ambiguity as to who is communicating electronically with the care team when it is someone other than the patient.⁵⁷ Growing capacity of electronic health records (EHRs) to accept patient- and care partner-reported health information such as self-assessments and uploading of legal documents amplifies the value of proper identity credentials to the integrity of electronic health information. Establishing the role of care partners through unique identity credentials enables more respectful and legitimate electronic interactions with care team members and facilitates shared knowledge through providing access to timely and comprehensive information about patient health and treatments, and the development of shared goals by creating a CHIT mechanism to interact with the care team and navigate care coordination tasks.

3.3 | Work outcomes

We recognize the relevance of multi-level outcomes involving people (patients, care partners, and care team members) as well as systems (quality, efficiency, and population health). Due to our focus on the person- and family-centeredness and CHIT, we emphasize experience of care measures (eg, satisfaction, perceptions of being seen and heard, and respect), as well as patient and care partner insight, activation of information, treatment burden, self-efficacy, and preparedness. We acknowledge the importance of clinical care team experience outcomes such as satisfaction with care, and burnout that may result from excessive electronic messaging⁵⁸ and administrative burden, which a small literature suggests are attenuated with higher relational coordination.⁵⁹ Finally, organizational outcomes that are pertinent to the Learning Health System, such as efficiency and staffing shortages and/or turnover, are the product of work system features, processes, and their interactions. Thus, our framework lends itself to recognizing and measuring both person- and organizational-level outcomes,

recognizing the special importance of person-reported outcomes for evaluating the experience of care—and organizational-level outcomes that affect what programs are adopted and scaled widely.

3.4 | Framework application: electronic agenda setting

Agenda setting is an approach to establishing relational “ground rules,” identifying priorities, and negotiating conversational focus in advance of a medical encounter.⁶⁰ Agenda setting explicitly elevates the patient voice, while improving patient satisfaction and physician time management.^{61,62} Members of our team have demonstrated the ability to successfully deploy pre-visit agenda-setting through the patient portal, enabling the strategy to be delivered at scale.^{63,64} In this approach, “OurNotes” sends patients a secure portal message prior to a scheduled clinic visit with an invitation to share their visit concerns; responses are saved in the EHR for clinicians to view prior to or during the visit; and auto-populate into the clinician's documentation. Although pre-visit agenda setting is especially relevant in the care of persons with complex health and social needs such as those with dementia^{65,66} CHIT modalities are less accessible in this subpopulation.

Building on this background, our team has developed a person-family agenda-setting approach to align the patient and care partner agenda in advance of a medical encounter. The approach sets forth a structured process for a patient and their care partner(s) to clarify expectations regarding the role of the care partner in an upcoming medical encounter and establish a shared visit agenda of patient health topics to discuss with the clinician. A series of randomized trials have demonstrated the approach is acceptable, leads to greater information exchange about lifestyle and psychosocial topics involving non-medical priorities, more person-centered communication (from analyses of audiotaped conversations), higher illness understanding among patients with actively engaged care partners, and no effect on visit duration.⁶⁷⁻⁷⁰

Our team is now testing a patient portal adaptation of patient-family agenda setting to identify care partners of older adults seen at UHealth Seniors Health Clinic in Colorado. In this context, the patient portal messaging function (a technology) is the conduit to portal users who engage with the message and its structured pre-visit questionnaire (a tool) to identify who is reporting on behalf of the patient in the context of agenda-setting (a task). A question: “Which of these applies to you?” is asked, with responses of “I am the patient, and I am completing this form myself” or “I am answering on behalf of the patient.” Care partner respondents are asked to identify their name and relationship to the patient (eg, spouse, adult child, and other) to further increase the transparency of communication. All of the OurNotes responses, including those who completed the agenda-setting questionnaire, are auto-populated into the clinician's visit documentation. This adaptation (a change in work systems) clarifies the author of OurNotes agenda-setting questions when they are someone other than a patient and supports care partner identification. Doing so lays the foundation for the development of shared knowledge, shared

goals, and problem-solving communication (improved work processes) by making the care team aware of the involvement and identity of care partners when authoring OurNotes responses within the patient record. Identifying non-patient contributions to electronic interactions within the patient record is important to ensuring the integrity of the health record and appropriate interpretation and actions by the care team.

4 | DISCUSSION

We have developed an integrative framework to guide the formulation of CHIT initiatives to explicitly engage and support the role of care partners in the care of persons with complex health and social needs that are particularly relevant within the context of a Learning Health System. Our framework articulates pathways through which clarifying and supporting the care partner role in CHIT work systems can advance relational coordination and the formulation of shared goals, shared knowledge, and mutual respect, reinforced by frequent, timely, accurate, and problem-solving communication—with benefits for individual and organizational experiences and efficiency.

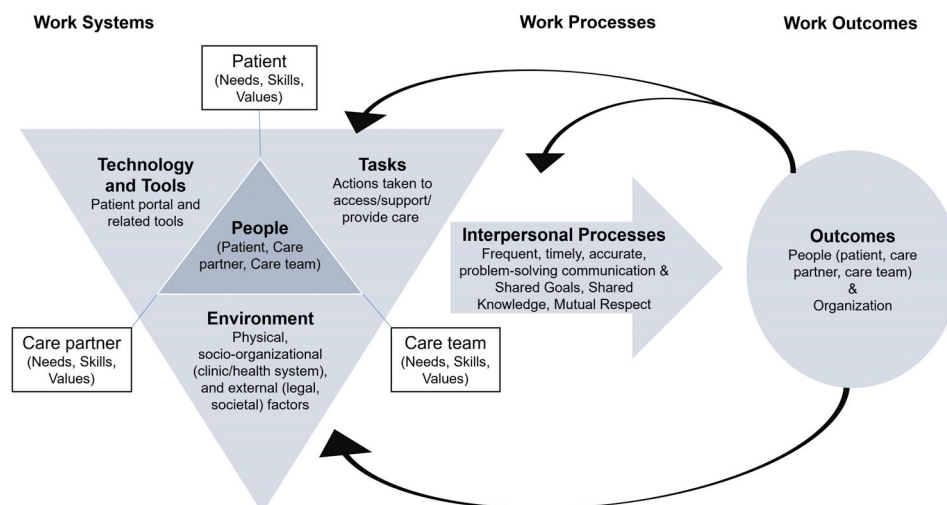
As patients and care partners commonly diverge in their perspective of patient health, behaviors, and experience of care, establishing the identity of who is contributing to electronic interactions is important to the reliability of “patient reported” information using electronic modalities: when conducting patient assessments, acting on secure messaging, and interpreting patient-reported quality measures. Supporting the role of care partners with unique identity credentials affords them access to transparent, timely, and accurate information about patient health while ensuring the integrity of information in the EHR. Supporting the role of care partners through CHIT is aligned with the 2022 National Strategy to Support Family Caregivers, most notably, Goal 2, to advance partnerships and engagement with family caregivers, including the recognition that they are essential partners in the care teams of the person(s) to whom they are providing support.⁷¹

Specifying the care partner role through CHIT represents an efficient approach to legitimizing their role and contributions to care processes while creating opportunities for delivering support at scale. Care partner knowledge, competence, capacity, and readiness to enact the patient’s care plan are generally not considered in the clinical context.⁵² As the competence and capacity of care partners affect care quality and outcomes, more effective support is a key opportunity for achieving savings in care delivery redesign.⁸ Importantly, new reimbursement opportunities are emerging that align with the assessment and support of the care partner’s role in care delivery: the final 2024 physician fee schedule put forward by the Centers for Medicare and Medicaid Services authorizes payment when practitioners train and involve caregivers to support patients in carrying out a treatment plan.⁷²

We recognize the complexity and fragmentation of care delivery work. Interactions span multiple modalities (eg, face-to-face visits, telehealth visits, secure messaging, and telephone interactions) and roles (eg, patients, care partners, primary care and specialist clinicians and staff, pharmacists, and therapists; insurers; and suppliers of durable medical equipment and other therapeutics). Our focus on electronic modalities and CHIT represents just a subset of care delivery interactions. Nevertheless, our framework merits attention given the accelerating pace of technological innovations including artificial intelligence, the disproportionate burden of electronic modalities on clinicians and staff, and the importance of negotiating and clarifying roles both within and outside the clinical context. Our contribution does not specifically consider implementation processes, which are critical in the evolutionary process of scaling applied CHIT innovations.

Preliminary evidence suggests the benefit of designating the care partner role in CHIT with respect to communication, confidence in the ability to manage care, and treatment adherence.⁷³⁻⁷⁵ Interventions to strengthen patient capacity and engagement in collaborative work processes and overcome health inequities have generally focused on introducing new health professionals, staff, and

Integrative Framework



technologies at the level of the individual patient. In contrast, our framework identifies opportunities to amplify the benefit of CHIT through clarifying and supporting the care partners who are already present and engaged in the care of persons with complex health and social needs.

Our framework has relevance to a range of research and LHS applications. Our framework can be used to guide the design of research studies to evaluate outcomes of CHIT applications that better identify, engage, or support care partners as members of the patient care team by strengthening their knowledge, capacity, and preparedness to enact the care plan. LHS may find value from our framework in evaluating how work system components facilitate or impede care partner inclusion, access, and support during in-person, remote, and CHIT interactions. Supporting the care partner role through CHIT is timely and could be impactful in the context of digital health inequities, accelerating reliance on electronic modalities, and fragmentation and complexity of work systems.

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CONFLICTS OF INTEREST STATEMENT

CT Lin reports serving as an unpaid advisory board member to Doximity Telehealth and Epic Physician Advisory Council. The remaining authors have nothing to disclose.

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