Journal of the American Medical Informatics Association, 28(1), 2020, 23–32
doi: 10.1093/jamia/ocaa207
Advance Access Publication Date: 5 November 2020
Research and Applications

Research and Applications

An implementation model for managing cloud-based longitudinal care plans for children with medical complexity

Grace Wang[1], Julia Wignall[1], Dylan Kinard[1], Vidhi Singh[1], Carolyn Foster[2], Sherri Adams[3,4,5], Wanda Pratt[6,7], and Arti D. Desai [1,8]

[1]Center for Child Health, Behavior & Development, Seattle Children's Research Institute, Seattle, Washington, USA, [2]Division of Academic General Pediatrics, Department of Pediatrics, Northwestern University Feinberg School of Medicine, Chicago, Illinois, USA, [3]Division of Paediatric Medicine, The Hospital for Sick Children (SickKids), Toronto, Ontario, Canada, [4]Child Health Evaluative Sciences, SickKids Research Institute, Toronto, Ontario, Canada, [5]Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, Ontario, Canada, [6]The Information School, University of Washington, Seattle, Washington, USA, [7]Biomedical and Health Informatics, University of Washington, Seattle, Washington, USA and [8]Department of Pediatrics, University of Washington, Seattle, Washington, USA

Corresponding Author: Arti D. Desai, MD, MSPH, M/S CW8-5, PO Box 5371, Seattle, WA 98122, USA; arti.desai@seattlechildrens.org

Received 17 June 2020; Revised 24 July 2020; Editorial Decision 3 August 2020; Accepted 27 August 2020

ABSTRACT

Objective: We aimed to iteratively refine an implementation model for managing cloud-based longitudinal care plans (LCPs) for children with medical complexity (CMC).
Materials and Methods: We conducted iterative 1-on-1 design sessions with CMC caregivers (ie, parents/legal guardians) and providers between August 2017 and March 2019. During audio-recorded sessions, we asked participants to walk through role-specific scenarios of how they would create, review, and edit an LCP using a cloud-based prototype, which we concurrently developed. Between sessions, we reviewed audio recordings to identify strategies that would mitigate barriers that participants reported relating to 4 processes for managing LCPs: (1) taking ownership, (2) sharing, (3) reviewing, and (4) editing. Analysis informed iterative implementation model revisions.
Results: We conducted 30 design sessions, with 10 caregivers and 20 providers. Participants emphasized that cloud-based LCPs required a team of owners: the caregiver(s), a caregiver-designated clinician, and a care coordinator. Permission settings would need to include universal accessibility for emergency providers, team-level permission options, and some editing restrictions for caregivers. Notifications to review and edit the LCP should be sent to team members before and after clinic visits and after hospital encounters. Mitigating double documentation barriers would require alignment of data fields between the LCP and electronic health record to maximize interoperability.
Discussion: These findings provide a model for how we may leverage emerging Health Insurance Portability and Accountability Act–compliant cloud computing technologies to support families and providers in comanaging health information for CMC.
Conclusions: Utilizing these management strategies when implementing cloud-based LCPs has the potential to improve team-based care across settings.

Key words: chronic disease, health information exchange, health information interoperability, hospital medicine, patient care planning, patient portals, pediatrics, transitional care, user-computer interface

INTRODUCTION

Background and Significance

The lack of well-structured care coordination is associated with high caregiver burden, ineffective communication between care team members, and patient safety issues.[1,2] This problem especially harms patients with multiple chronic conditions who typically receive care from a large care team spanning multiple care settings. Children with medical complexity (CMC) who receive care from an average of 13 different healthcare providers (henceforth referred to as providers) across multiple care settings are particularly affected by the lack of care coordination.[3–5] Exploring innovative health information technology strategies to promote coordinated team-based care for CMC can provide proactive lessons that may be applied to other patient populations and other team-based models of service delivery.[6,7]

One strategy to coordinate care within fragmented health information systems is the use of a longitudinal care plan (LCP).[8,9] An LCP is intended to be a portable medical summary that is continuously updated to reflect a patient's current management plan and the care goals of the child, the family, and their healthcare team.[9] For CMC, care team members may include the patient themselves, family caregivers, emergency and hospital providers, subspecialty providers, primary care providers, care coordinators, social workers, school staff, home health nurses or aides, and therapists. However, studies exploring the use of LCPs by families and providers who care for CMC highlight several limitations in their implementation that diminish their accessibility, their trustworthiness to provide accurate information, and their utility as a care coordination tool.[8,10–12]

Existing LCPs are typically printed on paper or scanned into the electronic health record (EHR) by an individual provider or provider team, restricting editing capability of other providers within the organization.[10,13] Some EHR-embedded LCPs may allow providers from a single organization to comanage care plan content; however, this excludes a multitude of providers who care for CMC outside of the organization from contributing or updating content.[10,14] Most importantly, printed, scanned, or EHR-embedded LCPs do not allow caregivers, who are integral members of the care team, to comanage their child's health information even though they have the most updated information about the child's day-to-day care.[10,12,14]

Cloud-computing technology can facilitate team-based care, in which families are integral members of the care team, by permitting multiuser accessibility and editing capabilities of LCPs within and across nonintegrated care settings.[10,15,16] In 2016, we conducted a qualitative study exploring the information needs of caregivers and providers who care for CMC and their perceptions of a cloud-based LCP.[10] Based on findings from this study, we created an initial implementation model for management of cloud-based LCPs for CMC (Figure 1).

Objective

The objective of this study was to iteratively refine this model by identifying barriers to management of cloud-based LCPs and potential strategies to mitigate barriers from the perspective of caregivers and providers who care for CMC in acute care settings.

MATERIALS AND METHODS

Study design, population, and setting

We conducted a qualitative study following user-centered design principles,[17] which involved iterative cycles of 1-on-1 design sessions with caregivers and providers who care for CMC, content

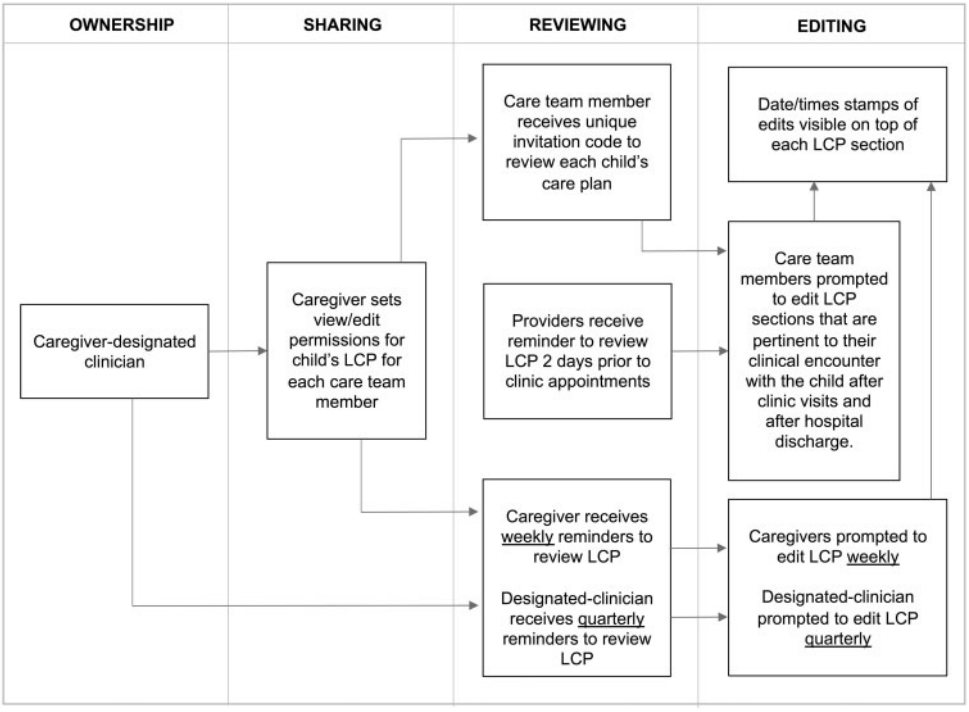

Figure 1. Initial implementation model for management of cloud-based longitudinal care plans (LCPs) for children with medical complexity.

analysis of session audio recordings, and refinement of the implementation model based on participant feedback. This study was informed by the Integrative Model of Behavioral Prediction, which predicts that individuals will be most likely to act on their intentions (ie, manage cloud-based LCPs) when (1) they have the necessary skills to perform an action and (2) when environmental factors do not impede behavioral performance.[18] Thus, our design sessions and resultant thematic analysis focused on identifying barriers to managing cloud-based LCPs and strategies to mitigate these barriers in terms of user abilities (eg, ability to access, share, review, or edit an LCP) and environmental constraints (eg, lack of time and support to manage LCP content and technology limitations). We chose to focus this study on CMC, as they represent a population of patients with multiple chronic conditions who receive care from a multidisciplinary team of providers across nonintegrated care settings.[14,16] To explore provider perceptions in depth, we limited our study scope to providers who care for CMC in acute care settings (eg, hospitals, primary and ambulatory care clinics), and we only included physicians, care coordinators, and case managers as provider participants. All study procedures were approved by the Seattle Children's Hospital Institutional Review Board.

We identified English-speaking caregivers of CMC (0-18 years of age) who were cared for at a tertiary children's hospital between August 2017 and March 2019. We approached caregivers of CMC who were followed by the institution's complex care service and who met the Pediatric Medical Complexity Algorithm complex chronic conditions designation.[19] CMC followed by the complex service have chronic conditions affecting multiple body systems, technology dependence (eg, tracheostomy, feeding tube), several subspecialists on their care team, and frequent hospital admissions. We used purposive sampling, a qualitative strategy to maximize participant diversity and the range of perspectives using the following demographic characteristics: child age, types of medical conditions, child and parent race-ethnicity, and geographic county. Trained research staff approached eligible parents either in person during the child's hospital admission or by telephone using a standardized recruitment protocol.

We identified providers who care for CMC within the study institution and within the study institution's 5-state catchment area through our provider referral network. We used purposive sampling to maximize diversity of our provider sample based on age, number of years in practice, practice location, and whether they had easy access to the main hospital's EHR (to gather perspectives from providers who do not have ready access to the child's hospital or subspecialty medical records). Trained research staff used a standardized email script to recruit providers.

We recruited and enrolled caregivers and providers until we achieved thematic saturation within groups of participants (caregivers or provider groups [ie, emergency care providers]) and across participants, meaning few new ideas or themes emerged from our analysis as we continued conducting design sessions.[20]

Data collection

We conducted audio-recorded design sessions in private hospital rooms and offices or by telephone for geographically distant participants. One to 2 research team members conducted each design session that lasted approximately 1 hour. We developed our interview guide based on the Integrative Model of Behavioral Prediction and included domains that mapped to 4 key processes for managing LCPs that were derived from our prior research as outlined in the initial implementation model (Figure 1):[10] (1) taking ownership of, (2) sharing, (3) reviewing, and (4) editing LCPs. We revised the interview guide after every 2-3 sessions as we identified new themes or areas of exploration within these domains through concurrent data analysis.[20] In earlier interviews, we focused more broadly on the information needs and workflow of participants when searching for information about their child or patient. In later interviews, we presented role-specific scenarios based on the most current version of our implementation model to understand how an individual may share, review, or edit an LCP. For example, we presented emergency providers with a scenario involving a CMC presenting to the emergency department without a parent. We asked participants to walk through the scenario using a cloud-based LCP prototype that we were concurrently developing. The LCP prototype only contained mock patient data. Between design sessions, we refined our implementation model based on content analysis of previous session audio recordings.

Participants completed a brief demographic survey at the end of the session including items assessing their comfort with technology. Participants were offered a $25 gift card after completing the design session.

Data analysis

We applied conventional content analysis techniques[21] and deductive coding[22] of audio recordings to identify implementation barriers and potential strategies to mitigate barriers in reference to the aforementioned 4 key processes for managing LCPs: (1) taking ownership of, (2) sharing, (3) reviewing, and (4) editing LCPs. We used inductive coding within these 4 processes to identify subprocesses.[22] We did not transcribe audio recordings, because we were concerned with losing subtle nuances in the conversation that would not have been adequately captured in a written transcript as participants interacted with the prototype.[23] Instead, research team members independently listened to audio recordings and documented memos with time stamps for each excerpt relating to that memo.

Initially, 2 research team members (G.W. and A.D.D.) independently documented memos and performed open coding of memos for the first 3 interviews. They then met to discuss memos and codes, resolved coding discrepancies, and constructed an initial codebook, relistening to audio recordings when necessary. For the remaining interviews, at least 2 research team members (G.W., J.W., and A.D.D.) met after every 2-3 design sessions to discuss memos, refine the codebook, and review excerpts from audio recordings to identify common barriers and potential strategies to mitigate barriers. These strategies were included in future iterations of the interview guide to identify new barriers and potential strategies related to the evolving implementation model. Once we completed all interviews, 1 of these research team members (G.W. or A.D.D.) and 1 other team member (J.W., D.K., or V.S.) independently listened to each audio recording and documented memos with time stamps using the final codebook. Two authors (G.W. and A.D.D.) reviewed all memos and excerpts from audio recordings to develop consensus on a list of implementation barriers and potential strategies to finalize the implementation model, which was reviewed by the full research team.

RESULTS

Demographics

We conducted 30 design sessions, 10 with caregivers and 20 with providers, to achieve thematic saturation within and across partici-

Table 1. Characteristics of caregiver and provider participants

Caregivers	n = 10
Age	
≤35 y	2 (20)
36-45 y	3 (30)
≥45 y	5 (50)
Ethnicity	
Hispanic or Latino	3 (30)
Not Hispanic or Latino	7 (70)
Race	
White	9 (90)
Non-White	1 (10)
Level of education	
At most high school graduate or GED	2 (20)
Some college/university	3 (30)
At least some 4-y university	5 (50)
Primary residence	
Within same county as study institution	4 (40)
Within state (but not same county as study institution)[a]	5 (50)
Out of state	1 (10)
Caregivers in the home	
1	1 (10)
2	4 (40)
≥3	5 (50)
Years child has had a care plan	
No care plan (not applicable)	4 (40)
<1 y	1 (10)
1-5 y	3 (30)
>5 y	2 (20)
Frequency caregiver refers to care plan	
No care plan (not applicable)	4 (40)
Never	1 (17)
1-2 times in past 6 mo	4 (66)
Daily	1 (17)
Providers	**n = 20**
Age	
≤35 y	8 (40)
36-45 y	6 (30)
≥45 y	6 (30)
Type of provider	
Complex care provider	4 (20)
Primary care provider	4 (20)
Emergency department provider	4 (20)
Subspecialty provider	4 (20)
Care coordinator/case manager	4 (20)
Years in practice	
0-5	8 (40)
6-10	4 (20)
11-20	5 (25)
>20	3 (15)
Primary practice location	
Based at study institution	13 (65)
In-state (not based at study institution)	5 (25)
Out of state	2 (10)
Has remote access to study institution's EHR	
Yes	18 (90)
No	2 (10)
Provider has created or reviewed a patient care plan	15 (75)
Provider comfort level caring for CMC[b]	94 (76-100)

Values are n (%) or mean (range)

CMC: children with medical complexity; EHR: electronic health record; GED: general equivalency diploma.

[a]Participants were from 5 different counties within the state.

[b]Higher ranking indicates higher comfort level.

pant groups. Of the 13 eligible caregivers that we approached, 10 (77%) participated in the study; of the 27 eligible providers that we approached, 20 (74%) participated in the study (Table 1).

Overview of study findings

For each of the 4 key processes, we present (1) our initial implementation model for the process, (2) common implementation barriers relating to that process, and (3) strategies to address these barriers through iterative refinement of our implementation model. Illustrative quotes regarding the perspectives of both caregivers and providers for each of these processes are presented in Table 2. Table 3 presents a detailed progression for how our implementation model evolved through this iterative user-centered design process.

Taking ownership of LCPs

Initial model

A caregiver-designated clinician with medical expertise, a holistic understanding of the child's health conditions, and who frequently saw the child would be the LCP "owner." This owner would be responsible for routine reviewing the LCP and overseeing content management.

Barrier to implementation

During design sessions, participants expressed that a single individual would not be sufficient to oversee a comprehensive LCP serving a diverse array of information needs. For example, emergency and inpatient providers would have expertise in overseeing medical information to guide appropriate health management decisions in hospital settings. Care coordinators would have expertise in managing pending tasks, appointments, and medical equipment needs. Caregivers would know day-to-day information to track symptoms, maintain an updated medication list, communicate care preferences, and outline care goals to promote shared decision making.

Strategies

We revised our implementation model to include a "core team" composed of a caregiver, a caregiver-designated clinician, and a caregiver-designated care coordinator, who would partner to oversee the major LCP information areas including medical, care coordination, and home and family information on a routine basis.

Setting LCP permissions

Initial model

Caregivers could share the LCP with individual care team members and grant either "view-only" or "view and edit" permissions for individual LCP sections to each care team member. For example, caregivers could choose to share only the school escalation plan with school nurses, rather than the entire LCP. The implementation barriers we identified were related to time-sensitive sharing, team-based sharing, and view and edit permissions.

Default access

Barrier to implementation. Some providers were concerned that a default setting of not having access to the child's LCP could compromise the delivery of time-sensitive care, especially in emergency situations.

Strategies. Participants recommended that both view and edit access should be automatically given to all providers at the child's

Table 2. Illustrative quotes from caregivers and providers regarding the management of cloud-based LCPs

Themes	Illustrative quotes
Taking ownership of LCPs	
Core team caregiver	"For example, I would want to double-check the medication list, because I have found times when we have been in the hospital where they got dosages wrong. I would definitely want to be able to update it or make sure that it always looks current, so that he doesn't get any wrong dosages." (Caregiver #7)
Core team clinician	"[Specialist] is the one that knows the overall things about her care. She's the one who coordinates with all the other specialists." (Caregiver #8)
Core team care coordinator	"[The hospital care coordinator] is the one who talks to doctors, finds appointments, and she is the one who is following up with home health agencies. Its easier to go to her instead of others because she knows how to work the system inside of the hospital." (Caregiver #9)
Setting LCP permissions	
Default access	"Each medic agency has somebody called a medical safety officer, who is kind of like a medical supervisor, and sometimes they'll arrive on scene. So you could have someone who'd been given permission to access a certain patient population's information. If one of these kids called 911, if there's a trigger, they could print out just the emergency information and have that available to the crews." (Provider #12)
Team-based sharing	"You would not want to have to verify everyone or grant access to everyone, so maybe there's a way you can suspend that requirement for a time while you're in the hospital. Maybe grant a blanket access to everyone that's in the hospital? I would still be interested in logging the information and be able to review that at my leisure." (Caregiver #4)
View/edit permissions	"I wouldn't necessarily want to edit [the active issues list], I would want a specific person in charge, like a medical professional, to make sure that was accurate at all times. Because if I can get in there and edit it, it wouldn't be as believable when you try to use it somewhere." (Caregiver #6)
Reviewing LCPs	
Care team member authentication	"I live in my email inbox day-to-day so I don't feel like I get anything done unless it comes to my inbox. When I'm actually in the hospital I'm in [the electronic health record] much more but I still have my email open. Would I miss it if it came to my email inbox while I'm on service? Not really." (Provider #2) "Could you make it be part of the [institution's] single sign-on? Because that would be easy. What I would do at the beginning of my shift is log into the platform and just minimize it and then if patients came in I would just look up their name." (Provider #8)
Review reminder notifications	"I would probably review it beforehand, to get to know the patient before I've seen them, and know what questions I need to ask besides just the cardiology questions. If I were going to make any changes, I could look to that to say, you know, this may or may not be a good idea, and do I need to contact this other specialist if my change may impact that organ system." (Provider #16)
Editing LCPs	
Edit notifications	"If I ended up having 15 patients on this list, I would need to be prompted to input information. If the edit notification email linked you to just the patient who is requesting information, that would be better " (Provider #16) "I'm happy to do it when I get the email. The email will be critical, because otherwise it's not on my radar: 'Do this, link here, makes it much easier." (Provider #11) "I would want a clear role in what to edit or not to edit. I would probably not proactively edit it unless someone told me to. I don't want to duplicate work." (Provider #14)
Double documentation	"My big concern is that with all of the demands on documentation that providers currently have, adding more to that, without having things automated or pulled in from the chart. Or have this talk to the EHR or vice versa." (Provider #14)
Tracking edits	"From a provider standpoint, you may want to know who changed the dosing, or who changed the rescue plan or seizure intervention, that sort of thing. That may be the type of thing that you could link in, so you could click on a sentence and it would say, "last updated by. . .'." (Provider #1) "Coming from a subspecialist who monitors airways, vents, and airway clearance, I would want that section to be specifically [marked as] updated. I think we've all had experiences where we've been using out of date information to make decisions about patients, because this is not directly linked to [the electronic health record]. I would want some additional assurance that this is being evaluated for accuracy and change over time." (Provider #14)

EHR: electronic health record; LCP: longitudinal care plan.

Table 3. User-centered design to inform the evolution of an implementation model for managing cloud-based LCPs

Initial model	Barriers to implementation	Solutions proposed
Taking ownership of LCPs		
Owner is a caregiver-designated clinician who has a holistic understanding of child's medical conditions.	A team of owners is needed to oversee the multitude of information areas that could be included in a comprehensive, cloud-based LCP.	A "core team" composed of a caregiver, caregiver-designated clinician, and caregiver-designated care coordinator work in tandem to oversee and facilitate management of updated LCP information.
Setting LCP permissions		
Caregivers have authority to grant view only or view and edit permissions of LCP section(s) to individual care team members.	Default access: With default settings corresponding to lack of access, the delivery of time-sensitive care may be compromised when access controls are limited to caregivers.	Revocable default view and edit permissions are automatically granted to individuals within the child's primary care setting and tertiary children's hospital. Permissions are not required to share specific emergency information.
	Team-based sharing: Individually granting access to the LCP is an impractical and laborious task for caregivers.	Caregivers can share the LCP with care teams using existing provider directories that are available in the EHR or from clinical sites.
	View/edit permissions: Unrestricted editing capability for non–healthcare provider users may compromise the trustworthiness of medical information within the LCP.	Editing restrictions will be placed on caregivers; they can submit edits to LCP sections with direct medical care recommendations, which require approval by a provider prior to incorporation in the LCP.
Reviewing LCPs		
New users log in with their email address and an individualized code linking the user to the patient.	Care team member authentication: Providers expressed concerns about keeping track of multiple patient codes.	Providers can log on through single sign-on, via a link in the institution's EHR, or via a secure email-embedded link to access their list of LCPs.
Providers receive email notifications 2 days before appointments. Caregivers receive weekly reminders to review recent changes and designated clinician receive reminders every 3 mo to resolve inconsistencies.	Review reminder notifications: Upcoming appointments may not be updated in the LCP to trigger review notifications. Weekly notifications were too frequent for caregivers and quarterly notifications were too infrequent for other core team members.	Upcoming appointments are auto-populated in the LCP from the EHR and from other calendar applications on caregiver mobile devices to trigger review reminders. All core team review reminders are sent monthly.
Editing LCPs		
Care team members are prompted via email to edit pertinent sections after appointments and hospital discharges. Core team members make necessary edits during routine reviews.	Edit notifications: Care team members may not know what information to update and may not be confident with contributing information to the LCP.	Edit notifications have clear instructions about the care team member's responsibilities and what information to include. Hover boxes within the LCP provide additional instructions for each section. The LCP includes a video tutorial.
Care team members directly edit all information within the LCP that is pertinent to their clinical encounter with the child.	Double documentation: A high burden is placed on providers to double-document between care plan and EHR.	Structured data fields will auto populate from the EHR to minimize double-documentation. Alignment of unstructured data fields between EHRs and the LCP should be incorporated in the design of the LCP. A back-end curator may be needed when providers do not update the LCP. Copy and paste functionality should be available between information systems when interoperability is not possible.
Updated time stamps with of most recent edits are visible on each care plan page with the name of the editing care team member.	Tracking edits: Care team members desired more granular data regarding edits to specific care plan sections and data fields.	Updated time stamps and signatures will be associated with subsections or data fields, visible as a hover action. Options will be available to view a full edit log or to highlight recent changes upon logon.

EHR: electronic health record; LCP: longitudinal care plan.

primary care clinic and the child's main tertiary children's hospital (defined as the location where they receive most of their inpatient and outpatient subspecialty care). However, caregivers should still retain the ability to manually revoke view or edit permissions of individual providers or care teams. Participants also noted that specific information regarding emergency care should be universally accessible without requiring authentication, as some emergency providers (eg, emergency medical technicians and local emergency department providers) may not be included in this default access.

Team-based sharing

Barrier to implementation. Participants were concerned that providing access to each care team member would be labor-intensive and an impractical task for caregivers. The permission setting process should be simplified without eliminating customizability. Furthermore, providers noted concerns with caregivers "cherry-picking" providers from team-based care groups.

Strategies. To support this, the cloud-based platform would allow caregivers to share the LCP with care teams and leverage existing provider directories from the EHR whenever possible (eg, nursing pools, service groups).

View and edit permissions

Barrier to implementation. Participants expressed concerns that LCP information may not be considered trustworthy without editing restrictions for nonhealthcare providers.

Strategies. Both caregivers and providers agreed that real-time editing restrictions should be present for certain sections of the LCP that provide direct medical care guidance such as the emergency care plan or contingency plan information for certain conditions (eg, medications that should be administered for a prolonged seizure). These sections would clearly state that only healthcare providers can edit the section in real time. Participants also suggested that caregivers should be allowed to submit edits, but the appropriate healthcare provider would need to review and approve edits prior to incorporation in the LCP. Although participants expressed varied opinions on whether this restriction should apply to the medication list, our final model permitted caregivers to edit the medications list, as participants agreed that caregivers have the most current information about how each medication is being administered on a day-to-day basis.

Reviewing LCPs

Care team member authentication

Initial model. To balance the need for quick access with Health Insurance Portability and Accountability Act–compliant security for care team members who would not have access to the LCP through an EHR, our initial model proposed that new users would login with their email address and enter an individualized code linking the user to the patient.

Barrier to implementation. Providers were wary of keeping an individualized code to review a child's LCP or maintaining multiple codes if they had access to multiple LCPs.

Strategies. Providers ideally preferred to access the LCP via a link embedded in the child's EHR or using single sign-on processes whenever possible. In the absence of EHR authentication, providers were supportive of using an email-embedded link to access all their patients' LCPs. Many providers stated that their email application was usually open as part of their workflow and that they would likely access LCPs on a desktop computer. Thus, we identified that the most efficient approach would be to have care team members enter their email address on a login page, and the individual would receive a new real-time active link via email. All email invitations to review the LCP should be personalized and sent from a trusted organization to enhance engagement. Caregivers agreed that this process would be simple, but also suggested using stored passwords or "touch ID" for access on mobile devices.

Review reminder notifications

Initial model. Care team members would receive reminder email notifications to familiarize themselves with relevant sections of the LCP 2 days prior to any appointments. Caregivers would receive weekly reminders to review the LCP for missing or inconsistent information, and the designated clinician would receive similar reminders every 3 months.

Barriers to implementation. Although the timing of appointment-related email notifications was well accepted by participants, our initial model required that all appointments across the care continuum would need to be up to date within the LCP. For routine reviews, caregivers expressed that weekly notifications were too frequent, and some participants noted that 3 months may be too long to catch missing information or inconsistencies.

Strategies. Information regarding upcoming appointments within the LCP would auto populate from existing EHRs to trigger the appropriate alerts. In the absence of such interoperability, the core team care coordinator and caregiver would be responsible for keeping appointment information up to date. Caregivers suggested syncing appointment information with other mobile applications (eg, personal calendar) would streamline this task.

Participants agreed that email notifications to review the LCP would be acceptable. Providers generally use the EHR only on clinical days; therefore, EHR-based review notifications may be missed on nonclinical days.

To simplify routine review reminders, participants suggested that monthly notifications would be sufficient without resulting in alert fatigue; therefore, we changed the frequency of these notifications to monthly for all core team members (ie, caregivers, designated clinician, and care coordinator).

Editing LCPs

Edit notifications

Initial model. All care team members would be responsible for contributing and updating information within the LCP that was pertinent to their role. Care team members would receive email notifications to edit relevant LCP sections after appointments and hospital discharge. Core team members would receive alerts to edit the LCP at the same time as routine review reminders.

Barriers to implementation. Some providers noted that if editing responsibilities are unclear, individual care team members may not take initiative to edit appropriate sections of the LCP. This would result in out-of-date LCPs. Furthermore, some caregivers and providers expressed concern regarding their knowledge of what content to include in an LCP and their confidence in regards to editing LCP content "correctly."

Strategies. To clarify editing responsibilities, each edit notification would include expectations of what information should be updated by the care team member based on their role (eg, physician, care coordinator, caregiver). To address hesitancy on the part of caregivers and providers to edit the LCP, participants suggested incorporating information buttons within the LCP with examples (ie, hints) of content they could include in various sections and a short video tutorial

for each care team member role. Depending on the institution's familiarity with LCPs and existing ownership structures, education campaigns may be required to clarify the purpose of these LCPs to maximize engagement.

Double documentation

Initial model. In the absence of interoperability for unstructured data, care team members would be responsible for manually entering relevant information from their clinical notes into the LCP.

Barrier to implementation. Our initial model imposed a high editing burden on providers in addition to their existing EHR documentation responsibilities, limiting the model's feasibility and sustainability. However, participants also made it clear that an LCP that only contained structured data from the EHR would likely reduce the quality and usefulness of the LCP.

Strategies. Providers expressed that interoperability between EHRs and the LCP would be required for structured data (eg, medication name, appointment date). For unstructured data, LCP "free-text" data fields should be carefully aligned with EHR data fields to automatically pull information from the EHR to maximize interoperability. In cases in which narrative text within a clinical note (eg, assessment and plan section) would be applicable to multiple LCP sections, a backup curator may be required if providers did not sufficiently update the LCP in a timely manner to ensure the quality and accuracy of information within the LCP. Finally, copy-and-paste functionality between information systems would help reduce the burden of double documentation when interoperability was not possible.

Tracking edits

Initial model. To keep care team members informed of revisions, date and time stamps with the name of the editing care team member would be visible at the top of each section.

Barriers to implementation. Participants indicated a desire for more granular data with regard to a revision history; however, they expressed that these data should not compromise a clear and clean presentation of the overall LCP.

Strategies. Updated date and time stamps should be visible for each subsection or data field rather than each section (eg, for each medication rather than for the entire medication list). Stamps could be displayed as a hover action to maintain a clean appearance. Participants also suggested that new LCP information should be highlighted each time a user accessed the system. Last, an option to view a full revision history should be made available on a separate page, should a care team member desire more detailed information.

DISCUSSION

This study provides an in-depth exploration of barriers to and strategies for managing cloud-based LCPs that allow for real-time, multiuser editing. The final implementation model we developed consists of a 3-member core team comprised of a caregiver, clinician, and care coordinator to oversee LCP content. A flexible, caregiver-controlled permission settings process and alert system notifying care team members to engage with the LCP in a timely manner would be important. Our model details strategies for team-based accessibility and streamlines login processes, attending to the complexity and time constraints of care teams. These strategies include integrating existing provider directories within the LCP sharing functionality, providing default access for providers within the child's primary care clinic and tertiary children's hospital, and unrestricted access to emergency LCP information. Our model proposes workaround strategies for data entry between the LCP and EHR when interoperability functionality may be limited, along with future steps to optimize interoperability.

Cloud-based LCPs expand care coordination beyond single care teams or institutions by thinking more holistically about integrated, team-based care across the healthcare system.[14,24] Commercially available EHRs do not promote co-production and co-management of health information across nonintegrated healthcare organizations.[12,13,25] Our study findings provide a model for collaborative management of LCP content across systems. For example, the proposed core team model does not assume that the child's patient-centered medical home is the primary care clinic, as recent studies suggest that some caregivers of CMC identify a hospital-based clinic as their child's medical home.[26–28] Instead, the model gives families flexibility in designating the best clinician and care coordinator to co-own their child's LCP.

Prior literature has shown that event notifications improve provider awareness of the patient's history and prompt timely interventions when necessary, whether they be medical or related to care coordination and referral needs.[29,30] Our implementation model details the timing, purpose, and targets of these notifications for timely review and editing of cloud-based LCP content. We also identify strategies to enhance care team member comfort with editing LCPs with hints and information boxes within the prototype and clear messaging about their role for managing the LCP through edit notifications. Drawing from the literature on co-management of EHR-based problem lists, we should also consider implementation strategies such as integrating smart searches when adding new data and using feedback loops with providers to structure free-text data and optimize data dictionaries to ease data entry.[31] Furthermore, providers may be more likely to engage in comanaging LCP information if we integrate data entry with clinical decision support (eg, adding an action item for a screening procedure would trigger an order for the test at the appropriate time) and if we integrate the management of LCP information into training and education programs such a family-centered rounds.[32] Thus, we need continued development and research in cloud-based strategies that allow all care team members (regardless of role and practice location) to access and contribute information within an LCP to accurately reflect the child's most current needs, care plans, and goals.

Cloud-based LCPs also provide families the opportunity to be integral partners in the care team, resulting in a system in which care is happening with them rather than to them. Findings from this study provide a model for how we may leverage emerging Health Insurance Portability and Accountability Act–compliant cloud computing technologies to support family-centered, team-based content management—in essence, marrying the personal health record with the longitudinal medical record—within a unified LCP.[33] While leading commercially available EHRs and health information exchange platforms are attempting to expand on-demand secure access to LCP information,[34] these platforms still do not support caregivers in comanaging health information even though they are often seen as the expert in their child's care.[4,35] The final implementation model we developed proposes several strategies to empower caregivers to comanage their child's LCP alongside providers. Caregivers

are considered a core team member and have control over who has access to their child's LCP. More importantly, caregivers have equivalent real-time view and editing capabilities as providers, with the exception of direct medical guidance; however, they may still provide suggestions. For example, a systematic literature review recommended that patients should be able to see, prioritize, and suggest additions or deletions to their own problem list as 1 of 15 strategies to problem list success and accuracy.[32] The findings of this study incorporate concerns, constraints, and preferences expressed by both families and providers, and we identify implementation strategies that actively target security and safety concerns about co-management of health information between families and providers. Moving forward, we need to ensure the design of patient-facing health information technology tools recognize that caregivers of CMC should have equitable partnerships with other care team members in managing their child's health information.

Limitations and future work

We recognize our study has some limitations. First, we only included CMC who receive care from a single tertiary care institution, which limits the generalizability of our findings. Second, our sampling method also excluded families with limited English proficiency; a critical step in future work will be to conduct additional formative studies to understand how to best tailor cloud computing technologies to support multiple languages. Third, we did not assess the digital health literacy of participants; therefore, future usability and feasibility studies should be conducted to understand how this model should be further adapted to meet variable levels of literacy. Fourth, we did not address a secure messaging system for care teams that would help facilitate seamless communication, a key component of collaborative information management. Last, this initial study focused on providers who care for CMC in acute care settings, and we did not include the perspectives of several provider groups who care for CMC within and outside the healthcare system, such as nursing professionals, therapists, school personnel, home health personnel, and social workers. Similar design work with these groups will be essential to enhance our understanding of how cloud-based LCPs can promote team-based care across interprofessional teams and nonintegrated systems of care.

We sought to challenge the existing clinical practice paradigm by elucidating how emerging information technologies may be leveraged to engage both families and providers in collaboratively managing patient health information. Refining this implementation model based on feasibility and effectiveness testing in real-world settings will be a critical next step.

CONCLUSION

Using a user-centered design framework, we developed and refined a novel implementation model for managing cloud-based LCPs for CMC. Future research will be needed to test this model in a real-world setting and examine associations with patient-centered health outcomes and healthcare utilization. However, this study will serve as a framework for collaborative management of LCPs to promote comprehensive, coordinated care for patients with multiple chronic conditions across the care continuum.

FUNDING

This study was supported by a Patient-Centered Outcomes Research Mentored Clinical Investigator Award from the Agency of Healthcare Research and Quality under award number K08HS024299 (PI: ADD).

AUTHOR CONTRIBUTIONS

GW conceptualized and designed the study, collected data, participated in data analysis, drafted the initial manuscript, and reviewed and revised the manuscript. JW collected data, participated in data analysis, and reviewed and revised the manuscript. DK and VS participated in data analysis and reviewed and revised the manuscript. SA, CF, and WP conceptualized and designed the study and reviewed and revised the manuscript. ADD conceptualized and designed the study, collected data, participated in data analysis, and reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

ACKNOWLEDGMENTS

We thank Drs. Rita Mangione-Smith and Maria Britto for their mentorship during the course of this study. We also thank Yooli Hardy, Steven Lundgren, and Charlie Kim from the Seattle Children's Hospital Digital Health Team for their valuable guidance during the conduct of this study.

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest relevant to this article to disclose.

REFERENCES

1. Corrigan JM, Adams, K, eds. *Priority Areas for National Action: transforming Health Care Quality*. Washington, DC: National Academies Press; 2003.
2. Bodenheimer T. Coordinating care–a perilous journey through the health care system. *N Engl J Med* 2008; 358 (10): 1064–71.
3. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttmann A. Patterns and costs of health care use of children with medical complexity. *Pediatrics* 2012; 130 (6): e1463–70.
4. Allshouse C, Comeau M, Rodgers R, Wells N. Families of children with medical complexity: A view from the front lines. *Pediatrics* 2018; 141 (Suppl 3): S195–201.
5. Turchi RM, Antonelli RC, Norwood KW, *et al*. Patient- and family-centered care coordination: a framework for integrating care for children and youth across multiple systems. *Pediatrics* 2014; 133 (5): e1451–60.
6. Kooij L, Groen WG, Van Harten WH. The effectiveness of information technology-supported shared care for patients with chronic disease: a systematic review. *J Med Internet Res* 2017; 19 (6): e221.
7. Marchibroda JM. The impact of health information technology on collaborative chronic care management. *Journal of Managed Care Pharmacy* 2008; 14 (2 Suppl): S3–11.
8. Dykes PC, Samal L, Donahue M, *et al*. A patient-centered longitudinal care plan: vision versus reality. *J Am Med Inform Assoc* 2014; 21 (6): 1082–90.
9. McAllister JW. Achieving a shared plan of care with children and youth with special health care needs. Lucile Packard Foundation for Children's Health. https://www.lpfch.org/publication/achieving-shared-plan-care-children-and-youth-special-health-care-needs Accessed April 6 2020.
10. Desai AD, Jacob-Files EA, Wignall J, *et al*. Caregiver and health care provider perspectives on cloud-based shared care plans for children with medical complexity. *Hosp Pediatr* 2018; 8 (7): 394–403.
11. Adams S, Cohen E, Mahant S, Friedman JN, MacCulloch R, Nicholas DB. Exploring the usefulness of comprehensive care plans for children with medical complexity (CMC): a qualitative study. *BMC Pediatr* 2013; 13 (1): 10.

12. Ranade-Kharkar P, Weir C, Norlin C, *et al*. Information needs of physicians, care coordinators, and families to support care coordination of children and youth with special health care needs (CYSHCN). *J Am Med Inform Assoc* 2017; 24 (5): 933–41.
13. Horsky J, Morgan SJ, Ramelson HZ. Coordination of care for complex pediatric patients: perspectives from providers and parents. *AMIA Annu Symp Proc* 2014; 2014: 681–90.
14. Amir C, Grosz BJ, Gajos KZ, Swenson SM, Sanders LM, Amir O. From care plans to care coordination: opportunities for computer support of teamwork in complex healthcare. In: proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems. 2015: 1419–28.
15. Amir O, Grosz BJ, Gajos KZ, Swenson SM, Sanders LM. AI support of teamwork for coordinated care of children with complex conditions. In: proceedings of the 2014 AAAI Fall Symposium Series. 2014.
16. Ranade-Kharkar P, Norlin C, Fiol DG. Formative evaluation of care nexus: a tool for the visualization and management of care teams of complex pediatric patients. *AMIA Annu Symp Proc* 2017; 2017: 1458–67.
17. Kinzie MB, Cohn WF, Julian MF, Knaus WA. A user-centered model for web site design needs assessment, user interface design, and rapid prototyping. *J Am Med Inform Assoc* 2002; 9 (4): 320–30.
18. Fishbein M. A reasoned action approach to health promotion. *Med Decis Making* 2008; 28 (6): 834–44.
19. Simon TD, Haaland W, Hawley K, Lambka K, Mangione-Smith R. Development and validation of the Pediatric Medical Complexity Algorithm (PMCA) version 3.0. *Acad Pediatr* 2018; 18 (5): 577–80.
20. Sandelowski M, Given LM. *The SAGE Encyclopedia of Qualitative Research Methods*. Thousand Oaks, CA: Sage; 2008.
21. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005; 15 (9): 1277–88.
22. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: a hybrid approach of inductive and deductive coding and theme development. *Int J Qual Methods* 2006; 5 (1): 80–92.23.
23. Markle DT, West RE, Rich PJ. Beyond transcription: Technology, change, and refinement of method. *Forum Qual Soc Res* 2011; 12 (3): 1564.
24. Katkin JP, Kressly SJ, Edwards AR, *et al*. Guiding principles for team-based pediatric care. *Pediatrics* 2017; 140 (2): e20171489.
25. Borbolla D, Taft T, Taber P, *et al*. Understanding primary care providers' information gathering strategies in the care of children and youth with special health care needs. *AMIA Annu Symp Proc* 2018; 2018: 272–8.
26. Cohen E, Friedman J, Nicholas DB, Adams S, Rosenbaum P. A home for medically complex children: the role of hospital programs. *J Healthc Qual* 2008; 30 (3): 7–15.
27. Cohen E, Jovcevska V, Kuo DZ, Mahant S. Hospital-based comprehensive care programs for children with special health care needs: a systematic review. *Arch Pediatr Adolesc Med* 2011; 165 (6): 554–61.
28. Pordes E, Gordon J, Sanders LM, Cohen E. Models of care delivery for children with medical complexity. *Pediatrics* 2018; 141 (Suppl 3): S212–23.
29. Vest JR, Ancker JS. Health information exchange in the wild: the association between organizational capability and perceived utility of clinical event notifications in ambulatory and community care. *J Am Med Inform Assoc* 2017; 24 (1): 39–46.
30. Anand V, Sheley ME, Xu S, Downs SM. Real time alert system: a disease management system leveraging health information exchange. *Online J Public Health Inform* 2012; 4 (3): ojphi.v4i3.4303.
31. Hodge CM, Kuttler KG, Bowes WA III, Narus SP. Problem management module: an innovative system to improve problem list workflow. *AMIA Annu Symp Proc* 2014; 2014: 661–70.
32. Hodge CM, Narus SP. Electronic problem lists: a thematic analysis of a systematic literature review to identify aspects critical to success. *J Am Med Inform Assoc* 2018; 25 (5): 603–13.
33. Rigby M, Georgiou A, Hyppönen H, *et al*. Patient portals as a means of information and communication technology support to patient-centric care coordination–the missing evidence and the challenges of evaluation. *Yearb Med Inform* 2015; 24 (1): 148–59.
34. Winden TJ, Boland LL, Frey NG, Satterlee PA, Hokanson JS. Care everywhere, a point-to-point HIE tool. *Appl Clin Inform* 2014; 05 (2): 388–401.
35. Kuo DZ, McAllister JW, Rossignol L, Turchi RM, Stille CJ. Care coordination for children with medical complexity: whose care is it, anyway? *Pediatrics* 2018; 141 (Suppl 3): S224–32.