Brief Communication

An environmental scan of shared access to patient portals

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ABSTRACT

We sought to understand the comprehensiveness of consumer-oriented information describing the availability of shared access to adult patient portals from publicly reported information on institutional websites of 20 large and geographically diverse health systems. All 20 health systems reported that they offer patients the ability to share access to their patient portal account with a family member or friend; however, the comprehensiveness of information regarding registration procedures, features, and terminology varied widely. Half of the systems ($n = 10$) reported having shared access available on their patient portal registration webpage. Few systems ($n = 2$) reported affording patients the ability to differentiate specific role-based privileges. No systems reported uptake of shared access among adult patients, which was variably described as "proxy," "caregiver," "parental," or "delegate" access. Findings suggest that engaging families through health information technology will require greater efforts to promote awareness and differentiate privileges that respect patients' choice and control in information-sharing preferences.

Key words: health information technology, electronic health records, family caregivers

INTRODUCTION

The patient portal is a personal health record that is tethered to an electronic health record through which patients may view their health information and perform health management tasks electronically. Although the patient portal is a valuable strategy for engaging patients in their care,[1,2] not all patients have access to or are capable of using a computer or mobile device to manage their health.[3,4] Individuals who are older, with lower educational attainment, impaired cognitive function, and more limited technology experience are less likely to use a patient portal[5,6] and are less able to perform health management tasks electronically.[7,8] It is parents who generally assume responsibility for digital health system interactions in pediatric medicine.

Some health systems allow adult patients to explicitly "share" access to their patient portal account with a family member or friend "care partner" through a registration process in which the care partner is provided with his or her own identity credentials (login and password). There are theoretical and practical reasons to believe that shared access could improve care, especially for patients who are more vulnerable, many of whom rely on and desire help from others.[9,10] Indeed, emerging evidence finds that care partners who have been authorized to access patient portal accounts are comparatively better educated, more confident in their ability to manage aspects of patient health, and more frequent users of health information technology than adult patients.[11] Interventional studies suggest

Table 1. Availability and features of shared access to the patient portal at 20 health care delivery systems

	Characteristics of System			Availability by Age Group			Available Information About Shared Access to Patients	
	Region	Vendor	User Base	Parent	Adolescent (<18)	Adult (18+)	Name of Access	Described on Registration Page
1	West	Vendor A	5 200 000	<12	Yes, limited	Yes	Caregiver	Yes
2	Northeast	Vendor A	240 000	<14	Yes	Yes	Caregiver	Yes
3	Southeast	In-house[a]	142 000	<13	Yes	Yes	Delegate	Yes
4	Mid-Atlantic	Vendor A	267 000	<13	Yes, limited	Yes	Proxy	No
5	Midwest	Vendor B[a]	330 000	<13	Yes, limited	Yes[b]	[c]	No
6	West	Vendor A	[c]	<13	[c]	No	Parental[c]	No
7	West	Vendor A	1 000 000	<12	Yes, limited	Yes	Proxy	Yes
8	Midwest	Vendor A	13 000	<13	Yes	Yes	Proxy	No
9	Northeast	Vendor A	[c]	<12	Yes, limited	Yes	Proxy	No
10	Southeast	Vendor A	396 000	<12	Yes, limited	Yes	Proxy	No
11	West	Vendor B	[c]	<12	Yes, limited	Yes	Proxy	No
12	West	Vendor A	[c]	<14	Yes, limited	Yes	Proxy	Yes
13	West	Vendor A	25 500	<12	Yes, limited	Yes[b]	Caregiver	Yes
14	Northeast	Vendor A	[c]	<12	Yes, limited	Yes	Proxy	Yes
15	West	Vendor B	100 000	<13	No	No	[c]	No
16	Midwest	Vendor A	2 100 000	<18	Yes	Yes	Caregiver	Yes
17	Northeast	Vendor A	239 800	<13	Yes, limited	Yes	Proxy	Yes
18	West	Vendor A	[c]	<12	Yes, limited	Yes	Proxy	No
19	Southeast	Vendor A	[c]	<12	Yes, limited	Yes	Proxy	No
20	Southwest	Vendor A	[c]	<14	Yes, limited	Yes	Proxy	Yes

[a]Making a transition between vendors, or vendor in use varies by location.
[b]Only available for legal guardians and care partners of patients with disabilities.
[c]Not specified or reported.

that there is clinical benefit from proactively engaging care partners through health information technology.[12–15]

A foundational step to engaging patients and care partners through consumer health information technology is promoting awareness of the availability and process through which technologies can be accessed. However, no study to date has examined how health systems communicate information about the availability of shared access to the public, or how they have approached the implementation of shared access registration and functionality. Therefore, we conducted an environmental scan of publicly reported information on the institutional websites of 20 geographically diverse health care delivery systems located in the United States to determine the availability of information about and features of shared access functionality to the patient portal.

METHODS

We conducted an environmental scan to assess the availability, functionality, and registration processes for shared access to patient portal accounts at 20 academic or not-for-profit health care delivery systems. We included regional centers of excellence and sought to achieve a relatively balanced distribution of systems by geographic region. Drawing on our prior work to date,[9,11] we developed a data abstraction tool to delineate pertinent features of patient portal functionality for each system. Information was extracted from consumer-oriented information reported on each system's institutional website between July 2016 and February 2017. Abstraction of information was independently performed by 2 coauthors, and disagreements were discussed and resolved by the study team.

For each health system, we abstracted information about the electronic health record vendor in use, the number of patients who

were reported as having registered for the portal, the availability of shared access to the patient portal by patient age group (ie, children, adolescents, adults), the term used to describe shared access for adult patients ("caregiver," "proxy," "delegate"), and whether the availability of shared access was specifically mentioned on the registration page for the patient portal (yes/no). Information about shared access registration procedures for care partners of adult patients included: mode of registration (online, mail/fax, in person), number of care partners who may be registered for a patient's portal account, and duration of shared access. Information regarding the functionality of shared access included degree of granularity (full *vs* partial access to features) and care partners' ability to view secure messaging between adult patients and their providers. We additionally assessed the comprehensiveness of information and note elements for which information was not reported. The identity of each health system has been anonymized.

RESULTS

Health care delivery systems were geographically located in the Northeast ($n = 4$), Southeast ($n = 3$), Southwest ($n = 1$), Midwest ($n = 3$), Mid-Atlantic ($n = 1$), and West ($n = 8$) and primarily relied on 2 electronic health record vendors (Table 1). All 20 systems described operating a consumer-facing patient portal on their institutional website. More than half ($n = 12$) of the health care delivery systems reported the number of registered patient portal users; the user base varied widely from 13 000 to 5.2 million. No systems reported the proportion or number of patients who had authorized one or more care partners with access to their patient portal account.

All 20 health care delivery systems included shared access functionality for parents or legal guardians of children ($n = 20$), and

Table 2. Registration and functionality for shared access to the adult patient portal at 20 health care delivery systems

	Registration Mode	# of Care Partners	Duration of Access	Granularity	Care Partner Viewing Patient Messaging
1	Online	1	[a]	Full access	Yes
2	Mail or Fax	≥1	Until terminated by patient	Full access	Yes
3	In Person[b]	≥1[b]	Until terminated by patient	Full or partial	Limited to one care partner
4	In Person	≥1	Until terminated by patient or prespecified date	Full or partial	If granted full access
5	In Person	[a]	Until terminated by patient or prespecified date	Full access	[a]
6	–	–	–	–	–
7	Mail or Fax	1[b]	Until terminated by patient	Full access	Yes
8	Online, Mail, or Fax	[a]	Patient specifies 6, 12, 18, or 24 months	Full access	[a]
9	Mail or Fax	[a]	Until terminated by patient or prespecified date	Full access	Yes
10	Mail, Fax, In Person	1	Until terminated by patient	Full access	Yes
11	In Person	[a]	Until terminated by patient	Full access	[a]
12	Mail	[a]	10-year intervals	Full access	[a]
13	In Person	≥1	[a]	Full access	Yes
14	Online[c]	[a]	[a]	Full access	Yes
15	–	–	–	–	–
16	Mail, Fax, or In Person	[a]	Until terminated by patient	Full access	Yes
17	Mail or Fax	[a]	Until terminated by patient	Full access	Yes
18	In Person	[a]	[a]	Full access	Yes
19	In Person	[a]	[a]	Full access	Yes
20	Mail or Fax	[a]	Until terminated by patient	Full access	[a]

[a]Not specified or reported.
[b]Conflicting information reported.
[c]Mail, fax, in-person registration for patients who do not have a patient portal account and do not wish to make one.

most offered shared access for adolescent ($n = 19$) and adult ($n = 18$) patients, although 2 systems exclusively offered shared access for legal guardians of adult patients or for adult patients with disabilities. The age at which access to a child's patient portal account terminates varied by system from: age 12 ($n = 9$), 13 ($n = 7$), 14 ($n = 3$), or 18 ($n = 1$); access to the patient portal account of an adolescent uniformly terminates at age 18. Most systems ($n = 14$) explicitly reported the availability of more limited patient portal features for adolescent patients, 1 system did not offer shared access functionality for adolescents, and 5 systems did not report whether features were more limited for this age group. Shared access functionality for adult patients was most commonly referred to as "proxy" ($n = 12$) or "caregiver" ($n = 4$) access; 1 system used the term "delegate" access and 1 system did not specify a term. Half of the systems ($n = 10$) mentioned the availability of shared access on the patient portal registration web page.

Registration for shared access for adult patients was reported as being online ($n = 3$), by mail/fax ($n = 9$), in person ($n = 9$), or by a combination of modalities (Table 2). Of 18 systems offering shared access functionality for adult patients, 4 reported allowing multiple care partners, 2 reported limiting access to 1 care partner, 11 did not specify this information, and 1 reported contradictory information. The duration over which care partners are granted access to an adult patient's portal account was variably reported. Most systems extended shared access to a patient portal account until termination by the patient with no prespecified date ($n = 8$) or with a prespecified date ($n = 3$). One health care delivery system reported requiring care partners to be reauthorized every 10 years, 1 system reported affording adult patients the ability to select 6, 12, 18, or 24 months of shared access, and 5 systems did not specify the duration of shared access.

Two systems reported affording adult patients the ability to differentially authorize care partners with granular privileges for spe-

cific portal features (eg, to schedule appointments or refill medications but not view health information). More than half of the systems ($n = 13$) reported that care partners were able to view secure messaging between adult patients and their providers; 5 systems did not specify whether care partners had this ability.

CONCLUSIONS

We examined the availability, registration procedures, and features of shared access to patient portals at 20 large, geographically distributed health care delivery systems in the United States. All 20 health systems reported the availability of shared access functionality; 18 health systems reported shared access availability for adult patients. However, shared access registration procedures, features, and terminology varied widely, as did the comprehensiveness of publicly reported information on institutional websites. None of the systems reported the number of registered patient portal users with authorized care partners. Half of the systems we examined ($n = 10$ of 20) described the availability of shared access on the main patient portal registration page. Few systems afforded patients the ability to selectively grant care partners specific functionality for their patient portal accounts (eg, to schedule appointments or view health information without exchanging secure messaging with providers).

Results of this environmental scan indicate that consumer-oriented information about the availability and features of shared access to patient portals has not been consistently or comprehensively reported on health systems' institutional websites. The lack of attention to reporting this information stands in stark contrast to patients' expressed preference for sharing their electronic health information with family members and close friends[2,16–18] and the importance of providing information access to family caregivers.[10,19–21] In light of the important role that family members and close friends

assume in the care of vulnerable patients,[16,22] respecting an individual's preference to formally authorize a family member with shared access to his or her patient portal account merits greater attention and effort as a strategy to facilitate the delivery of person- and family-centered care[23] and improve appropriate information access and communication between patients, families, and care providers.[12–15]

The terms "proxy" and "caregiver" were most commonly used to describe shared access functionality on health systems' institutional websites. As these terms are typically used to refer to circumstances involving physical or cognitive impairment, they may not resonate with the broader population of patients who may desire to formally authorize a family member or friend to participate in their care.[18] Patients' motivations for sharing access to their portal accounts are highly variable,[11] suggesting that there are drawbacks to the prevailing use of role-based terms for promoting awareness and uptake of shared access functionality. Adopting terminology that better resonates with patients and families could increase awareness and uptake of shared access to provider-sponsored patient portals.

It is notable that just 2 of the 20 systems reported having the availability of granular role-based functionality, whereby adult patients can select differentiated, and more limited, privileges for care partners; the majority of health systems appear to afford care partners full privileges to the entire spectrum of patient portal functionality. Most health systems reported that care partners are able to view secure messaging between patients and providers. Because patients' preferences for sharing their electronic health information vary widely,[18,24] affording patients the ability to specify preferences for care partner privileges merits consideration, in order to provide patients with greater choice and control in their information-sharing practices and to more effectively differentiate the value of shared access functionality.

Although this environmental scan provides preliminary insight regarding how health care delivery systems have structured registration and functionality so that patients can share access to their patient portal accounts, limitations merit comment. We examined a convenience sample of 20 health systems that primarily relied on 2 electronic health record vendors, and our findings therefore have limited generalizability. We examined publicly reported information and cannot confirm the accuracy of information reported on institutional websites with respect to actual registration processes or functionality. Likewise, we were unable to examine the actual implementation or internal communication processes that advertise shared access to patients, providers, and administrators. This study did not examine "out-of-the-box" shared access functionality of mainstream electronic health record vendors, which undoubtedly affects the implementation decisions of integrated health systems, given the expense, effort, and time that customization requires. Finally, we did not examine and are unable to comment on the clinical or policy implications relating to shared access implementation. Future studies should evaluate how organizational characteristics and registration processes affect the uptake and use of shared access functionality and its effects on care quality.

In light of projected increases in the numbers of Americans living with age-related cognitive and sensory deficits and the continued diffusion of health information technology and use of secure messaging as a mainstream mode of communication,[25] the importance of identifying strategies to clarify and execute individual preferences for engaging family care partners in electronic health system interactions will only grow in the coming years. The ability of health care delivery systems to distinguish whether providers are electronically interacting with patients, family members, or both will be necessary if learning health systems are to effectively leverage the patient portal in patient-reported data capture[26,27] and quality reporting.[28] Efforts to streamline registration processes, clarify terminology, and promote awareness and use of shared access may help to achieve this goal.

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CONFLICT OF INTEREST

The authors declare that they do not have a conflict of interest.

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