

Shared Access to the Patient Portal

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Introduction

Millions of Americans manage their health with the help of family, friends, and other care partners. These care partners have a profound effect on the quality of care and patient outcomes, but they often don't have access to crucial information when coordinating or enacting the patient's care plan. In 2019 a convening of researchers, clinicians and health system representatives [summarized](#) the importance of shared access for patient privacy, integrity of electronic health record data, and respecting the role of care partners delivering and coordinating care. The group evolved into the Coalition for Care Partners—led by the Johns Hopkins Bloomberg School of Public Health and Beth Israel Deaconess Medical Center—and launched a demonstration project, funded by the John A. Hartford Foundation and Cambia Health Foundation, to increase shared access across three health systems. We expanded stakeholder engagement to better understand the national landscape on this topic while learning from the ongoing demonstration project. Here we build on our prior work by summarizing these activities, what was learned, and our recommendations for policymakers, clinical leadership, patients, and care partners.

Shared Access allows a patient to grant a trusted friend or family member access to their patient portal account using unique login credentials.

Who Benefits from Shared Access?



Jill gave her partner access to her patient portal in case of emergency. Shared access gives them both peace of mind.



Bob sees a lot of specialists. With shared access, his wife Carla can access his medication list and send messages to his care team to help coordinate his medications. Bob's healthcare team feels more comfortable knowing who they are communicating with because Carla has her own login. Shared access helps Bob get the best care and keeps him safe.



Nina has dementia. Her daughter Gabriela, who lives on the other side of the country, manages Nina's appointments and billing. José, who lives nearby, goes to Nina's appointments and communicates his concerns to the doctor ahead of the visit using secure messaging. Shared access keeps everyone on the same page.

What we DID 2019-2025



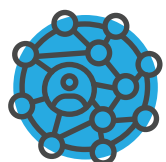
Engage

Prior to launching the demonstration, we conducted a planning phase of partner engagement in 2020-2021. First, we identified three geographically diverse healthcare organizations to co-design an initiative to increase the uptake of shared access. [Human-centered design methods](#) were incorporated into 73 engagements with patients, care partners, clinicians and clinic staff, medical informatics teams, marketing and communications staff, administrators, funders and thought leaders. We co-developed pilot materials to test at participating organizations and created customizable templates for other organizations interested in implementing their own shared access campaigns.



Test

From 2021 to 2024, we conducted a demonstration using the customized educational materials developed in the planning phase. The demonstration was deployed across five clinics within the three participating healthcare organizations. The goal was to test whether the educational materials increased shared access registration among patients aged 65 or older over a 12-month period.



Assemble

In 2022, we formed two subgroups of the [Coalition for Care Partners](#) — the Shared Access Learning Collaborative and the research group— to facilitate partnerships, disseminate research evidence, and support policy.

[The Shared Access Learning Collaborative](#) is a diverse group of healthcare organization representatives, clinicians, patients, care partners, and electronic health record (EHR) vendors. The group meets quarterly to advance patient portal-based solutions to help older adults and their care partners access medical information. Since its launch in 2022, the group has:

- ✓ Conducted and published results of a “[secret shopper](#)” study wherein members documented their experiences as they attempted to give or gain shared access to the patient portal;
- ✓ Collaboratively developed and submitted public comment to inform the National Strategy to Support Family Caregivers;
- ✓ Co-developed instructional toolkits for [patients and care partners](#) and for [clinicians and health systems](#) seeking to advance shared access initiatives;
- ✓ Deployed human-centered design methods to develop recommendations for expanding the shared access demonstration beyond the original three organizations.

The Coalition for Care Partners Research Group supplements what was learned in the demonstration with findings from other sources, (e.g., published literature, national datasets, health system EHR-based data sources). These studies aim to better understand the national landscape of shared access and how vulnerable groups (e.g., persons with dementia or sensory loss) and their care partners use the patient portal.

What we LEARNED

- ✓ **Care partners commonly use patient portals**, but fewer than 3% are formally registered with shared access. Among care partners who are formally registered, their level of use is similar to or higher than patient users.
- ✓ **Educational campaigns** in the clinical setting are feasible (appropriate, useful, undemanding and low-cost). However, these campaigns are limited in achieving increased shared access registration and use within the context of competing clinical demands and lack of organizational best practices. Patients who were newly registered for the portal during our demonstration period were twice as likely to have a care partner registered, suggesting that education and implementation of shared access registration should be targeted during initial patient registration.
- ✓ **Health systems play a large role in barriers and facilitators** to shared access registration through policies (e.g., requiring in-person registration), customization of their patient portal, and whether shared access is promoted among employees and patients. Shared access policies, functionality, and awareness vary widely across healthcare organizations.
- ✓ **Health data privacy concerns are prevalent.** Patients and care partners desire granular privacy controls in shared access to customize what is shared according to the care partner's role (e.g., scheduling appointments, communicating with the care team, managing billing). However, few organizations allow for customizations at the individual level.
- ✓ **Collaborative forums, such as the Shared Access Learning Collaborative, are important** for eliciting diverse stakeholder perspectives and experiences. In our case, these forums made it possible to identify the need for standardized terminology (i.e., shared access, care partners), gather insights about usability of technology, and define competing priorities. Human-centered design methods can be a helpful tool for this type of engagement and idea synthesis.



What we RECOMMEND

Patients and Care Partners

- ✓ Join and advocate within a Patient/Family Advisory Council, the [Shared Access Learning Collaborative](#), and within research teams at your health system.
- ✓ Learn more in this [Patients & Care Partners](#) toolkit

Healthcare Teams

- ✓ Ensure front desk and clinical staff are aware of shared access registration procedures.
- ✓ Introduce shared access at optimal times, e.g., during annual visits, advance care planning conversations, and patient portal registration.
- ✓ Learn more in this [Clinicians & Health Systems](#) toolkit

Healthcare Organizations

(administration, leadership, etc.)

- ✓ Implement an opt-out approach to shared access registration during the patient portal registration process.
- ✓ Include education in regular training of healthcare teams to maintain awareness and account for turnover.
- ✓ Remove barriers and implement facilitators to care partner registration for shared access. Examples include: allowing for online registration instead of requiring in-person or mailed registration; creating pathways for care partners to register if they are not also patients within the same health system; and creating [easy-to-follow guided facilitation](#) for patients and care partners such as online training videos embedded into the patient portal.
- ✓ Learn more in this [Clinicians & Health Systems](#) toolkit

Electronic Health Record (EHR) Vendors

- ✓ Work with health systems to implement granular privacy controls and options for levels of access.
- ✓ Engage patients and care partners in designing solutions that increase usability. Consider incorporating human-centered design methods when partnering with patients.

Advocacy Organizations

(national health information technology groups, provider groups, patient/family groups)

- ✓ Educate consumers and healthcare professionals about shared access using shared access [toolkits](#).
- ✓ Define organizational best practices for shared access.

Policymakers

- ✓ The Joint Commission and the Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology should require health systems to report on shared access uptake and ways they promote functionality for user-friendly shared access.
- ✓ Organizations implementing quality measures and improvement initiatives (e.g., CMS, Leapfrog, Institute for Healthcare Improvement) should incorporate shared access into healthcare systems' measurement, reporting and other activities. For example, shared access is aligned with the IHI Age-Friendly Health Systems initiative, as care partners play a critical role in coordinating older adults' healthcare.

What we've WRITTEN

2019

Engaging Family Caregivers through Shared Access to the Patient Portal: Challenges, Opportunities, and an Action Agenda for Transformational Change

Wolff et al.

[JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH](#) 

2022

Coalition for Care Partners: Connecting Care Partners Through Health Information Technology: A Roger C. Lipitz Center for Integrated Health Care and OpenNotes Issue Brief

Wolff et al.

[JOHNS HOPKINS BLOOMBERG SCHOOL OF PUBLIC HEALTH](#) 

2022

Shared Access to Patient Portals for Older Adults: Implications for Privacy and Digital Health Equity

Wolff et al.

[JOURNAL OF MEDICAL INTERNET RESEARCH](#) 

2022

Patient Portals to Support Care Partner Engagement in Adolescent and Adult Populations

Gleason et al.

[JAMA NETWORK OPEN](#) 

2023

Co-Designing an Initiative to Increase Shared Access to Older Adults' Patient Portals: Stakeholder Engagement

Dukhanin et al.

[JOURNAL OF MEDICAL INTERNET RESEARCH](#) 

2024

Patient Portals Fail to Collect Structured Information About Who Else is Involved in a Person's Care

Salmi et al.

[JOURNAL OF MEDICAL INTERNET RESEARCH](#) 

2024

Shared Access to Adults' Patient Portals: A Secret Shopper Exercise

Wachenheim et al.

[APPLIED CLINICAL INFORMATICS](#) 

2025

Users' Perspectives on a Demonstration to Increase Shared Access to Older Adults' Patient Portals

Dukhanin et al.

[BMC HEALTH SERVICES RESEARCH](#) 

2025

A Multisite Demonstration of Shared Access to Older Adults' Patient Portals"

Gleason et al.

[JAMA NETWORK OPEN](#) 

Identifying Solutions for Increased Adoption of Shared Access to the Patient Portal: A Human-Centered Design Approach

Scerpella et al.

IN REVIEW

