

# COALITION FOR CARE PARTNERS: CONNECTING CARE PARTNERS THROUGH HEALTH INFORMATION TECHNOLOGY

A Roger C. Lipitz Center for Integrated Health Care  
and OpenNotes Issue Brief

---

Summer 2022



JOHNS HOPKINS  
BLOOMBERG SCHOOL  
of PUBLIC HEALTH

---

Roger C. Lipitz Center  
for Integrated Health Care



# TABLE OF CONTENTS

---

- 2 Introduction
- 4 Using the Electronic Health Record to Engage Care Partners through Shared Access
- 6 Current Research by the Coalition
- 8 References and Acknowledgments





## INTRODUCTION

---

Millions of Americans manage their health with the involvement of family, friends, caregivers, and other care partners, who are too often not well integrated with the "formal" care delivery system of health professionals. Engaging with care partners has a profound effect on quality of care and health care utilization, but is not well supported in care delivery. At a most basic level, few care partners report being asked by clinicians and other health care

workers about their need for help managing care for their loved one; information that is necessary and appropriate when coordinating or enacting the patient's care plan.

Cait DesRoches, DrPH, executive director of [OpenNotes](#) and associate professor of Medicine at Harvard Medical School, Jennifer Wolff, PhD, the Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management and the director of the [Roger C. Lipitz Center for Integrated Health Care](#) (Lipitz Center) at the Johns Hopkins Bloomberg School of Public Health, and an interdisciplinary group of colleagues and affiliate organizations are launching *Coalition for Care Partners: Connecting Care Partners through Health Information Technology*, a new effort to build knowledge and tools directed at strengthening health system capacity to systematically identify, engage, and support care partners in care delivery, with support from The John A. Hartford Foundation, the Ralph C. Wilson Foundation, Cambia Health Foundation, and the National Institute on Aging.

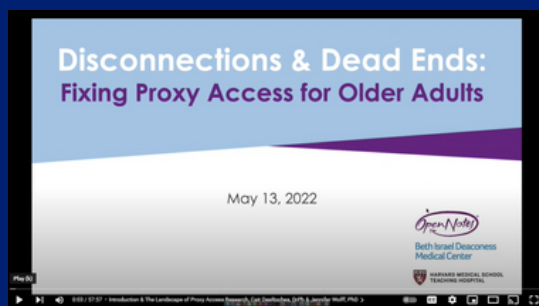
A [new article published in \*The Journal of Medical Internet Research\*](#) by affiliates at OpenNotes and the Lipitz Center makes the case that attaining the full promise of consumer health information technologies will require advancing strategies that meet the needs and preferences of all patients, including those who delegate or co-manage their care with the involvement of a care partner.

A patient portal is a secure, online platform, which individuals may access their electronic medical records, schedule appointments, view test results, and securely message clinicians. Most recently, the patient portal played a prominent role in delivering telehealth, and the scheduling and provision of COVID-19 test results and vaccinations. However, people who are older, in poor health, with low health literacy, and with limited technology experience are less able and willing to use portals. Organizational efforts to promote awareness and use of the patient portal are primarily focused on patient education and engagement.

This brief highlights original research and activities led by OpenNotes and the Lipitz Center, which feature the existing patient portal functionalities and the developing, testing, and scaling of new consumer-oriented technologies to effectively engage care partners in care.



## WEBINAR: DISCONNECTIONS & DEAD ENDS: FIXING PROXY ACCESS FOR OLDER ADULT



In this webinar, Cait DesRoches, DrPh, and Jennifer Wolff, PhD, share the new initiative by OpenNotes and the Johns Hopkins Bloomberg School of Public Health, which aims to help fix the gaps in health information technology for older adults. Learn about the multi-site demonstration projects serving older adults in Portland, OR, Rochester, NY, and Salt Lake City, UT and hear a patient and physician and family care partner describe their lived experiences navigating proxy access.

# USING THE ELECTRONIC HEALTH RECORD TO ENGAGE CARE PARTNERS THROUGH SHARED ACCESS

---

Health care organizations commonly allow patients to authorize a care partner to “share access” to their portal account in a registration process where care partners receive their own identity credentials, such as using login information or a password. This type of access is typically referred to as “proxy access”. Formalizing care partner involvement through shared portal access is respectful of patient preferences and offers benefits to care partners such as greater visibility among the care team, convenience, access to timely and comprehensive information about patient health, and a mechanism to navigate health system demands. Formative work by the OpenNotes team finds that patients commonly share electronic visit notes with a care partner and care partners value such information even more than patients.

Work led by the Lipitz Center in partnership with OpenNotes and Geisinger Health System found that sharing visit notes with care partners through shared access was acceptable and improves patient confidence in managing care. Another study conducted at the Lipitz Center, with support from

Susan G. Komen, found that uptake and use of the patient portal by care partners was associated with improved illness understanding and lower symptoms of anxiety, and was widely desired by patients and valued by families.

Work by the Lipitz Center found that implementing shared access is variable across healthcare organizations, and uptake by patients is limited. In one study, nearly half of hospital-based personnel recommended that patients share their login/password with a care partner rather than seek shared access. A commentary by OpenNotes describes how sharing identity credentials poses risks of confusion and mistakes; for example, when clinicians do not know with whom they are interacting, or when legal documents that were submitted through the patient portal by someone other than the patient must be retracted. The implementation of federal information blocking rules in April 2021 has increased the timeliness, volume, and types of health information available through portals, some of which may be sensitive, further heightening the importance of proper identity credentials.

Shared portal access can be relevant and beneficial in improving care quality for older adults with complex needs, as they are more likely to experience breakdowns in communication and poor quality care. By serving as a mechanism to distinguish proper identity credentials of the patient, care partner(s), or both, the patient portal can be used to improve communication around what matters to patients, one of the central tenets of the age-friendly health system movement. Most importantly, by clarifying and respecting differentiated identity credentials, shared portal access sets the stage to not only build trust through protecting the privacy and security of personal health information but also supporting individual rights and appreciation for the reality of the broader social context in which patients commonly co-manage their care.



## CURRENT RESEARCH BY THE COALITION

---

### ENGAGING FAMILY CAREGIVERS THROUGH SHARED ACCESS TO THE ELECTRONIC HEALTH RECORD

This project seeks to implement, evaluate, and disseminate low-cost and light touch interventions designed to increase the number of care partners with shared access to the patient portal. This three-year project is supported by The John A. Hartford Foundation and involves collaboration among OpenNotes, the Roger C. Lipitz Center for Integrated Health Care at the Bloomberg School, and leaders

from three geographically diverse health systems, including University of Rochester Medical Center (Dr. Supriya Mohile and colleagues from geriatric oncology), University of Utah Geriatrics (Drs. Tim Ferris and Mark Supiano), and Providence Institute for Human Caring (Drs. Ira Byock, Mathew Gonzalez, Marianne Parshley, Doug Niehus, and Caroline Reay).

Support from the Cambia Health Foundation has enabled the translation of all materials to Spanish and several other languages specific to each clinical site for broader reach and impact. Finally, a learning collaborative for health care organizations is being convened with the goal of disseminating best practices and lessons learned to facilitate broader scaling. For more information about how to get involved with the learning collaborative, please contact Cait DesRoches ([cdesroch@bidmc.harvard.edu](mailto:cdesroch@bidmc.harvard.edu)).

### ENGAGING AND SUPPORTING CARE PARTNERS IN DEMENTIA CARE

Shared portal access may be particularly relevant in dementia care due to the long disease course, high rates of co-occurring medical conditions, and the progressive and profoundly disabling nature of needs that necessitate heavy reliance on assistance from others. Evidence-based models of support for care partners of persons living with dementia have typically been developed outside real-world care settings; few explicitly engage family at the point of care or are poised for widespread diffusion.



Little is known about electronic information-sharing preferences and practices of persons with dementia and their care partners, or the feasibility of deploying novel interventions through consumer health information technologies to better support Alzheimer's Disease and Related Dementias (ADRD) care and management.

A new five-year project, led by Jennifer Wolff and supported by the National Institute on Aging, is convening an interdisciplinary group of talented social scientists and clinician-scientists from Johns Hopkins University and external institutions to better understand and address the needs of care partners of persons living with dementia. The grant aims to produce new knowledge of individual, contextual, and organizational factors that affect patient portal use and contribute evidence regarding the effects of access and use of such technologies on ADRD care quality and outcomes and understand how persons with dementia and their care partners, clinicians, and other relevant stakeholders perceive and use consumer health information technology, and identify and test novel technology-supported scalable innovations, such as person-family agenda-setting and OurNotes.

### **USING INFORMATION TRANSPARENCY TO IDENTIFY CARE PARTNER NEEDS IN A CLINICAL SETTING**

Identifying care partners in the clinical setting and connecting them to needed resources could help reduce care partner stress and improve outcomes for patients. This three-year project, supported by the Ralph C. Wilson Jr. Foundation, aims to use the patient portal to identify care partners, assess their needs, and connect them to resources. It will evaluate the effect of this intervention on patients, care partners, and clinical workflow. Collaborators include three clinical sites and ARCHANGELS, a caregiver support network that has developed a caregiver intensity index. The project is still seeking a third clinical site in upstate New York or Eastern Michigan. For more information about getting involved, please contact Deb Wachenheim at [dwachen@bidmc.harvard.edu](mailto:dwachen@bidmc.harvard.edu).





## REFERENCES

---

DesRoches CM, Walker J, Delbanco T. Care Partners and Patient Portals-Faulty Access, Threats to Privacy, and Ample Opportunity. JAMA Intern Med. 2020 Jun 1.

Jackson SL, Mejilla R, Darer JD, Oster NV, Ralston JD, Leveille SG, Walker J, Delbanco T, Elmore JG. Patients who share transparent visit notes with others: characteristics, risks, and benefits. J Med Internet Res. 2014 Nov 12.

Jackson SL, Shucard H, Liao JM, Bell SK, Fossa A, Payne TH, Reisch LM, Radick AC, DesRoches CM, Fitzgerald P, Leveille S, Walker J, Elmore JG. Care partners reading patients' visit notes via patient portals: Characteristics and perceptions. Patient Educ Couns. 2022 Feb.

Wolff JL, Darer JD, Larsen KL. Family Caregivers and Consumer Health Information Technology. Gen Intern Med. 2016 Jan.

Wolff JL, Berger A, Clarke D, Green JA, Stametz R, Yule C, Darer JD. Patients, care partners, and shared access to the patient portal: online practices at an integrated health system. J Am Med Inform Assoc. 2016 Nov.

Wolff JL, Darer JD, Berger A, Clarke D, Green JA, Stametz RA, Delbanco T, Walker J. Inviting patients and care partners to read doctors' notes: OpenNotes and shared access to electronic medical records. J Am Med Inform Assoc. 2017 Apr 1.

Wolff JL, Kim VS, Mintz S, Stametz R, Griffin JM. An environmental scan of shared access to patient portals. J Am Med Inform Assoc. 2018 Apr 1.

Wolff JL, Aufill J, Echavarria D, Heughan JA, Lee KT, Connolly RM, Fetting JH, Jelovac D, Papathakis K, Riley C, Stearns V, Thorner E, Zafman N, Levy HP, Dy SM, Wolff AC. Sharing in care: engaging care partners in the care and communication of breast cancer patients. Breast Cancer Res Treat. 2019 Aug.

Wolff JL, Aufill J, Echavarria D, Blackford AL, Connolly RM, Fetting JH, Jelovac D, Papathakis K, Riley C, Stearns V, Zafman N, Thorner E, Levy HP, Guo A, Dy SM, Wolff AC. A randomized intervention involving family to improve communication in breast cancer care. NPJ Breast Cancer. 2021 Feb 12.

Wolff JL, Dukhanin V, Burgdorf JG, DesRoches CM. Shared Access to Patient Portals for Older Adults: Implications for Privacy and Digital Health Equity. JMIR Aging. 2022 May 4.

## ACKNOWLEDGMENTS

---

This issue brief was written by Jennifer Wolff, PhD, the Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management and the director of the Roger C. Lipitz Center for Integrated Health Care at the Johns Hopkins Bloomberg School of Public Health, in collaboration with Cait DesRoches, DrPh, associate professor at Harvard Medical School and the executive director of OpenNotes.

Support was provided by The John A. Hartford Foundation, the Cambia Foundation, the Ralph C. Wilson Foundation, and the National Institute on Aging (R35AG072310).