

Disconnections & Dead Ends: Fixing Proxy Access for Older Adults

May 13, 2022



Beth Israel Deaconess
Medical Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Proxy Access Learning Collaborative

Email Alex Duncan at:

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Introductions



Cait DesRoches, DrPH

Executive Director, OpenNotes
Associate Professor, Harvard Medical School



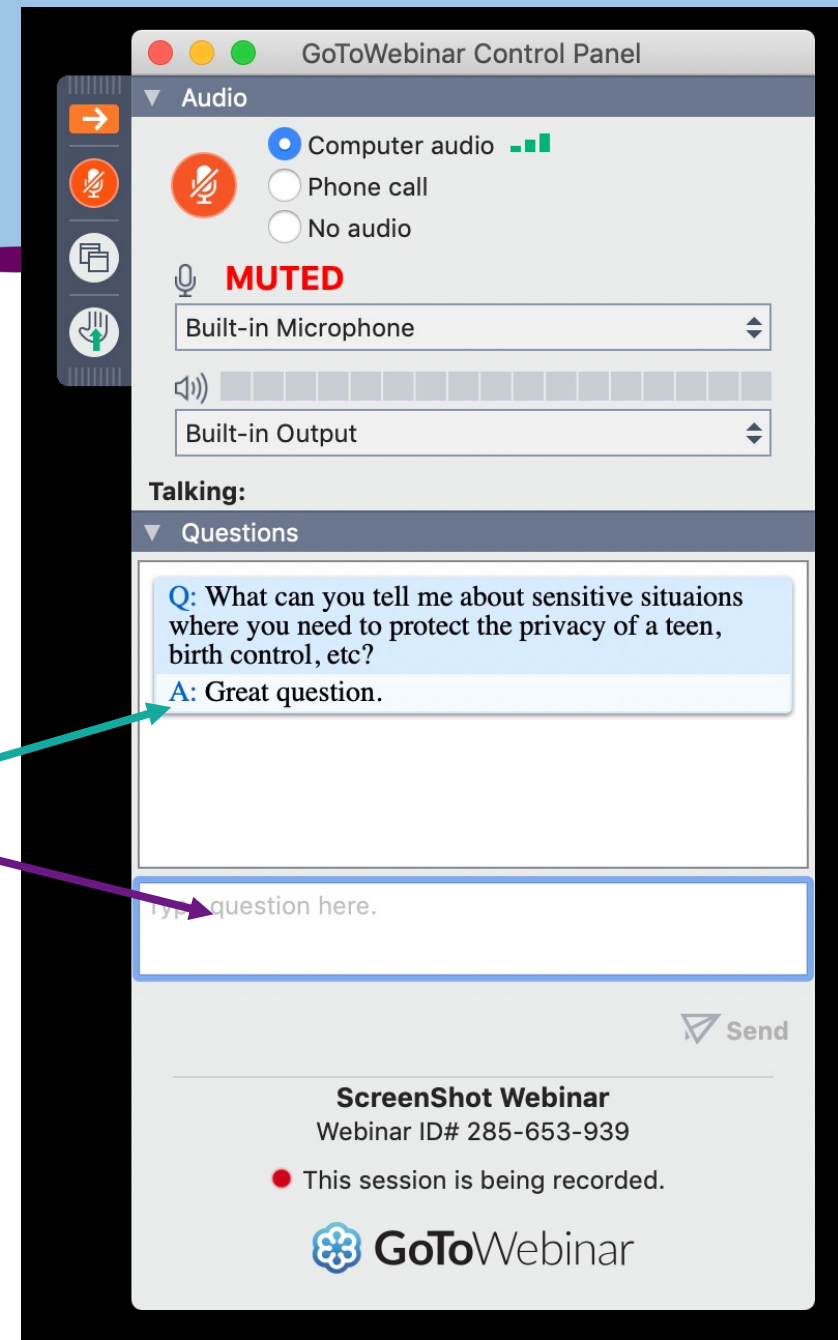
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Housekeeping

- Attendees are muted.
- During the session, **type questions into the “question” section**, and we will address them at end of prepared comments.
- Some answers may be provided during the presentation. Those answers will appear underneath your question.
- The presentation recording will be available at **opennotes.org** and **youtube.com/myopennotes**
- You will receive an email with links to these presentations.



About OpenNotes

OpenNotes is NOT a product or software.

About OpenNotes

Based at the Beth Israel Deaconess Medical Center in Boston, a major Harvard Medical School teaching hospital. **OpenNotes studies** the effects of open and transparent communication on patients, care partners and clinicians.

About OpenNotes

OpenNotes vs. “open notes”

About OpenNotes

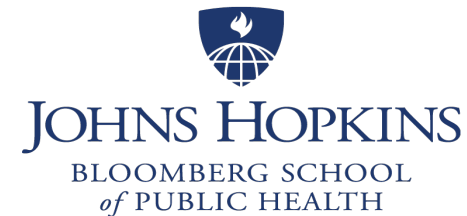
- For the last 11 years, we've worked with collaborators around the country and overseas to foster and evaluate the spread and implementation of shared clinical notes (which we call “open notes”).
- Today, in addition to research, we also focus on advocacy and education—like this webinar.
- We're funded entirely by federal and philanthropic grants and gifts.

The Landscape of Proxy Access Research



Jennifer Wolff, PhD

Johns Hopkins Bloomberg School of Public Health



Unpaid. Unappreciated. Untrained. Undercounted. Exhausted. But vital.

“America’s stealth weapon against chronic illness is a 46-year-old woman with a family, a high-school degree, a full-time job and a household income of \$35,000. She has no particular training in health care. And, to tell you the truth, sometimes she doesn’t feel that great herself...”

-- AMA Medical News, 2001

IMPLEMENTATION CHALLENGES IN CAREGIVER ENGAGEMENT

1. Misaligned reimbursement: lack of compensation for provider time and effort to identify & support family
2. Prevailing orientation toward patient autonomy and privacy
3. Patient-oriented information systems: absence of structured fields to document information about identity and characteristics of involved family members/friends

NASEM, Families Caring for an Aging America, 2016

THE PROVIDER-SPONSORED PATIENT PORTAL

- Secure online website linked to patient electronic health record.
- Patients may register family/friend care partners to “share access” to their portal account with unique identity credentials (login/password).
- Shared (proxy) access:
 - Allows patients to identify who to involve in their care
 - Legitimizes care partners involvement
 - Provides greater information transparency
 - Allows clinicians to know **who** is involved in health system interactions when someone other than the patient
 - Facilitates bidirectional information exchange between clinicians and care partners

LANDSCAPE OF SHARED ACCESS

- Older adults commonly rely on and desire care partners ability to access their health information (Zulman 2011; Crotty 2015; Latulipe 2018).
- Shared access functionality is widely available at integrated care delivery systems (Wolff JAMIA 2018).
- Use of shared access may facilitate improved patient & care partner satisfaction with communication & confidence managing care (Wolff, 2016; 2021).
- Uptake of shared access is limited (Reed 2018; Wolff 2016) and care partners most often access the patient portal using patient identity credentials (Latulipe, 2020; Ramirez-Zohfeld, 2020; Pecina, 2020).

THE STATUS QUO

- 752,550 adult patient portal messages: 99.3% using patient login credentials; 0.7% using proxy credentials

Pecina, 2020

THE STATUS QUO

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- 3,000 randomly selected adult patient portal messages: 83.8% (n=2512) sent by patient

Pecina, 2020

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Pecina, 2020

THE STATUS QUO

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- 3,000 randomly selected adult patient portal messages: 83.8% (n=2512) sent by patient; 7.4% (n=221) sent from someone other than the patient; 8.9% (n=266) identity of sender unclear

Pecina, 2020

Thank you



Jennifer Wolff, PhD

Johns Hopkins Bloomberg School of Public Health



Who dropped the ball?

A cautionary tale about proxy access from
people who should know better



Liz (and Brett) Salmi,

OpenNotes, Beth Israel Deaconess Medical Center

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she/her



Beth Israel Deaconess
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Overview

- Personal experience with proxy access
- Efforts to “do it the right way,” and how we failed
- What we did instead
- What we will do differently next time



Liz

- Patient advocate
- Interested in patient access to health information
- Patient portal nerd for >15 years
- OpenNotes
- Patient co-design in research

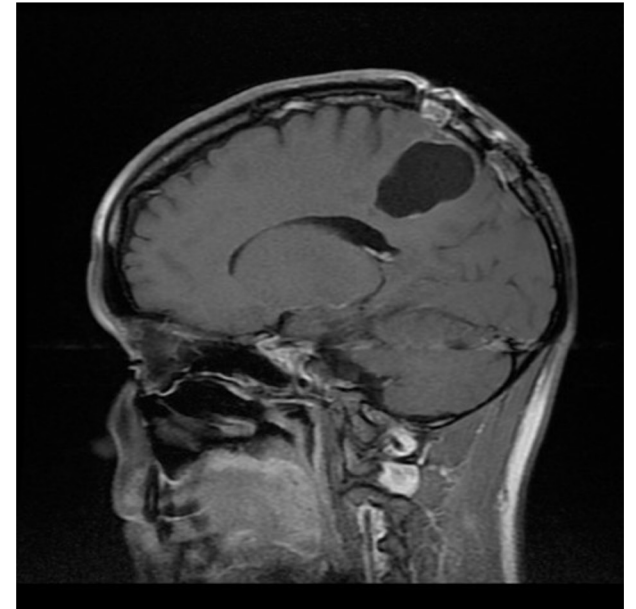


Brett

- Communications analyst
- Interests: Star Wars, cats
- Care partner for Liz, aging parents, sibling with depression/anxiety

Liz & Brett

- Began dating at ages 27 & 29
- **Liz:** grade 2 astrocytoma at age 29
- **Brett:** caregiver at age 31
- *Had been dating for 18 months at diagnosis*
- 2 surgeries, 2 years chemotherapy, PT + OT



Liz makes Brett proxy in patient portal

- Married at ages 31 & 33
- **Liz grants Brett proxy access in portal**
- *Worries: seizures, tumor recurrence*
- Sends copies of:
 - Appointment notifications
 - Test results
 - Messages between Liz & medical team



“anything can happen at any time”



KAISER PERMANENTE®

Life changes

- Change jobs
- Change health insurance
- Pick new doctors
- Don't think about proxy access



KAISER PERMANENTE®



Liz & Brett: Fall 2021

- Liz has recurrence!
- 3 weeks to prepare
- Liz facing cognitive impairment

Did Liz add Brett as a proxy?

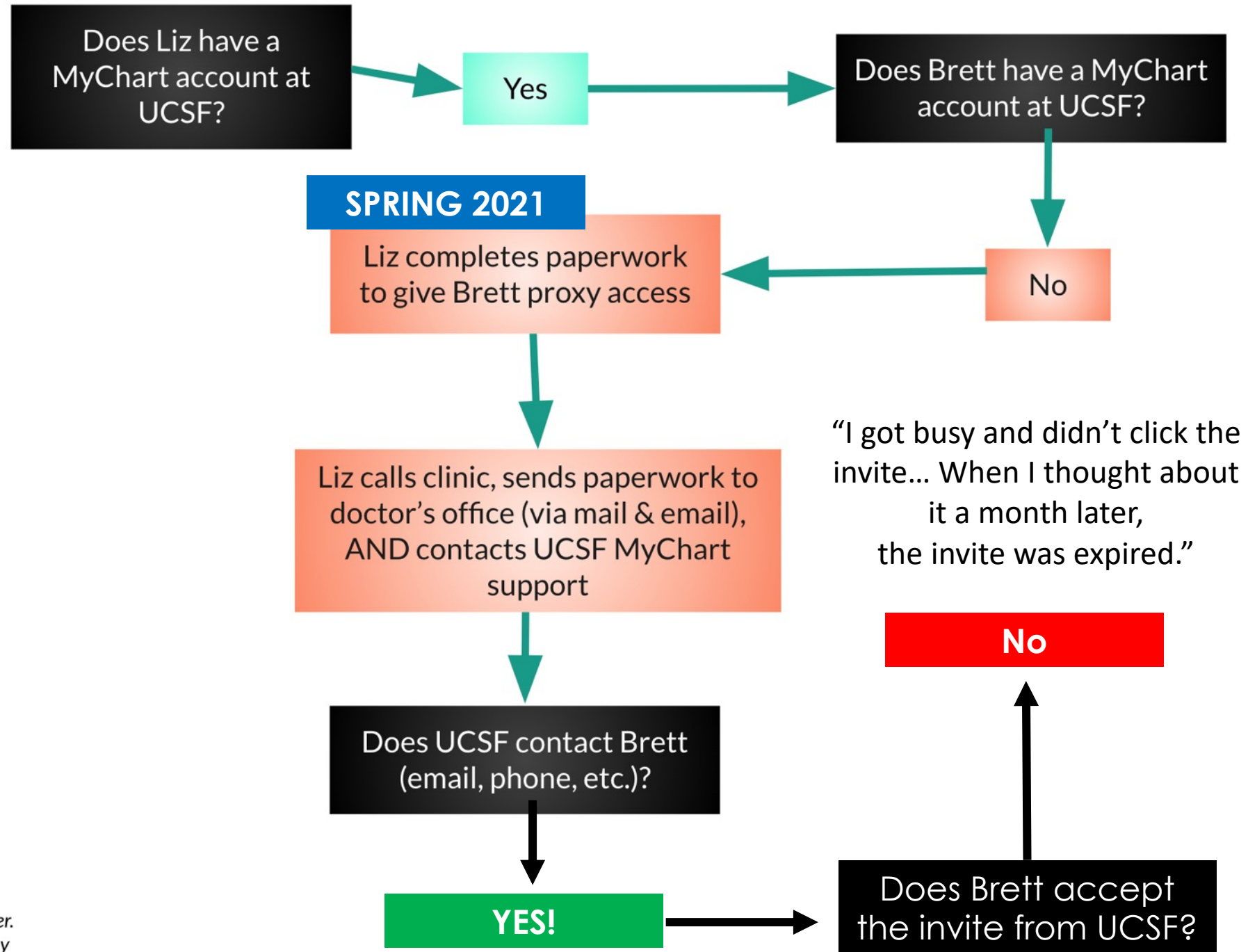
PROXY WORKFLOW



Patient workflow: Proxy access

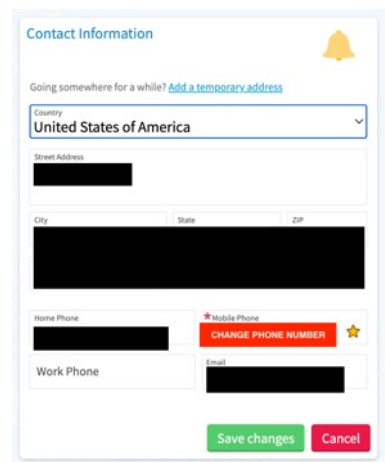
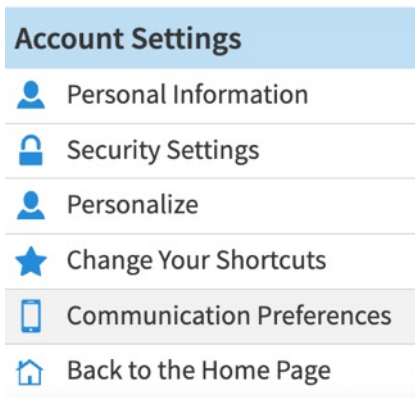
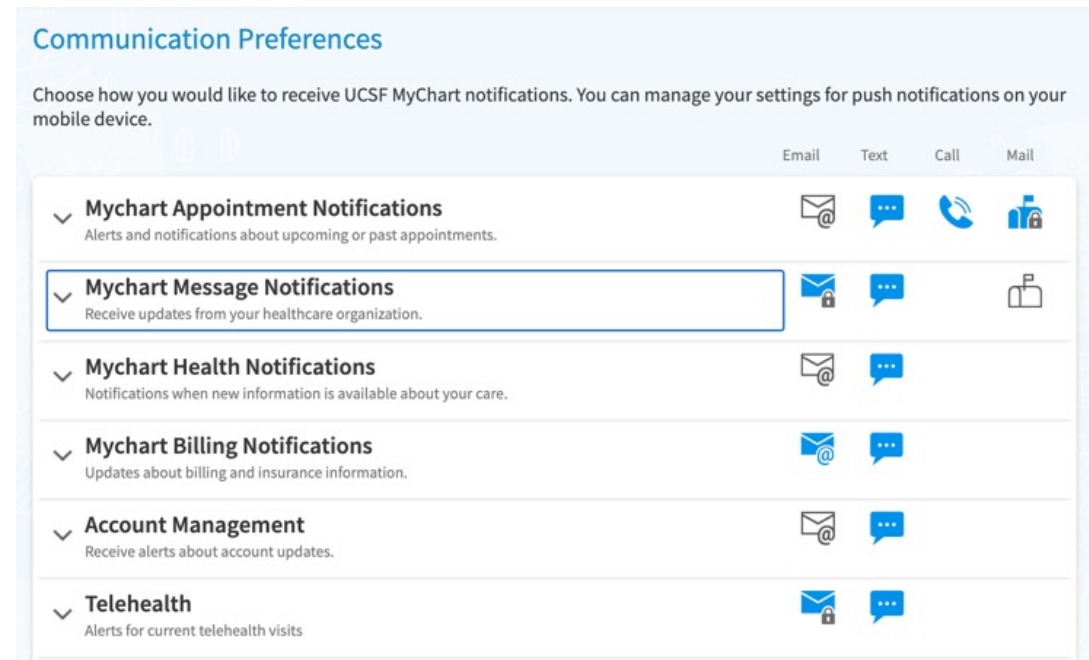
Liz (42yo) wants to allow her husband, Brett, to see her health record so Brett can help with Liz's care when cognitively impaired.

Liz Salmi. OpenNotes. Beth Israel Deaconess Medical Center.
May 13, 2022 • lsalmi@bidmc.harvard.edu • @TheLizArmy



MyChart notifications for your care partner

- Download MyChart to their phone
- Login with your username & password
- Edit **Communications Preferences** to send text updates to your care partner
- Subscribe to all text notifications

A screenshot of the 'Contact Information' form. It has a blue header with the text 'Contact Information' and a yellow bell icon. Below the header is a link: 'Going somewhere for a while? Add a temporary address'. The form contains several fields: 'Country' (a dropdown menu showing 'United States of America'), 'Street Address' (a text field with a blacked-out address), 'City', 'State', and 'ZIP' (text fields with a blacked-out address), 'Home Phone' (a text field with a blacked-out number), 'Mobile Phone' (a text field with a blacked-out number and a red 'CHANGE PHONE NUMBER' button), 'Work Phone' (a text field with a blacked-out number), and 'Email' (a text field with a blacked-out email address). At the bottom are two buttons: 'Save changes' (green) and 'Cancel' (red).A screenshot of the 'Communication Preferences' form. It has a blue header with the text 'Communication Preferences'. Below the header is a paragraph: 'Choose how you would like to receive UCSF MyChart notifications. You can manage your settings for push notifications on your mobile device.' To the right of the paragraph are four tabs: 'Email', 'Text', 'Call', and 'Mail'. Below the tabs is a list of notification categories, each with a dropdown arrow, a title, a description, and icons for the notification methods. The categories are: 'Mychart Appointment Notifications' (Alerts and notifications about upcoming or past appointments.), 'Mychart Message Notifications' (Receive updates from your healthcare organization.), 'Mychart Health Notifications' (Notifications when new information is available about your care.), 'Mychart Billing Notifications' (Updates about billing and insurance information.), 'Account Management' (Receive alerts about account updates.), and 'Telehealth' (Alerts for current telehealth visits). The 'Mychart Message Notifications' category is highlighted with a blue border. The icons for each category are: Email (envelope), Text (speech bubble), Call (phone), and Mail (mailbox).

Brett receives near-instant updates while Liz in the hospital

^

Mychart Health Notifications



Notifications when new information is available about your care.



Prescription Ready



Research Study Invitation via MyChart



Test Result ⓘ

☐ Once daily notifications at 8:30am, Monday through Friday









Today 12:46 PM

Dear Liz Salmi, You have a new message in MyChart. Please log in to your MyChart account at: <https://www.ucsfhealth.org/ucsfmychart/> or with the app to view this message.



What Liz & Brett would like to see

- Make proxy access easier for people receiving care at >1 health system
- Create a process **for the patient to bug the care partner** with reminders
- Send **email & text message** reminders to proxies about completing the sign-up process

Do you think Liz and Brett learned their lesson?

Liz & Brett: Epilogue

- Liz just had 3rd recurrence
- Scheduled for surgery next week
- Using MyChart notification strategy
- We promise to do this right next time!



Thank you



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Two Tales of Proxy Access



David Dorr, MD, MS
Oregon Health & Science University



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What I do:

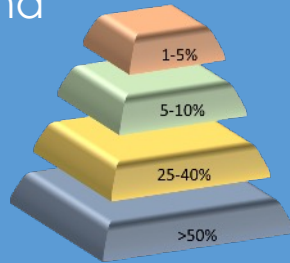
The Mission of Care Management Plus

is to better understand how data, information, and knowledge can assist in transforming health for our most vulnerable patient populations.

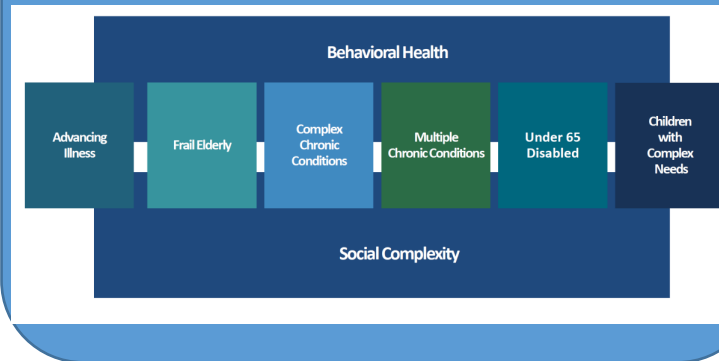


Identifying vulnerable people

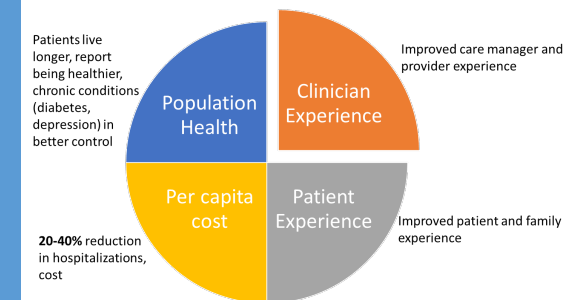
Risk stratification and segmentation



Tailoring care to these needs



Improving outcomes



Major Points

- For effective **care coordination, home self-management**, we need to engage the whole team – including the person and their care partners, especially for older adults and those with multiple chronic conditions
- **Models of care** have helped to some extent, but a major gap has remained **Health Information Technology** – data is fragmented, hard to access, and hard to understand.
- This is the story of an (over)qualified care partner

1st Example: Aunt

- 70-year-old txed for breast cancer with sudden onset of severe abdominal pain, radiating to the whole body; liver shows inflammation.
- Sister's son gets involved to be a care partner.
- Extremely tech savvy and well connected.
- Care is very fragmented.

How to assist in diagnostic next steps?



Southern California Health System

- 500,000 outpatients,
- 75,000 inpatients
- 15k employees

1st Example: Part 2

- Sends a variety of results by email, but many questions remain.
- Initiates Scripps proxy access to nephew
- Allows one to establish as a non-patient proxy, and, after 4 days, has a manual, asynchronous authorization
- Result: Recommend ERCP, curative.

Aunt Transaminase

☆
📌
🔄

File
Edit
View
Insert
Format
Data
Tools
Extensions
Help

🗨️

🔒 Share

↶
↷
🖨️
🔍

100%
\$
%
.0
.00
123

Default (Ari...
10

	A	B	C	D	E	F	G
1	Medication use		?			Data	value
2	●Chronic viral hepatitis (hepatitis		No			AST	23
3	●Alcoholic liver disease		No			ALT	48
4	●Hemochromatosis		No			AST	39
5	●Nonalcoholic fatty liver disease		Maybe			ALT	48
6	●Autoimmune hepatitis		Unlikely			Alk Phos	78
7	●Wilson disease		no			AST	39
8	●Alpha-1 antitrypsin deficiency		No			ALT	204
9	●Congestive hepatopathy		Maybe			Alk Phos	360
10	●Adult bile ductopenia		Maybe				
11	●Malignant infiltration (most often		? imaging				
12	●Muscle disorders (eg, subclonica		No				
13	●Thyroid disorders		No				
14	●Celiac disease		Unlikely				
15	●Adrenal insufficiency		Maybe				
16	●Anorexia nervosa		No				
17	●Macro-AST (moderate elevation:		No				
18							

+
≡
Sheet1
 Explore

2nd Example: Mom

- 80-year-old, multiple chronic conditions.
- Phenomenal primary care, all care through single system
- After 20+ phone calls asking to look at labs and help with decision-making, brings phone to son who requests proxy access.



5 Western States + additional areas

- 28.1 million patient visits
- 52 hospitals
- >120k employees

2nd Example: Part 2

- Son submits information, doesn't work
- Proxy access requires you are a patient
- If not a patient, a front-line staff member must initiate the non-patient request
- Front line staff member has never done this
- Calls help desk, after 30 minutes of everyone's time, initiates the request
- Doesn't work – still won't authorize the account
- After 5-6 tries, give up.

High Level Thoughts

- No real difference in the recognition that this is important
- Overall care excellent yet ...
- One system recognizes proxies may not be patients; the other essentially does not
- One system recognizes that front line care teams may not be the best to manage these needs; the other does not
- Knowing what is possible is often a barrier!
 - E.g., good intentions aren't enough – we have to be committed to improvement and innovation

Thank you



David Dorr, MD, MS
Oregon Health & Science University



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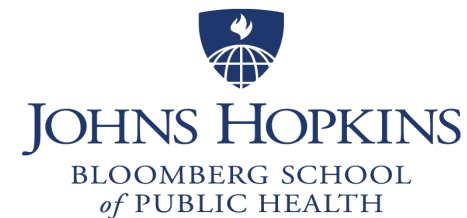
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Proxy Access Research: Looking Ahead



Jennifer Wolff, PhD

Johns Hopkins Bloomberg School of Public Health



John A. Hartford Foundation Funded 36-Month Project Multi-Site Demonstration

Goal: stimulate widespread scaling of adoption of shared access to the electronic health record's patient portal among family caregivers to older adults. Focus is on existing functionalities.



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Patient and Care partner-facing Materials

- What did the doctor say – campaign hook
- Visual alignment with each partner organization's guideline
- Different level of details in different materials
- IRB marks on the materials
- QR codes

MYCHART PROXY ACCESS

MyChart makes it easy to review details about your medical visits. With MyChart Proxy you can share important information about your health with those you trust most.

Your MyChart Proxy will be able to:



View your diagnoses, visit notes, medicines, vaccines, and test results.



Request appointments and prescription refills for you.



Help you communicate with your health care team.



Share portions of your chart with other doctors and hospitals.

CHOOSE A MYCHART PROXY

[HEALTH SYSTEM] patients over age 18 can appoint any adult as a MyChart Proxy. MyChart is compliant with federal and state laws. Your health information is private and secure.

Pick someone you trust to help with your healthcare. Your Proxy can be a close friend, a family member, or someone who lives nearby.

You can appoint more than one MyChart Proxy. This is helpful if someone manages your health from far away.

Who do you trust most with your healthcare?
Write their name here, and talk with them about it.

My MyChart Proxy:

My Proxy's email address:

SET UP YOUR MYCHART PROXY

It is easy to set up your MyChart Proxy. Do one of the following to get started:

> **Online:** Visit [website] to assign a MyChart Proxy using your computer. You can scan the QR code using your a phone camera to open the website link.



> **Phone:** Call your doctor's office at [PHONE NUMBER], or the [HEALTH SYSTEM] MyChart [Help Desk] at [PHONE NUMBER], and tell them you want to set up a MyChart Proxy.

> **In-Person:** Ask about MyChart Proxy at your next medical appointment.

People remember less than half of what their doctors say.

"What did the doctor say?"

There is a lot to manage when it comes to your health.

Invite the person you trust most to stay connected with your health using MyChart Proxy.

healthcare.utah.edu/mychartproxy
#IRB000000 #Version



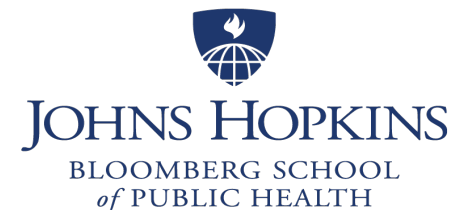
Clinician and Staff-facing Materials

To facilitate discussions between clinicians and patients and their care partners about shared access

- Talking points for discussions
- How-to and proxy registration tips sheet for designated staff
- Smart (dot.) phrases embedded in EHRs
- Webpage FAQs (new or revision of existing materials)



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MyChart Uptake: Monthly Reports

Monthly MyChart reports will allow to monitor adoption at each clinic in aggregate with breakdowns by age (65-80, >80), race, gender, ethnicity, and whether the most recent visit was in-person or telemedicine.

This will allow to:

- track progress on ongoing basis
- compare progress between sites
- actively react on and adjust the implementation



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Implementation Endpoints

Measures of Implementation	Examples of metrics
Acceptability	Patient and care partners' perceptions of usefulness of individual Demonstration materials, clinician and staff perceptions that Demonstration materials and revamped processes are not burdensome for routine mainstream practice use (+REDCap survey)
Adoption	Uptake and use of shared access (MyChart monthly report and 24-month individual-level data pull)
Appropriateness	Whether our materials helped clinicians in conversations with patients and care partners, that materials are helpful and reflect the actual registration process. Patient and care partners' perspectives on how materials may be further improved (+REDCap survey)
Feasibility	Awareness of the intervention and its components; Awareness of shared access. Experiences with Demonstration, including reasons for not using (+REDCap survey)
Fidelity	Adherence to Demonstration materials by site
Cost	Cost of materials, training time (implementation), time spent on proxy registration and portal interactions, perceptions of changes in clinical workload (ongoing)
Penetration	Spread of intervention within the clinics based on extent and consistency of MyChart adoption across clinicians (MyChart 24-month individual-level data pull)
Sustainability	Continued use of Demonstration materials (intent). (+MyChart additional data pull)
Outcomes	Patient and care partner treatment outcomes and experience (REDCap survey)

R35AG072310 - Consumer Health Information Technology to Engage and Support ADRD Caregivers

To increase evidence regarding the role and use of consumer health information technology and of novel, scalable, high-impact health information technology-supported interventions to improve dementia (ADRD) assessment, care, and management.

Aim 1: To produce new knowledge of individual, contextual, and organizational factors that affect patient portal use and evidence regarding the effects of access and use of such technologies on ADRD care quality and outcomes.

Aim 2: To understand how persons with ADRD (mild through severe), caregivers, clinicians, and other relevant stakeholders (e.g., case managers, direct care workers, residential care staff) perceive and use consumer health information technology and identify novel technology-supported interventions that hold promise to improve ADRD care and management across the spectrum of residential and care delivery settings.



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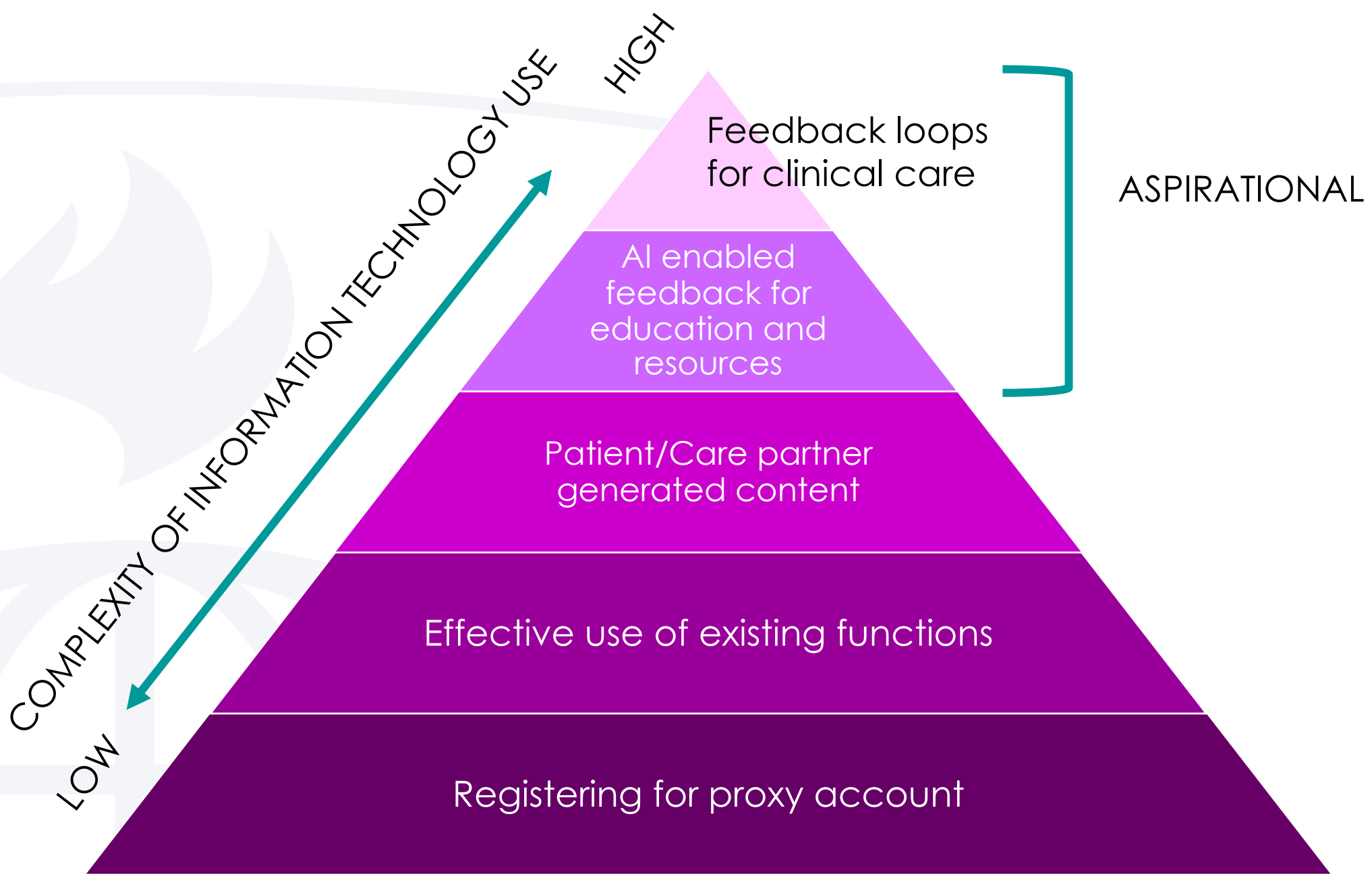


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Ralph C. Wilson-Funded Project (DesRoches, PI)

- Collaboration between OpenNotes, JHU, and ARCHANGELS
- 3 clinical sites
 - Catholic Health (Buffalo, NY)
 - Beth Israel Lahey Health Primary Care (Eastern MA)
 - ? TBN
- Identify care partners in the clinical setting and connect them with services
 - IT Component
 - In person component



Thank you



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Proxy Access Learning Collaborative

Email Alex Duncan at:

`aduncan1@bidmc.harvard.edu`



Q&A

opennotes.org / [@myopennotes](https://twitter.com/myopennotes) / [#opennotes](https://twitter.com/myopennotes)

