

Fixing Proxy Access for Older Adults Complete Q&A

Questions that did not get answered during the webinar:

Q: I am an older person and I really struggle with the patient portals. I would like to be able to sign a release that would allow me to communicate in regular email now and then. Any chance that might ever be acknowledged and allowed?

A: Most healthcare organizations are unwilling to communicate with patients outside of the portal due to concerns about data security and compliance with federal rules. I do not see this changing anytime soon.

Q: What are your thoughts on the importance of having multi-proxy access? For example, multiple adult children of an elderly individual may have different perspectives.

A: This is an important issue. Some EHR vendors do offer the option to grant more than one person proxy access.

Q: Can you list the website for the caregiver complexity index again?

A: <https://www.archangels.me/for-caregivers>

Q: Is there a formal way to become part of your learning collaborative?

A: Please email Alex Duncan (aduncan1@bidmc.harvard.edu) to let her know of your interest. We'll include you on all future emails about the collaborative.

Q: Does anyone have data published or anecdotal on significant harms when a proxy logs in as the patient (not including adolescents)?

A: We have not seen any published data on this topic, although clinicians do reference intimate partner violence and elder abuse as concerns when talking about efforts to include proxy portal registrations. But these are concerns whether a person logs on as the patient or as a proxy because in either case the person in question could see personal details unless the clinician knows to block it from the portal. This will be the case until there are ways for the clinician to control what goes to the proxy and what doesn't and/or until patients have granular control over what the proxy can see.

Q: It sounded like Dr. Dorr used proxy access to provide a 2nd opinion as well as caregiver support to his aunt. Is that a kind of "off label" use of proxy access or is that a function that could be useful for other clinicians?

A: Proxy access to the patient portal allows the patient to grant access to a trusted person for any reason, including weighing in on clinical care and care plans.

Q: What do you find is the best operational process to approve proxy access? I've heard some organizations route them to HIM. We do not allow our MyChart support staff to create proxy accounts. They are currently routing to IS&T.

A: We are examining this issue as part of our work. We hope to have an answer to this question later in 2022. Stay tuned!

Transcript of questions that were answered in the chat during the webinar:
(questions answered verbally in the webinar recording are not included)

Q: Are you aware of any health system that does "patient or proxy education" regarding portals?

A: We do know of one place in the LA County system that has actual classes for patients on the portal, which is amazing. I can connect you if you're interested in learning more. It's a rehab hospital. If you would like more information, contact Deb Wachenheim at dwachenh@bidmc.harvard.edu

Q: Can you please define how you're using the term "proxy" such that it would exclude children? / Is there information about getting proxy access for children/adolescents?

A: It's not that we are excluding children in the definition, but we are specifically focused on proxy access to the patient portal for older adults in this work. The mechanics of offering proxy access to parents of non-adolescent children are similar. We have a previous webinar about notes for pediatrics/adolescents and that addressed proxy access as well in terms of looking at issues like privacy, etc. You can access that webinar here:

<https://www.opennotes.org/webinars>

Q: A question from my own cancer: is there a problem with someone logging in as me, vs having their own proxy access?

A: We have been told by staff at health systems that it can be confusing when you don't know who is communicating with you, who is filling out questionnaires, there may be multiple people using the same log-in, and also there also privacy issues. Also with proxy access then the patient can grant and revoke access.

Q: So if I grant proxy access to my spouse via MyChart, does that mean my spouse can call in and make appt etc.? They already have access to my medical records via MyChart.

A: It depends on whether your health system has varying levels of access, but someone who is a proxy can usually schedule appointments for the other person, yes. Not sure if they can call and make appointments, but they could make appointments via MyChart, if your health system allows for scheduling within MyChart. You'd have to ask your clinic if that person can also call to schedule for you.

Q: How do I become a member of BIDMC OpenNotes if I don't know my login?

A: It's not a membership thing. You need to contact the office that assists patients in signing up for the BIDMC patient portal. Once you can log in to your patient portal you can then access your notes as one part of the information available on the portal. Email patsite@bidmc.harvard.edu

Q: Is there a specific customer service desk (e.g., a genius bar like service) for you to troubleshoot proxy access?

A: The help line number for the patient portal at the health system where you receive care should be able to help, but sometimes they tell you to do it in person at your clinic.

Q: What if an adult woman had an abortion and didn't want her proxy to know? It's not just adolescents. We patients need easy-to-use granular control over what our proxies can see.

A: We are in complete agreement on the need for granular privacy controls in the hands of patients.

Q: Can EMRs handle if you have something that you want to hide from your proxy (e.g., an adolescent who is taking birth control without their parent's approval)?

A: When it comes to adolescents, that's a whole other topic in terms of privacy of information, and health systems deal with that differently, some by hiding specific items (eg. birth control) and some by restricting access to the portal all together. For adults, it's usually up to the clinician to determine what to not send to the portal, or if the patient is savvy enough they can ask the provider not to send something. We would love to see more granular control for patients in terms of what gets shared with proxies. It would also be helpful for there to be more granular control for providers to be able to send something just to the patient-facing portal but not the proxy-facing portal.

Q: If you are able to gain proxy access, is that person able to communicate with your healthcare providers via the portal? If so, is the patient able to see that communication thread?

A: Yes, usually they can communicate with your provider. This is something you can double check with your health system. I am unsure if the patient is always able to see the communications. I know for my adolescent children, for example, I can click on whether or not my child sees the communication (I am her proxy). So I assume in my health system the same would apply if I was a proxy to an adult.