Bright Spot: Sharing Providers' Notes

"Open Notes" is an international movement inviting patients to read the notes doctors, nurses, and other health care providers write to describe a health care visit (the OpenNotes research initiative was launched in 2010 at Beth Israel Deaconess Medical Center).[1] Though always part of the medical record, these notes are more easily available thanks to digital platforms like patient portals. To foster the spread of note sharing in New York State, NYSHealth funded adoption of OpenNotes at hospitals and health systems.

GetMyHealthData supported two of these systems to inform and expand their efforts to share notes. We administered a survey on patients' and family caregivers' experiences accessing and reading their notes at four hospitals, with a Spanish language survey option available at three of the institutions. 1, 140 individuals completed the survey. We also administered a provider experience survey to a small number of participating doctors and conducted interviews with staff leading implementation efforts. These findings and recommendations – directly from patient and clinician feedback – can help health care leaders promote the adoption and spread of note sharing within their institutions.

Patient Experiences Reading and Understanding Notes

Across the board, respondents experienced positive effects reading clinical notes. These benefits included: improved relationship with and increased trust in their provider, a better understanding of their medical conditions and an increased ability to adhere to treatment plans. People rated notes most highly for their ability to affect understanding of health and medical conditions and helping to follow their doctor's treatment recommendations.

Reading providers' notes online prompted patients to take action. Approximately 95 percent took at least one action as a result of reading their notes. Half of respondents reported looking up more information online and better following a treatment plan. Other common activities included making a change to daily activities and talking to friends or family.

Respondents were very likely to recommend reading notes to friends and family. The net promoter score (NPS) is a core measurement of customer experience often used to predict business growth. It is calculated from the answer to a key question, using a 0-10 scale: "How likely is it that you would recommend [brand] to a friend or colleague?" Any NPS above 0 is considered good and an NPS above 50 is considered excellent.[2] In the four hospitals surveyed, the NPS ranged from 50-91, which indicates that respondents were extremely likely to recommend reading notes to others.

In their Own Words: Patient Quotes

"Reading the notes by my NP or Dr helps me to better understand my visit and gives me comfort in knowing they listened, and I truly matter."

"I wish all of my doctors would do this. I always wondered what was put in the notes and it made me shy and apprehensive to really talk during appointments."

"Notes are a great idea to refresh your memory. There is a tendency to forget the doctor's instructions or part of them sometimes especially when you are nervous to start with."

"I think it's a great idea... I love to have more to do with my health. Also it's totally language I can understand."

Spanish Speakers Embrace Notes

The survey was offered in Spanish and English at three hospitals. Respondents who completed the survey in Spanish:

-Were most likely to take the survey on a smartphone (88%) and to use a phone to access their patient portal (76%).

-Were most likely to look up more information online as a result of reading their notes.

- Selected a NPS that was, on average, 7 points higher than English-speaking respondents.

- Consistently rated understanding notes as more difficult than those who completed the survey in English.

Providers' notes were easy to understand

When asked to rate how easy it was to understand their notes on a scale from zero to 100 (with zero being very easy and 100 being very difficult), responses ranged from 18-32. Generally, respondents who answered the survey in English found it easier to understand their notes than those who took the survey in Spanish.

Provider Experiences: Highlights

Skeptics question whether notes are helpful to patients. While clinicians are supportive overall, some doubt reading notes will help patients better understand their health and medical conditions. They shared concerns that patients would not benefit from the nuanced level of their medical information, or would be confused by medical jargon and/or offended by diagnoses.

Concerns spending extra time responding to patients are unfounded. Clinicians often cite concerns over changing the way they write notes and spending more time answering questions and responding to patient concerns as barriers to sharing clinical notes. The majority of providers who participated in note sharing pilot programs said they found the process of sharing notes minimally burdensome and did not report spending more time answering patient questions after implementation. In short, as one patient engagement leader described, predictions that providers would spend additional time assuaging patient concerns did not materialize.

Preserving clinician choice is critical. Most providers support sharing clinical notes with patients, including the format where notes are shared automatically. However, clinicians still want the ability to turn off the sharing function for select notes. Providing the ability to opt out of sharing particular notes is critical for cultivating clinician support and engagement.

Advocates of Opening Notes said...

"[Sharing notes is the] natural evolution of health information sharing."

"Patients enjoy understanding what we discussed in clinic."

Skeptics of Opening Notes said...

"If [patient] have poor prognosis, they do not need to know that before every treatment option is used."

"I think as providers, there are certain things to share and other things we need to preserve as a medical privilege for ourselves."

Recommendations

Embrace Notes Sharing: Health systems should enthusiastically embrace and publicly promote their adoption of online notes sharing, drawing upon the overwhelmingly positive reception by diverse patients at hospitals and health systems across the state of New York. In addition to fostering better relationships with patients, the availability of providers' notes should be celebrated as a market differentiator. Furthermore, access to clinicians' notes could drive

increased uptake and utilization of patient portals. Notes provide additional detail and context for the clinical information typically made available and seem to enhance patients' perception of the portal's value.

Prioritize mobile access: Over eight in 10 individuals in the U.S. now own a tablet or smartphone.[3] Hundreds of respondents took the patient experience survey on a mobile device. In open-ended comments, many expressed a desire to read their provider's notes on their mobile device. Making notes available via the patient portal mobile app should be a top priority in design and implementation decisions made with technology vendors.

Set appropriate expectations: Acknowledge upfront that the medical terminology may be difficult to understand and explore how best to support patients in understanding their providers' notes (e.g., offer recommendations for trusted resources like the National Library of Medicine; encourage use of secure messaging to ask follow-up questions; explore best practices for clinical documentation). Ultimately, questions about medical terminology are an indication of an engaged patient and should be celebrated.

In their Own Words: Patient Suggestions and Commendations

"You need to redesign the layout for ease of navigation especially for mobile devices which people use given their busy schedules."

"Better lay person terms would be helpful and a consistent usage of the notes. We are in an era where responsibility to my health is a team effort...I want to be involved with the expectation that they are the expert."

"This is a great tool to participate in your health care."

Partner with patients and families: Providers should work with patients and families – via patient-facing surveys, Advisory Council meetings and other engagement opportunities – to understand their information needs and share these perspectives with clinicians. Providers are more likely to support note sharing if they hear directly from their patients about the value of this information. Additionally, partnering with patients and families will strengthen implementation and maintenance efforts, such as informing educational materials or providing input on patient portal features. Patients had several notable suggestions for improving the notes feature and the patient portal overall, such as text message notifications when new notes are available, non-English language translation options, and downloadable medication lists.

Become a Champion!
Interested in sharing or reading notes? Ask your health system about sharing clinical notes with patients and family caregivers today.

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1 https://www.opennotes.org/

2 https://www.questionpro.com/blog/nps-considered-good-net-promoter-score/

3 Pew Research Center (2018, February). *Mobile Fact* Sheet. Retrieved 20 November 2018 from http://www.pewinternet.org/fact-sheet/mobile/