Implementing OpenNotes: Improving patient access to notes on patient portals

An OpenNotes White Paper, November 2018

Introduction

At institutions or practices that have joined the OpenNotes movement and invite their patients to read their clinicians' notes, an important question that arises is: How many patients actually read the notes they are invited to review? With the help of many participants that have offered both invaluable insights and data to us, OpenNotes is beginning to develop metrics to answer a related fundamental question: What is Practice A's "note-reading rate?" In other words, if x notes are shared by clinicians via the patient portal, what percent of these are actually opened and viewed by patients with portal accounts?

Multiple factors affect how widely and deeply OpenNotes is woven into practice in institutions and health systems. How actively are patients asked to register on a patient portal - by default, by invitation from their doctor or nurse, or through small print in the corner of a hospital website? What is the demographic mix of patients? Are the patients served generally eager or not so eager to turn to computers or mobile devices to help with their care? Are patients urged to use the portal, do they use it often to look up results, email their clinician, order prescriptions, or does the subject come up only rarely? How many clinicians encourage patients to read notes? Do practices brand the "find your notes" process distinctly on the portal? Are patients reminded to read notes once they are available?

And importantly, how easy is it for patients to find notes? As indicated in Appendix 1, and from many anecdotes we hear from patients, navigating a portal successfully can be an enormous challenge for many patients who might well profit from reading their notes.

Most of the information we've gathered so far to address some of these issues and, in particular, portal navigability comes primarily from OpenNotes implementers using electronic health records (EHRs) by Epic, but we are working with several institutions that use "homegrown" portals or those furnished by three other vendors offering OpenNotes functionality: Cerner, Meditech, and Allscripts.

This report provides an overview of steps we are taking to gather and assess information. It offers some early insights and gives brief illustrative examples of two institutions that have achieved higher note-reading rates: a) an Epic "out of the box" user that has achieved success, b) a hospital with a "homegrown" portal that has "branded" its OpenNotes initiative and has 5 years of experience with note sharing.

In addition, we attach three Appendices: Appendix 1 includes a letter written by the new National Health Information Technology Patient Family Advisory Council (HIT PFAC), organized jointly by OpenNotes and PFCC Partners. These patients and family members discuss some of the challenges they face in navigating patient portals and accessing notes and offer suggestions for improvements. Appendix 2 is a screenshot of a Beth Israel Deaconess Medical Center (BIDMC) portal homepage which includes

the OpenNotes logo and text directing patients to their notes. Appendix 3 is an example of how one vendor (Epic) is working to improve portal navigation for patients.

Data Gathering and Assessment

When we learn of institutions implementing OpenNotes, we reach out, asking a series of questions about their implementation and the number of patients registered on their portal. In late 2017, we looked at information submitted to us over the previous 1-2 years by 91 healthcare organizations that had implemented OpenNotes. Drawing on our early experiences, we hypothesized that an organization-wide default decision to share most notes (an "opt-out" rather than an "opt-in" plan for clinicians) and automated email notifications to patients about the availability of new notes would be associated with higher note-opening rates. But we found that those indicators needed to be viewed in a much broader context.

In early 2018, we reached out to 86 OpenNotes implementers we had in our database, asking them to provide their best information on the number of notes available to and opened by patients registered on their portal. Using what we believe are reasonably similar metrics, a subset of these implementers (mostly Epic systems, for reasons outlined later in this report) submitted data on the number of available notes opened by patients. We asked also about efforts to communicate with patients about the availability of notes, including the use of email alerts and posters/flyers, branding with OpenNotes, and information on the portal homepage or website. In most cases, we do not have granular organizational data, such as patient mix, the percent of patients served who are registered on portals, educational efforts for clinicians and staff, and internal metrics about other aspects of portal use.

Nevertheless, our early findings are informative. Twenty-six implementers offered information on what they believe to be their note-opening rates. They range widely, as summarized in Table 1 below.

Table 1

Organization	Vendor	Note-Opening Rate (% of shared notes opened / viewed by patients)
A	Homegrown	34.0
B	Epic 2017	26.0
C	Epic 2017	22.0
D	Homegrown	21.0
E	Epic 2017	10.0
F	Epic	8.5
G	Epic 2017	7.0
H	Epic 2015	7.0
I	Epic	7.0
J	Epic 2017	6.0
K	Epic 2017	6.0
L	Epic 2017	6.0
M	Epic 2017	5.0

N	Epic 2017	4.5
O	Epic	4.0
P	Epic 2015	3.6
Q	Epic 2017	3.5
R	Epic 2017	3.5
S	Epic 2015	3.0
T	Epic 2017	3.0
U	Epic 2015	3.0
V	Epic 2017	2.2
W	Epic 2015	2.0
X	Epic	1.3
Y	Epic 2017	1.0
Z	Epic 2015	0.3

Note: percentages rounded for consistency.

Four implementers reported strikingly higher rates than the other respondents. Implementer A has both a longstanding homegrown portal and extensive experience with OpenNotes. It has focused primarily on developing portal functionality that encourages patients to read their notes. Implementers B and C are both Epic implementers who have taken multiple steps to optimize their Epic version to make notes easier to find. Implementer D, a recent implementer, was very active in its marketing of OpenNotes and has a homegrown portal. In each of these four, sharing notes is the default, and patients receive notifications when new notes are posted.

Some of those reporting note-opening rates of 6-10% tried multiple communications with patients. We know some have tried configuration changes in their portals, and we eagerly anticipate updates from them regarding whether those changes have resulted in increased note-opening rates.

Programs in the third group of implementers, those in the 0-5% range, were less likely to have had substantial communications efforts or to have changed configuration, although some did offer patient-facing communications. We are also working to gain updates from this group.

Two examples:

a) The Vancouver Clinic (Implementer C) shared specific steps they took to improve their note-opening rates. These include:

- Quick Link within MyChart patient portal (labeled 'View clinical notes shared by your provider');
- Text at top of Visit Summary section directs patients to click on Clinical Notes tab;
- MyChart home page 'News for You' contains paragraph on notes and a hyperlink;
- Notes are viewable on both the Visit Summary report and the Clinical Notes tab (with some exceptions);
- Clinicians' notes are shared by default (with a few exceptions);
- Auto MyChart message sent to portal user when visit is closed:
    - Auto generates email notification and home page alert;
    - Message subject reads 'New MyChart@TVC Visit Note';
    - Body of message contains navigation steps and hyperlink directing patients to Appointment and Visits page.

b) The Beth Israel Deaconess Medical Center (Implementer A) has focused on its homegrown portal where it now brands clinicians' notes as "OpenNotes". The portal landing page displays the OpenNotes logo prominently, accompanied by a short explanatory text directing patients toward their notes and a hyperlink to the patient pages on the OpenNotes Website (see Appendix 2). A click on the logo leads the patients to their notes on the portal, and they are labeled as "OpenNotes".

Working with Vendors

Epic reports overall that their customers have shared millions of notes, but they are not authorized to provide us with note-opening rates at individual organizations. We shared our read rate data with Epic after de-identifying individual institutions. After reviewing the data, Epic communicated additional portal configuration options to healthcare organizations through their individual Epic representatives, but as of the fall of 2018, uptake among their customers appears to be limited. We have been in ongoing discussions with Epic about more definitive changes aimed at improving patient navigation to notes on MyChart. Appendix 3 includes a summary of Epic enhancements designed to improve navigation.

With respect to patients finding notes on their portals, we believe that Cerner implementers also have varied navigation options (based on anecdotal reports from both health systems and patients using Cerner systems). However, organizations with Cerner systems have not generated note-opening rates. While they can report the number of patients who have viewed their notes, they have been unable to count the number of shared notes that have been opened. Anecdotal reports suggest that note-opening rates are likely variable, and we have patient reports that it's easier or harder to find notes in different versions of the Cerner EHR across different organizations. We are now working with a few Cerner sites to generate a note-opening rate.

Meditech and Allscripts publish their notes as a "report" (along with other reports, such as radiology reports). They can provide a "report read rate," but not a specific "note read rate." While it appears that navigation to notes in both is fairly straightforward, we do not have a specific sense of the note-opening rate in those systems.

Our goal is to develop metrics around use of the portal and note-opening rates to evaluate the extent to which notes are shared by clinicians and opened by patients at implementing organizations. To this end we are working with multiple organizations to better define, develop, and refine metrics and measure portal registrations and note open/read rates.

For now, we believe the definition used by Epic to measure note-opening rates is reasonable as a starting point (this definition applies to notes shared over any defined time frame):

Numerator = Notes listed in denominator that are viewed by a patient portal user.

Denominator = Signed notes from completed encounters written on a portal active patient (or patients activated within a month of the visit) that are shared to patient portal.

We recognize this definition is not being used across all healthcare systems, and not even across all Epic systems. We view it as a starting point for working with those interested in developing more robust and meaningful metrics.

Conclusion

From the data we have gathered, it is likely multiple factors, including portal navigation, lack of or ineffective reminders to read notes, and insufficient communication strategies contribute to low note-opening rates. We need a note-opening metric in order to measure and improve the quality of OpenNotes implementations. The Epic metric appears to be a reasonable start.

As we work to advance patient access to more transparent healthcare information, we look forward to continuing to work with organizations implementing OpenNotes. The data that we and many others are gathering demonstrate increasingly that sharing notes with patients may improve the quality and safety of care, and perhaps contribute to cost containment. Many patients now have notes available. We need to make it much easier for them to read them!

Please contact Deborah Wachenheim (dwachenh@bidmc.harvard.edu) with any questions or comments.

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Appendix 1

The National HIT Patient Family Advisory Council (PFAC) is an impartial group committed to improving the ability of technology to support the patient/physician relationship. We are focusing on technology issues related to patient portals and finding opportunities to further their availability and accessibility to all patient populations, and our first area of focus is access to notes.

The council consists of a diverse group of members who use portals from multiple vendors (including Cerner, Epic, and AllScripts) or different versions from the same vendor. While technology experiences range among our members, we are all regular users of patient portals. We seek to offer our experiences to help provide the best patient portals possible.

We are finding a lack of ease for patients in obtaining access to their notes. Some of the reported challenges include:

- Lack of knowledge about notes;
- Too many clicks to find notes, even when the user knows they exist;
- Varied placements of notes;
- Various titles for notes;
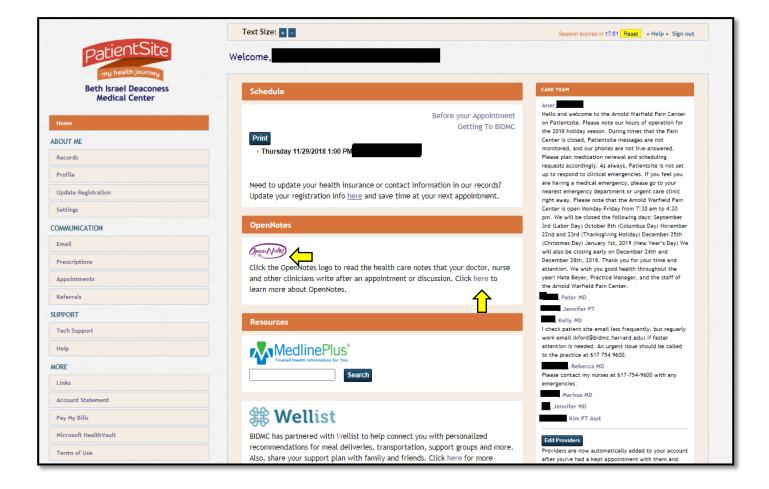- Some clinicians in the same system share notes and some do not.

These issues leave patients and caregivers frustrated in the use of patient portals as a source for accessing their notes. In this age of better patient communication and transparency, we believe that patient portals should be used as a way to share healthcare information with patients. As patients and caregivers, we acknowledge the additional effort and time it takes health professionals to provide these notes but believe that ultimately this time will be well rewarded through better communication and understanding between patients and physicians, and ultimately patients becoming more actively engaged in their healthcare.

We suggest you consider the following steps to improve patients' access to notes:

- Work with your Patient and Family Advisory Council on outreach and education regarding notes;
- Work with your communications/marketing department on an information campaign;
- Convene a focus group of patients/families to better understand the barriers;
- Talk with your EHR/portal vendor to discuss options for easing navigation to notes;
- Reach out to us to discuss what we have learned from our own experiences.

We look forward to working with you to improve access to and use of clinical notes as a resource. Please contact Deb Wachenheim, Assistant Director of Dissemination at OpenNotes, at dwachenh@bidmc.harvard.edu or 617-975-7617 for more information.

Appendix 2

Appendix 3

Summary of Epic initiatives related to OpenNotes navigation issues

Epic has been part of discussions related to OpenNotes navigation issues since early 2017. Epic is taking positive steps forward to making OpenNotes even more powerful and user friendly for both patients and care givers. Additionally, they have engaged directly to hear feedback, attended OpenNotes conferences, and created a work group of clinicians to inform these features. The following changes have been made or are under planning for future implementation as a result of these discussions:

Epic 2017/2018 Enhancements and Optimization Features

1. Send custom AVS tickler when notes are shared;

2. Show AVS alert on home page;

3. Customize the notes tab;

4. Add quick link to past visits list;

5. Display help text on past visits page;

6. Improved reporting capabilities on sharing and viewership—this feature starts November 2018. Links: Open the Door to Reporting on Open Notes, Setup Instructions (available to Epic clients only).

Future Enhancements

Moving forward, Epic is committed to further improving OpenNotes. They have a robust roadmap that includes making notes more front-and-center in MyChart and adding improved MyChart Mobile support. Want to be a part of the conversation or learn more? Participate here: Epic's UserWeb.

More information for Epic users only:

Epic has made a pdf available elaborating on these changes on their UserWeb post: Open Notes in MyChart - Build Recommendations and Future Development.

- This is available to all Epic community members;
- If you have a UserWeb account you can review, add comments, and discuss with other organizations.