Who Reads Their Doctor's Notes? Examining the Association between Preconceptions and Accessing Online Clinical Notes

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Patients who use online portals to review their clinicians' notes may become more actively involved in their healthcare, but the healthcare industry knows little about factors that may facilitate or inhibit patients' use of this new practice. To look into this topic, researchers from the University of Washington School of Medicine, based in Seattle, WA, and Beth Israel Deaconess Medical Center, Harvard Medical School, based in Boston, MA, compared baseline perceptions about online portals between patients who ultimately did or did not access their doctors' primary care visit notes, using data collected through the OpenNotes initiative.

Why Conduct the Study

Millions of patients have access to their electronic health records via patient portals, with an increasing number of portals offering access to doctors' notes.[1] Patient access to doctors' notes provides numerous potential benefits including better patient-provider communication, enhanced patient satisfaction, the ability to share records with caregivers, and increased opportunity for self-management.[2–4] Federal requirements for the meaningful use of electronic health records also mandate that providers offer access to online portals and incentivize organizations to encourage patient use of these portals.[5]

Facilitating online viewing of doctors' notes affords a unique opportunity to educate, motivate, and engage patients.[6] With 926 million office visits in the US every year, there are ample opportunities to engage patients via note reading.[7] However, a multitude of these opportunities are lost because—depending on the portal availability and implementation strategy—only a small fraction of patients view doctors' notes.[8] It is unclear whether a strategy touting the benefits of online note viewing or assuaging concerns would be more effective at encouraging patients to use this new tool. Identifying patient perceptions of facilitators or barriers to accessing their doctors' notes is important to harnessing the promise of patient engagement. This study evaluates whether baseline differences in perceptions about viewing doctors' notes among patients with online portal access predict the likelihood of accessing notes.

Study Materials and Methods

OpenNotes is a national initiative that invites patients to review the visit notes written by their doctors, nurses, or other clinicians. The OpenNotes study methods, including survey design and validation, have been described in detail previously.[9,10] In short, patients were given access to their primary care doctors' visit notes via secure, web-based patient portals for a time period of 12 to 18 months during 2010 and 2011. Patients at three geographically diverse locations (Beth Israel Deaconess Medical Center (BIDMC) in Boston, MA; Geisinger Health Systems (GHS) in Danville, PA; and Harborview Medical Center in Seattle, WA) were invited to participate. At the time of the original study these were the only participating sites in OpenNotes. During the intervention, patients of participating doctors were given access to their primary care visit notes for the first time.

The baseline OpenNotes study survey, completed by patients prior to the start of the intervention, queried patients about demographics (age, gender, race, education, employment, healthcare site), internet behavior (frequency of use, location of access), and validated indicators of current health status (self-reported health, utilization, comorbid conditions, ambulatory care experience, perceived efficacy of interactions with doctors).[11,12] Perceptions of the risks and benefits of viewing notes were captured using a four-point Likert scale of agree, somewhat agree, somewhat disagree, and disagree. Of those patients invited to participate, 9,043 (40 percent) completed the baseline survey.

Two sites, BIDMC and GHS, provided data on comorbid conditions and utilization of outpatient and inpatient services from billing records. All sites provided data indicating whether or not a patient accessed physician notes online.

Patients who completed the baseline survey and saw their primary care doctor at least once during the study intervention period were included so that a minimum of one visit note was available for the patient to read. For the analysis described in this article, survey responses to perception questions were dichotomized into agree/somewhat agree versus disagree/somewhat disagree to account for small numbers in the extreme Likert response categories. Patients who viewed at least one visit note during the intervention period were considered to have accessed their clinical notes.

Differences in patient characteristics and baseline perceptions between those who did or did not access their visit notes during the intervention period were performed using the chi-square statistic for categorical dependent variables and simple logistic regression for continuous variables. Multivariate models evaluated associations between patients' baseline perceptions and the likelihood of accessing notes. Odds ratio estimates were adjusted for potential demographic, health, and utilization confounders including age, sex, race, education, employment status, self-reported health, study site and a measure of healthcare utilization (number of office visits during the study period). All statistical analyses were conducted using SAS software, version 9.4. All study procedures were approved by the institutional review boards of BIDMC, GHS, and the University of Washington.

Table 1: Baseline characteristics of patients who did or did not access at least one clinical note during the intervention period

Patient Characteristics[a]	N	Accessed note during intervention period; N=5,630	Did not access note during intervention period; N=520
Demographics			
Age at baseline[b] (range 18-95)			
18-39	934	89%	11%
40-49	1,168	88%	12%
50-59	1,973	92%	8%
60-69	1,421	94%	6%
≥70	653	94%	6%
Sex[b]			
Men	2,564	89%	11%

Women	3,586	93%	7%
Race[b]			
Black or African American	150	76%	24%
Other or Multiracial	378	82%	18%
White	5,467	93%	7%
Education			
High school/GED or less	1,121	91%	9%
Some college	1,476	91%	9%
College graduate	1,187	92%	8%
Post college	2,257	92%	8%
Employment status[b]			
Unemployed/unable to work	501	84%	16%
Retired	1,178	94%	6%
Employed/self-employed/ homemaker	4,239	92%	8%
Health status and healthcare use[c]			
Self-reported health			
Poor/fair	830	91%	9%
Good/very good	4,523	92%	8%

Excellent	689	90%	10%
Office visits in 12 months preceding OpenNotes access[b]			
0	455	93%	7%
1-2	2,664	92%	8%
3-4	1,690	94%	6%
5+	1,092	96%	4%
Office visits in 12 months following OpenNotes access[b]			
1-2	3,040	91%	9%
3-4	1,719	95%	5%
5+	1,142	96%	4%
Hospitalized at least once in 12 months preceding OpenNotes access			
Yes	387	95%	5%
No	5,514	93%	7%
Hospitalized at least once in 12 months following OpenNotes access[b]			
Yes	307	96%	4%
No	5,594	93%	7%
Comorbidities[d]			

Congestive heart failure/Coronary artery disease	334	96%	4%
Asthma[b]	343	97%	3%
Low back pain[b]	353	96%	4%
Anxiety/Depression	422	93%	7%
Diabetes[b]	689	97%	3%

a. Some data missing for age, race, education, employment status, and self-reported health.
b. Significant difference between groups with $P < 0.05$.
c. Healthcare utilization and co-morbidity were obtained through patient medical records at BIDMC and GHS. Information unavailable for Harborview patients.
d. Based upon billed visit ICD-9 diagnoses during the study period (2010-2011).

Study Results

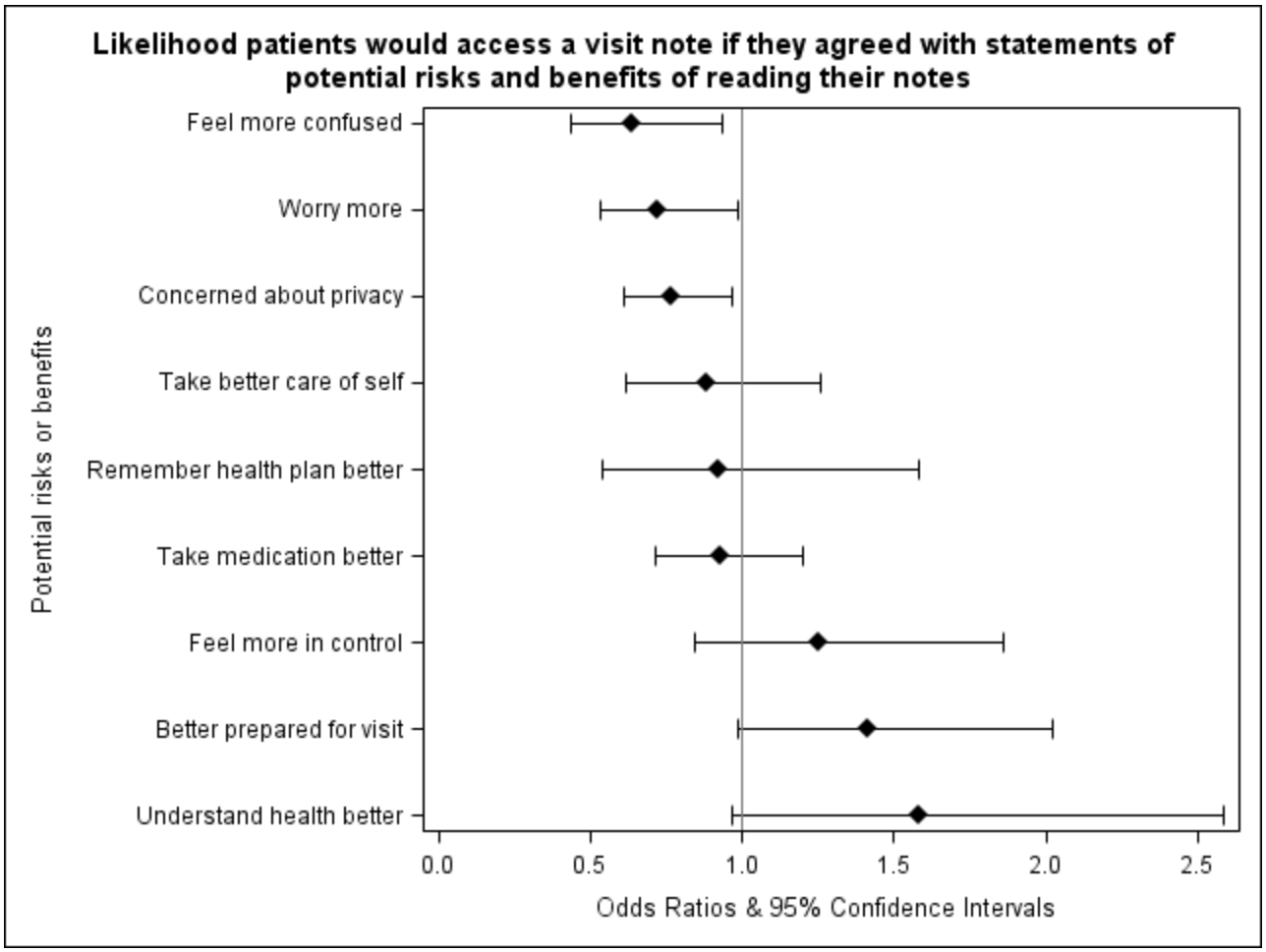
Of the 6,150 patients who responded to the baseline survey and had at least one visit note available to review during the intervention period, 5,630 (92 percent) accessed at least one doctor note while 520 (8 percent) did not access any notes. Table 1 above presents patient characteristics reported in the baseline survey for those who did and did not access visit notes. A higher proportion of patients who accessed their notes were older, white, female, and retired relative to patients who did not view their notes (all p-values <0.001). Patients with a greater number of office visits were more likely to access notes ($p<0.001$). High proportions of patients (93-97 percent) with common chronic diseases—including congestive heart failure, asthma, and diabetes—accessed their notes.

Patient-reported ratings of overall satisfaction with their doctor and of doctor-patient communication were not significantly different between patients who accessed or did not access their notes (data not shown). Internet access was not a significant barrier to viewing notes, as all but 71 of 6,041 patients (one percent) reported internet use at least twice a month and 85 percent were daily internet users.

Patients' baseline perceptions of potential facilitators and barriers to viewing a note were associated with accessing their clinic note during the study period. Specifically, patients more concerned about the potential risks were less likely to ultimately view a note ($p=0.005$). See Table 2 below for more information.

Figure 1

This chart shows the adjusted likelihood patients would access a primary care clinic visit note using their patient portal if they agreed with baseline survey statements of potential risks and benefits of reading their notes.[a]



a. Adjusted for age, sex, race, study site, and number of office visits during the study period.

After adjusting for patient characteristics that remained significant in a multivariate model (age, sex, race), study site, and the number of office visits during the study, patients had lower odds of accessing notes if they felt that the visit notes would be confusing (OR 0.63, 95 percent Confidence Interval (CI) 0.43-0.94, p-value <0.02), anticipated worrying more as a result of reading notes (OR 0.72, 95 percent CI 0.53-0.99, p<0.04), or if they had concerns about privacy (OR 0.77, 95 percent CI 0.61-0.96, p-value 0.02) (see Figure 1 above). Baseline attitudes about potential benefits of viewing notes were not statistically associated with subsequently accessing the notes, though anticipating being better prepared for the visit or understanding their health better after reading notes attained borderline statistical significance.

Table 2: Perceptions of patients who did or did not access at least one clinical note during the intervention period

Perceptions of Barriers and Facilitators to Viewing Doctors' Notes[a]	N	Accessed note during intervention period	Did not access note during intervention period
Concerns			
The notes would be more confusing than helpful[b]			

Agree/somewhat agree	431	87%	13%
Disagree/somewhat disagree	4,778	92%	8%
I would worry more			
Agree/somewhat agree	762	90%	10%
Disagree/somewhat disagree	4,564	92%	8%
I would be concerned about my privacy[b]			
Agree/somewhat agree	2,069	90%	10%
Disagree/somewhat disagree	3,764	92%	8%
Benefits			
I would take better care of myself			
Agree/somewhat agree	4,679	91%	9%
Disagree/somewhat disagree	695	93%	7%
I would remember the plan for my care better			
Agree/somewhat agree	5,710	92%	8%
Disagree/somewhat disagree	274	91%	9%
I would be more likely to take my medications as prescribed			
Agree/somewhat agree	3,718	91%	9%
Disagree/somewhat disagree	1,572	92%	8%

I would feel more in control of my healthcare			
Agree/somewhat agree	5,507	92%	8%
Disagree/somewhat disagree	407	91%	9%
I would be better prepared for visits			
Agree/somewhat agree	5,174	92%	8%
Disagree/somewhat disagree	487	90%	10%
I would understand my health and medical conditions better			
Agree/somewhat agree	5,637	92%	8%
Disagree/somewhat disagree	233	90%	10%

a. Missing data (2-15 percent) occurred for all perception questions and are not included in this table.
b. Significant difference across groups with $p < 0.05$.

Why Most, But Not All, Accessed Their Records

While the majority of patients in the study anticipated many potential benefits from accessing their clinic notes, a small—but important—minority of patients did not access their clinic notes, and these patients reported more baseline concerns about privacy issues and fear of being confused or worried by reading their doctors' notes. While reading their doctors' clinic notes has the potential to engage them between face-to-face encounters, and thus improving the quality of care and the patient experience, these patients cannot benefit if they do not log in to the online portal and read their medical records. Thus, interventions focused on overcoming these patients' reservations may prove more productive than simply reiterating known benefits.

Patients' fear of finding their clinical notes more confusing than helpful might be appropriately founded. Medical terminology, shorthand acronyms, and large amounts of templated or copied and pasted data are frequently used in clinical notes. Therefore, improving the clarity, approachability, and understandability of doctors' notes is a first step to addressing the worry that the notes will be confusing.[13] Electronic health record vendors could advance technologically feasible improvements by including integrated hyperlinks in visit notes, embedded definitions for medical jargon, and provision of enhanced patient education materials within patient portals. Doctor education on note writing—such as avoiding acronyms, using a clear writing style, avoiding bulky templates, and giving patients the opportunity to review the notes with staff or the doctor—could help alleviate patient concern and confusion.[14]

Peer navigators could proactively engage concerned patients, providing reassurance and helping to interpret new or unfamiliar terms. With these innovations, it is possible that viewing notes could ultimately allay patient anxiety about reading their medical records.

Given the numerous sensitive topics addressed by doctors—such as suspected malignancy, genetic screening, mental illness, and addiction—it should come as no surprise that some patients expect to worry more as a result of reading clinical notes. Some evidence suggests doctors underreport sensitive topics when documenting their visits.[15,16] Simple habits such as "writing what you discuss, and discussing what you write" can ground patient expectations and even alleviate anxiety.[17] Plans outlined in clinic notes should be clear and candid to avoid misperceptions that could exacerbate worry. Again, peer navigators with experience reviewing clinical notes could assuage distressed patients. And in the rare instance when a doctor feels that the content of a note could harm a patient (e.g., discussion of alleged intimate partner violence by a partner accessing the record), most electronic systems permit a specific note to be omitted from the patient portal.

Patients concerned about information privacy were also less likely to view their notes. This is a legitimate concern given news headlines about online data breaches[18,19] and can result in increased patient apprehension regarding online portals.[20,21] While acknowledging that the risk of a data breach cannot be completely eliminated, federal law—including HIPAA and the Health Information Technology for Economic and Clinical Health (HITECH) Act—impose robust protections for patient data.[22] Patients should protect their health information by safeguarding their own login and password information. Ultimately, patients should be educated that their data is already in electronic form and failing to access this information simply limits its usefulness without affording additional protection.

While this study included patients from three geographically distinct areas with varied online health records, this analysis had several limitations. The patient portal was developed *de novo* at the safety-net clinic site, requiring in-person enrollment and limiting representation of racial/ethnic minorities in the study population. Participating patients were likely early adopters of online access to doctors' notes, as suggested by the high rate of viewing notes. While this limits the ability to generalize, it also suggests that even more patients could have concerns about viewing notes online in a broader population. Although study researchers found associations between baseline perceptions and subsequent online note viewing, researchers cannot say whether the perceptions are the reason patients did or did not access their notes. The study's researchers suspect that many patients allowed informal proxy access (e.g., provided login and password information to family and other caregivers), but did not formally assess the degree to which this was associated with baseline potential concerns.[23,24] Finally, although researchers controlled for multiple potential confounders, residual confounding could influence the results.

More Work Needed to Convince Patients to Access Notes

Patients are gaining unprecedented access to their electronic health records, including doctors' notes that were previously difficult for patients to obtain. Accessing this information can be valuable for doctor-patient communication and for enhancing patient self-management, although patients' preconceptions are associated with subsequent use of this technology. Developing strategies to engage patients who have worries about confusion or privacy, such as using peer educators, improving electronic health records, and refining doctors' documentation, may increase the proportion of patients who take full advantage of benefits offered by viewing doctors' notes.

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Notes

1. OpenNotes. "Who Is Sharing Notes?" 2016. www.opennotes.org/who-is-sharing-notes/.
2. Ross, Stephen E. and Chen-Tan Lin. "The Effects of Promoting Patient Access to Medical Records: A Review." *Journal of the American Medical Informatics Association* 10, no. 2 (March/April 2003): 129-138.
3. Honeyman, Alasdair, Benita Cox, and Brian Fisher. "Potential impacts of patient access to their electronic care records." *Informatics in Primary Care* 13, no. 1 (2005): 55-60. https://pdfs.semanticscholar.org/718f/fdcafb46c9f11ba55e2111ac6b8d63d536b6.pdf.
4. Delbanco, Tom et al. "Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead." *Annals of Internal Medicine* 157, no. 7 (October 2, 2012): 461-

470. http://annals.org/aim/fullarticle/1363511/inviting-patients-read-doctors-notes-quasi-experimental-study-look-ahead.
5. Office of the National Coordinator for Health IT. "Step 5: Achieve Meaningful Use Stage 2: Patient Ability To Electronically View, Download & Transmit (VDT) Health Information." HealthIT.gov. 2014. www.healthit.gov/providers-professionals/achieve-meaningful-use/core-measures-2/patient-ability-electronically-view-download-transmit-vdt-health-information.
6. Walker, Jan et al. "The Road toward Fully Transparent Medical Records." *New England Journal of Medicine* 370, no. 1 (January 2, 2014): 6-8. www.nejm.org/doi/citedby/10.1056/NEJMp1310132#t=article#t=citedby.
7. Centers for Disease Control and Prevention. "National Ambulatory Medical Care Survey: 2012 State and National Summary Tables (Tables 1, 11, 16)." National Center for Health Statistics. 2012. www.cdc.gov/nchs/data/ahcd/namcs_summary/2012_namcs_web_tables.pdf.
8. Mafi, JN et al. "Patients learning to read their doctors' notes: the importance of reminders." *Journal of the American Medical Informatics Association* 23, no. 5 (September 2016): 951-955.
9. Delbanco, Tom et al. "Inviting Patients to Read Their Doctors' Notes: A Quasi-experimental Study and a Look Ahead."
10. Leveille, Suzanne et al. "Evaluating the impact of patients' online access to doctors' visit notes: designing and executing the OpenNotes project." *BMC Medical Informatics Decision Making* 12, no. 32 (April 13, 2012).
11. Ibid.
12. Maly, Rose C. et al. "Perceived Efficacy in Patient-Physician Interactions (PEPPI): Validation of an Instrument in Older Persons." *Journal of the American Geriatrics Society* 46, no. 7 (July 1998): 889-894.
13. Klein, Jared W. et al. "Your Patient is Now Reading Your Note: Opportunities, Problems, and Prospects." *American Journal of Medicine* 129, no. 10 (2016): 1,018-1,021. www.amjmed.com/article/S0002-9343(16)30548-4/pdf.
14. Ibid.
15. Hormes, JM, KR Gerhardstein, and PT Griffin. "Under-reporting of alcohol and substance use versus other psychiatric symptoms in individuals living with HIV." *AIDS Care* 24, no. 4 (2012): 420-423.
16. Khadjesari, Zarnie et al. "Alcohol consumption screening of newly-registered patients in primary care: a cross-sectional analysis." *British Journal of General Practice* 63, no. 615 (2013): e706-e712.
17. Kahn, Michael W. et al. "A Piece of My Mind: Let's Show Patients Their Mental Health Records." *Journal of the American Medical Association* 311, no. 13 (2014): 1,291-1,292.
18. Abelson, Reed and Matthew Goldstein. "Anthem Hacking Points to Security Vulnerability of Health Care Industry." *New York Times*. February 5, 2015. www.nytimes.com/2015/02/06/business/experts-suspect-lax-security-left-anthem-vulnerable-to-hackers.html.
19. Terhune, Chad. "UCLA Health System data breach affects 4.5 million patients." *Los Angeles Times*. July 17, 2015. www.latimes.com/business/la-fi-ucla-medical-data-20150717-story.html.
20. Simon, Steven R. et al. "Patients' Attitudes Toward Electronic Health Information Exchange: Qualitative Study." *Journal of Medical Internet Research* 11, no. 3 (July-September 2009): e30. www.jmir.org/2009/3/e30/.
21. Whiddett, Richard et al. "Patients' attitudes towards sharing their health information." *International Journal of Medical Informatics* 75, no. 7 (July 2006): 530-541.
22. Office of the National Coordinator for Health IT. "Guide to Privacy and Security of Electronic Health Information." April 2015. www.healthit.gov/sites/default/files/pdf/privacy/privacy-and-security-guide.pdf.
23. Jackson, Sara L. et al. "Patients Who Share Transparent Visit Notes With Others: Characteristics, Risks, and Benefits." *Journal of Medical Internet Research* 16, no. 11 (November 2014): e247. www.jmir.org/2014/11/e247.
24. Wolff, Jennifer L. et al. "Inviting patients and care partners to read doctors' notes: OpenNotes and shared access to electronic medical records." *Journal of the American Medical Informatics Association* 24, no. 1 (April 2017): e166-e172.

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