



Published in final edited form as:

BMJ Qual Saf. 2017 April ; 26(4): 262–270. doi:10.1136/bmjqs-2015-004697.

When doctors share visit notes with patients: a study of patient and doctor perceptions of documentation errors, safety opportunities and the patient–doctor relationship

Sigall K Bell¹, Roanne Mejilla¹, Melissa Anselmo¹, Jonathan D Darer², Joann G Elmore³, Suzanne Leveille^{1,4}, Long Ngo¹, James D Ralston⁵, Tom Delbanco¹, Jan Walker¹

¹Division of General Medicine and Primary Care, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, Massachusetts, USA

²Chief Medical Officer at Medicalis, San Francisco, CA

³Division of General Internal Medicine, University of Washington School of Medicine, Seattle, Washington, USA

⁴College of Nursing and Health Sciences, University of Massachusetts Boston, Boston, Massachusetts, USA

⁵Group Health Research Institute, Group Health Cooperative, Seattle, Washington, USA

Abstract

Background—Patient advocates and safety experts encourage adoption of transparent health records, but sceptics worry that shared notes may offend patients, erode trust or promote defensive medicine. As electronic health records disseminate, such disparate views fuel policy debates about risks and benefits of sharing visit notes with patients through portals.

Methods—Presurveys and postsurveys from 99 volunteer doctors at three US sites who participated in OpenNotes and postsurveys from 4592 patients who read at least one note and submitted a survey.

Results—Patients read notes to be better informed and because they were curious; about a third read them to check accuracy. In total, 7% (331) of patients reported contacting their doctor’s office about their note. Of these, 29% perceived an error, and 85% were satisfied with its resolution. Nearly all patients reported feeling better (37%) or the same (62%) about their doctor. Patients who were older (>63), male, non-white, had fair/poor self-reported health or had less formal education were more likely to report feeling better about their doctor. Among doctors, 26% anticipated documentation errors, and 44% thought patients would disagree with notes. After a year, 53% believed patient satisfaction increased, and 51% thought patients trusted them more. None reported ordering more tests or referrals.

Correspondence to Dr Sigall K Bell, Division of General Medicine and Primary Care, Beth Israel Deaconess Medical Center, 330 Brookline Ave, CO-1309 Boston, MA 02215, USA; sbell1@bidmc.harvard.edu.

Additional material is published online only. To view please visit the journal online (<http://dx.doi.org/10.1136/bmjqs-2015-004697>).

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

Conclusions—Despite concerns about errors, offending language or defensive practice, transparent notes overall did not harm the patient–doctor relationship. Rather, doctors and patients perceived relational benefits. Traditionally more vulnerable populations—non-white, those with poorer self-reported health and those with fewer years of formal education—may be particularly likely to feel better about their doctor after reading their notes. Further informing debate about OpenNotes, the findings suggest transparent records may improve patient satisfaction, trust and safety.

INTRODUCTION

Transparent healthcare is developing momentum, as mounting evidence suggests that active patient engagement yields better outcomes and better experiences with care.^{1–3} Personalised health records are gaining traction worldwide, and several countries are working towards offering patients easy access to their records, the ability to exercise preferences and controls, and in some cases a parallel opportunity to track their own thoughts.^{4–8} Patients are increasingly demanding their data,^{9,10} and while safety experts and patient advocates underscore the need for full transparency, critics worry about potential consequent harms, both to patients and clinicians.

OpenNotes, an innovation that invites patients to read their visit notes online, began with just >20 000 patients of 113 primary care physicians (PCPs) at three US health centres.¹¹ After a year of sharing notes, patients reported several health benefits, and doctors reported few workflow effects. The movement has grown, and today more than eight million patients at multiple healthcare organisations nationwide have secure online access to their notes, with interest also growing throughout Europe and other continents.^{6,12} Despite this growth, only a small fraction of Americans and Europeans have such access, and policy discussions related to transparent notes are still marked by controversy. Proponents anticipate increased patient engagement, safety and relational benefits, positing that patients will appreciate the honesty and become better care partners. Sceptics worry that errors in the notes, inaccurate portrayal of the visit or offending comments could damage the patient–doctor relationship. They fear sharing notes with patients will fuel defensive medicine and place doctors at increased risk of being sued.

Coupled with the information revolution of the internet and shifting social norms about patient roles, the patient–doctor relationship is in flux. Doctors and patients alike are navigating new terrain, seeking the right balance in an era of increasing patient engagement. Public awareness of medical errors, cost containment strategies and institutional performance reports bring more wary patients to healthcare encounters.^{13–16} Previously gaining ‘blind trust’ from patients, today’s doctors may need to work harder to earn patients’ trust.¹⁵ Ineffective or distrusting patient–doctor relationships may exacerbate several costly problems with serious consequences including spotty adherence to medical regimens, inconsistent or absent follow-up with doctors or costly litigation.^{17–20}

When doctors invited their patients to read their visit notes online through a secure patient internet portal in the OpenNotes study,¹¹ we wondered whether such transparency would bring patients and doctors closer together, or push them farther apart. Would patient-

perceived errors in notes damage the therapeutic relationship? If patients identify mistakes in their notes, would they speak up or fear they may anger their doctor and receive subsequent retribution?²¹ Would doctors order more tests or referrals? Overall, would the patient–doctor relationship be enhanced or eroded? We hypothesised that despite sceptics’ concerns, inviting patients to read their notes would positively influence their relationship with their doctor.

METHODS

A total of 113 PCPs volunteered to participate, inviting 22 703 of their patients to access visit notes over secure internet portals in three US sites over 2010–2011;¹¹²² the methods have been previously reported.¹¹²² Patients and doctors were surveyed before and after the 12-month intervention. The pre-intervention PCP survey included questions about the perceived likelihood of patients finding errors or disagreeing with what they read in their notes, and the postintervention survey included items pertaining to satisfaction, trust, practice of defensive medicine and liability. We analysed responses from doctors who completed both surveys (n=99). To gain further insight into how reading notes affected the patient–doctor relationship, we surveyed patients about why they read notes, whether they thought they were accurate, whether they contacted the doctor’s office about their note, and how they felt about their doctor as a result of reading their note. We restricted the patient sample to those who reported on the postintervention survey that they read at least one note during the intervention, and this was verified using portal tracking data. The surveys included both questions with Likert scale responses and open-ended, free text questions with opportunity for commentary. The full surveys are available on request.

We analysed data stratified by site and using descriptive statistics. A multivariable generalised linear model using a log link function and binary error was used to determine predictors of the likelihood that patients felt better about their doctor as a result of reading their notes. Patients who responded ‘do not feel better or worse’ and ‘feel somewhat worse or worse’ served as the reference. The length of the patient–doctor relationship was derived from the patient’s first visit with his or her provider, as recorded in the electronic medical record up to the start of the intervention. The effect of length of relationship was studied at two sites, but not at the third, due to lack of data at that site permitting inference about the length of the patient-provider relationship. Variables included in the model were patient sociodemographic characteristics and postintervention survey items, such as patient-reported ease of readability and accuracy of notes. Age was examined in quartiles, length of patient-provider relationship was examined in quintiles and the analyses of patient surveys were adjusted for both the provider and site. We performed all data analysis using SAS software V.9.3 (SAS Institute, Cary, North Carolina, USA) (SAS/STAT User’s Guide. 2000. Version 8). The project and surveys were approved by the institutional review board at each site.

RESULTS

Of the 113 doctors initially participating in OpenNotes, 105 (93%) completed the intervention.¹¹ Of these, 99 (94%) completed both presurveys and postsurveys. In total, 13 564 patients had at least one visit note available during the study period, and 11 797 (87%)

viewed at least one note based on patient portal tracking data. Of 11 797 patients who viewed at least one note, 5391 (46%) submitted postintervention surveys. In total, 4592/5391 (85%) of these patients self-reported reading a note, and this comprised our study sample. Patient characteristics are shown in table 1.

Reasons for reading notes and contacting the doctor's office

When asked why they chose to read notes, patients responded (multiple categories permitted): 'To know about my health' (58%), 'To be sure I understood what the doctor said' (55%), and because 'I was curious' (48%) and 29% reported 'to check that the notes were right' (table 2).

Across the three sites, 97% of patients found it 'somewhat easy' or 'very easy' to understand their notes. In addition, 95% of patients reported that the note always or usually accurately described the visit (table 2). When we examined these responses by study site, gender, race, self-reported health status and educational level, there were no significant differences in proportions of patients who thought the note accurately described the visit, or who reported it was easy to understand the note (data not shown).

In total, 7% (331) patients reported contacting their doctor's office about a question related to their notes (see online supplementary appendix 1). The most common reasons patients reported for contacting their doctor's office, selected from a list of prompts with multiple responses permitted, were: 'Wanted an explanation of something in my notes' (54%) and 'Wanted to report something I thought was an error in my notes' (29%). In addition, 28% reported 'Another' reason, most commonly described in free text as following explicit instructions in the note to follow-up with the doctor, confirming information, scheduling an appointment or referral discussed in the note, adding new information, clarifying or updating a medication, asking about a concerning laboratory result and expressing appreciation. Five per cent selected 'Wanted something removed from my permanent record' as the reason for contacting the doctor's office. Overall, 85% of patients were satisfied with the resolution after contacting their doctor's office.

An additional 129 patients (3%) considered contacting the doctor's office, but did not, citing the following reasons: 'Did not think it was important' (37%), 'Did not want to waste the doctor's time' (30%) or another reason (38%), predominantly described in free text as planning to raise the issue at the next visit. In total, 18% decided not to contact the office fearing doctor anger or retribution ('Did not want my doctor to be angry with me', 'Worried my doctor may not take as good care of me' and 'Worried my doctor may get back at me'.)

Effects of reading notes on how patients felt about the doctor

Of all patients, 37% felt somewhat or much better about their doctor after reading their notes; the majority of patients (62%) did not feel better or worse. In each of the sites, 1% of patients felt somewhat or much worse about their doctor. Multivariable modelling revealed that patients who were older, male, non-white, had fewer years of formal education or had fair or poor self-reported health were more likely to report feeling better about their doctor after reading their visit notes (table 3). Among these groups, 42%–44% of patients in each category reported feeling better about the doctor after reading notes. Patients who thought

notes ‘always’ or ‘usually’ accurately described the visit were more likely to feel better about the doctor than those who reported notes ‘sometimes or never’ accurately described the visit, although the majority of patients (95%) were in the former group (tables 2 and 3). However, there were no significant differences in likelihood of feeling better about the doctor between patients who reported that notes were somewhat or very easy to understand compared with patients who thought the notes were somewhat or very difficult to understand.

Patients who had 5 notes available were also significantly more likely to report feeling better about their doctor than patients with only one note, and we observed a general trend suggesting that patients felt better about their doctors with increasing numbers of notes (table 3). In the two sites with length of relationship data, the mean length of patient–doctor relationship was 5.8 years (SD 3.0) (site 1 mean=5.7 years (SD 2.6); site 2 mean=5.8 years (SD 3.4)). Patients with the shortest relationships with their doctor (<3.0 years) were more likely to report feeling better about their doctor after reading visit notes, compared with patients who had the longest relationships with their PCPs (>8.7 years). Although a full qualitative analysis was beyond the scope of this paper, of >3000 open-ended survey responses reviewed, the vast majority were positive and echoed many of these findings (table 4).

Doctors’ perceptions of satisfaction, trust, errors, defensive medicine and risk of liability

Characteristics of doctors participating in the OpenNotes study have been previously reported.¹¹ Before open notes were introduced, 26% of PCPs thought patients would find significant errors in their notes, and 44% predicted patients would disagree with what they write in the notes (table 5). The primary concern of participating doctors was the potential negative effect on workflow.¹¹

After a year of experience with open notes, 51% of PCPs reported that their patients who read their visit notes trusted them more as their doctor (an additional 36% reported ‘don’t know’). About half of doctors (53%) felt that patient satisfaction had improved, and no doctors at any site reported ordering more tests and/or referrals. Most doctors reported that their risk for lawsuits remained the same (26%) or that they do not know (67%); 2% thought their risk for lawsuits increased and 5% thought it decreased (table 5).

DISCUSSION

As electronic health record transparency and patient portals gain momentum worldwide, how much data to share on such portals is a topic of ongoing debate. Our study highlights several key findings that may help inform such discussions. First, despite sceptics’ concerns that the patient–doctor relationship may be harmed as a result of reading poorly written, confusing, offensive, erroneous or even untruthful notes, open notes did not make patients feel worse about their doctors. Instead, more than a third of patients who read at least one note reported feeling better about their doctor; especially older, non-Caucasian patients and those with lower self-reported health or formal education. Second, few patients reported contacting their doctor’s office after reading notes. Of those who did, about a quarter identified a possible error, underscoring a potential role for OpenNotes in patient safety.

Finally, over half of doctors felt patient satisfaction and trust increased, and no doctors reported ordering additional tests or referrals as a result of open notes. Taken together, our findings suggest that open notes may have overall positive effects on the patient–doctor relationship, enhancing patient engagement and patient safety efforts.

Potential effects of an enhanced patient–doctor relationship on patient engagement

While one might anticipate that highly educated, technology-savvy patients would be those most likely to benefit from open notes, our findings suggest that older patients and traditionally more vulnerable populations—non-white patients, those with poorer self-reported health and those with fewer years of formal education—may be particularly likely to ‘feel better about their doctor’ after reading their notes. The literature suggests that black patients may have more distrust of the healthcare system,^{23–25} and that the source of distrust may be more rooted in concern about non-concordance of healthcare providers’ values with their own, rather than scepticism about their competence per se.²⁶ Patients of other cultural backgrounds may hold similar concerns. Sharing notes may help align patient and provider views, a factor known to influence patients’ perceptions of their doctor positively.²⁷ In our study, 44% of non-white patients (as well as 44% of patients with poorest self-reported health and lowest educational attainment) reported feeling better about the doctor after reading notes. These findings, underscoring benefits for traditionally more underserved populations complement our previous results where older patients, self-described African–American patients and those with lowest education and self-reported health status were as likely or more likely than patients in less vulnerable populations to anticipate benefits from reading their notes, including better remembering the plan of care, feeling more in control and taking medications better as prescribed.²⁸

In as much as shared notes helps patients to see what their doctors are thinking (nearly half of patients reported this as a reason for reading their notes), and may motivate doctors to write mindfully about their patients’ preferences and beliefs, opening notes to patients may provide a relatively simple but effective strategy for building patient engagement. Sharing visit notes with patients may send a powerful message of open communication and inclusivity. Sensitivity to literacy, access to translators and other considerations may help scale this potential benefit to broader populations.

The positive relational effect of sharing notes was also greater in patients newer to their doctors, compared with those with the longest relationships, raising the possibility that sharing notes may help patients gain more rapid confidence and trust in their doctors. The potential opportunity to strengthen the therapeutic alliance in a way that moves young patient–doctor relationships toward the kind of alliance that is traditionally cultivated over years offers promise for efforts to promote patient engagement. If the trends in our data—suggesting that the more notes patients have available to read, the more likely they are to feel better about their doctors—hold true, sharing notes may quickly have implications for satisfaction metrics, such as Consumer Assessment of Healthcare Providers and Systems scores.

Of all the predictors of a positive patient–doctor relationship, time spent with the patient is a commonly reported factor. In one study, each additional minute spent was correlated with

increased patient trust.²⁹ In another, primary care doctors who spent an average of 3 min longer than their peers were less likely to get sued.³⁰ Our experience to date raises the intriguing possibility that shared visit notes may help to ‘extend the visit’, as patients return to the notes and revisit what the doctor said, long after the appointment is over. As one doctor suggested in an interview following the study, ‘Perhaps we overestimate the importance of the patient’s visit alone... a vast majority of people’s time is spent not in the office visit. This is a powerful tool. There is something about seeing something in writing that I think may be very powerful to amplify or to reinforce a plan or a priority’. Patients may agree, as one patient attested when commenting about open notes: ‘At the end of the day with all due respect to all the care providers... most of my care as a diabetic is delivered in my bathroom, my bedroom and my kitchen, so ultimately whether or not I am a good diabetic or a bad diabetic is ... determined by the decisions that I make. I do a lot of denial, so things like OpenNotes and being able to print out a copy... I can give things to my wife so she can be on my case when [my doctor] isn’t there’. In practical terms, the note is a tangible part of the visit that patients can return to for reminders or instructions after leaving the doctor’s office. Metaphorically, OpenNotes may allow the doctor to have a presence in the day-to-day experience of illness or wellness, a journey travelled largely outside the clinic walls.

Potential effects of an enhanced patient–doctor relationship on patient safety

Although relatively few patients—7% overall—reported contacting the doctor’s office about their note, about a quarter that did so reported a perceived error, highlighting the opportunity for open notes to improve patient safety. Such findings are consistent with prior studies demonstrating that patients are eager and capable to provide accurate feedback about their healthcare information.³¹ That up to a third of patients reported reading notes to check accuracy suggests that a moderate proportion of patients may be readily engaged in safety efforts.

Several leading organisations have advanced programmes enhancing safety partnerships with patients, and the National Patient Safety Foundation Lucian Leape Institute has endorsed OpenNotes in its Patient Engagement in Safety and Transparency Roundtable reports, with a call to action for all healthcare leaders to provide patients access to their notes.^{32,33} Similarly, a recent Institute of Medicine report highlights shared notes as a patient engagement strategy for improving diagnostic accuracy.³⁴ Open notes may help connect patients and providers between visits, where ambulatory vulnerabilities such as missed tests, referrals and delayed diagnoses can compound.³⁵ In addition to helping patients remember next steps, they may activate patients and families to report documentation errors including medication errors, or share care concerns that may otherwise go undetected.^{36–41}

The Obama Administration has also supported this strategy and further advocates a patient reporting tool as a national goal.⁴² With about a quarter of doctors in our study anticipating that patients might identify errors in their documentation, open notes may offer a natural vehicle for patient-sourced error reporting, enabling patients to provide updates, feedback or new information affecting the diagnostic process. In these ways, open notes can create a

‘learning EHR’, building a closed loop system for diagnosis and treatment that includes feedback from patients.

Compared with clinician-driven reporting systems, patient reporting tools are in their infancy. Even where patient reporting tools have been effectively launched, a primary challenge has been getting patients to use them. Open notes may serve as a powerful hook. Patients are already on the portal and can refer readily to notes to describe perceived inaccuracies. But engaging patients in safety will require a concerted effort to help patients speak up.^{43–45} Although absolute numbers were too small to draw conclusions, it is intriguing that almost one in five patients who considered contacting their doctor but did not do so expressed fears about angering the doctor or retribution. Patient and clinician education to enable patients to speak up—and to ensure that they are heard and responded to—will dictate how effective we will ultimately be in engaging patients as safety partners.

While the Health Insurance Portability and Accountability Act already gives patients legal access to their medical records, doctors may naturally harbour concerns that easy access to notes may translate into patients taking them to their lawyers. Although we were not able to measure actual claims or lawsuits in the period of study, few doctors in this study perceived increased liability, although the majority stated they did not know. In addition, while 44% thought patients would disagree with notes, not a single doctor reported practising defensive medicine as a result of open notes, and about half of doctors believed the intervention increased patient satisfaction.

In studies examining physician characteristics related to liability, in contrast to doctors who have been sued, doctors with a ‘no claims’ status are more likely to educate patients, solicit patients’ opinions, check understanding and encourage patient input³⁰—all behaviours supported by open notes. And even though most doctors did not know whether patients were reading notes (as it was rarely discussed at or between visits), we were surprised that over half of doctors thought sharing notes increased patient trust, an important factor in influencing claims. Because patients had largely positive experiences with their notes, doctors’ perceptions of patient satisfaction and trust may be even higher than reported here (eg, if they had discussed notes with their patients). As doctors learn to write their notes with the awareness that their patients may read them, note writing may be leveraged to encourage patient trust.⁴⁶ Indeed, we anticipate that over time notes may become an important component of the treatment.⁴⁷

With transparency and trust as the cornerstone, inviting patients to read their notes may ultimately prove a liability strategy, in addition to enhancing safety and quality of care. Some malpractice insurers already forecast decreased claims with shared notes.⁴⁸ Doctors may find that communicating and sharing information openly mitigates any sense of ‘hidden information’ and makes adversarial stances or litigation less likely, as seen in other transparency initiatives such as medical error disclosure.^{49–51} Actual liability data over the long-term will be needed to assess how open notes affect claims.

Study limitations include voluntary participation by doctors in the intervention and a limited response rate from patients, although the response rates were similar to other web-based

surveys. Moreover, because participation stemmed from only three US regions, and patient respondents were predominantly white and female, our results cannot be generalisable to all patients and patient care settings. Although one study site was a safety net hospital, the total number of participants from that site was small compared with the other sites, limiting the representation of non-Caucasian patients and biasing toward an educated population in our study sample. Our findings merit further study with larger, more diverse populations. Finally, portal data were limited to whether patients clicked to view a note at least once; we were not able to reliably track how many notes were read by each patient at all the sites. Future studies correlating outcomes based on number of notes read are needed.

In summary, shared visit notes had overall positive effects on the patient–doctor relationship and physician perceptions of patient trust and satisfaction. More than a third of patients overall, and 44% of some traditionally underserved populations, reported feeling better about the doctor after reading notes, and 1% of all patients reported feeling worse. Although doctors anticipated that patients would find significant errors, and that patients might disagree with what they wrote, no doctor reported ordering extra tests or studies. Of patients who contacted their doctor’s office to discuss their notes, a substantial proportion did so because of a perceived error in the note, highlighting a potential role for open notes in improving safety. The extent to which open notes may serve as a safety tool and mechanism for partnering with patients for safety may depend on the ability to encourage patients to speak up, and on developing systems to respond meaningfully to their concerns.

Portions of this article were presented at the 2013 International Conference for Communication in Healthcare, September 29–October 2; Montreal, Quebec.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Funding

The Robert Wood Johnson Foundation’s Pioneer Portfolio (grant 65921 to JW, SB and TD), the Drane Family Fund, the Richard and Florence Koplow Charitable Foundation (TD) and the National Cancer Institute (grant K05 CA 104699 to JGE).

REFERENCES

1. Greene J, Hibbard JH, Sacks R, et al. When patient activation levels change, health outcomes and costs change, too. *Health Aff* 2015;34:431–7.
2. Greene J, Hibbard JH, Sacks R, et al. When seeing the same physician, highly activated patients have better care experiences than less activated patients. *Health Aff* 2013;32:1299–305.
3. Hibbard JH, Greene J, Shi Y, et al. Taking the long view: how well do patient activation scores predict outcomes four years later? *Med Care Res Rev* 2015;72:324–37. [PubMed: 25716663]
4. NHS England. Health and social care leaders set out plans to transform people’s health and improve services using technology. 13 11 2014 <http://www.england.nhs.uk/2014/11/13/leaders-transform/> (accessed 30 Jul 2015).
5. Australian Government Office of the Australian Information Commissioner. E-Health records. <http://www.oaic.gov.au/privacy/privacy-act/e-health-records> (accessed 30 Jul 2015).

6. European Commission EHealth Stakeholder Group. Report of the eHealth Stakeholder Group: Patient access to electronic health records. 6 2013 http://ec.europa.eu/newsroom/dae/document.cfm?doc_id=5169 (accessed 12 May 2016).
7. Pagliari C, Detmer D, Singleton P. Potential of electronic personal health records. *BMJ* 2007;335:330–3. [PubMed: 17703042]
8. Delbanco T, Walker J, Darer JD, et al. Open notes: doctors and patients signing on. *Ann Intern Med* 2010;153:121–5. [PubMed: 20643992]
9. Lohr S The healing power of your own medical records. *The New York Times*. 31 3 2015 http://www.nytimes.com/2015/04/01/technology/the-healing-power-of-your-own-medical-data.html?_r=0 (accessed 10 Jul 2015).
10. e-Patient Dave. Imagine someone had been managing your data, and then you looked. *e-patients.net* 1 4 2009 <http://e-patients.net/archives/2009/04/imagine-if-someone-had-been-managing-your-data-and-then-you-looked.html> (accessed 9 Jul 2015).
11. Delbanco T, Walker J, Bell SK, et al. Inviting patients to read their doctors' notes: a quasi-experimental study and a look ahead. *Ann Intern Med* 2012;157:461–70. [PubMed: 23027317]
12. Walker J, Meltsner M, Delbanco T. US experience with doctors and patients sharing clinical notes. *BMJ* 2015;350:g7785. [PubMed: 25670182]
13. Calnan MW, Sanford E. Public trust in health care: the system or the doctor? *Qual Saf Health Care* 2004;13:92–7. [PubMed: 15069214]
14. Jacobs AK. Rebuilding an enduring trust in medicine: a global mandate. Presidential Address American Heart Association Scientific Sessions 2004. *Circulation* 2005;111:3494–8. [PubMed: 15983264]
15. Rowe R, Calnan M. Trust relations in health care—the new agenda. *Eur J Public Health* 2006;16:4–6. [PubMed: 16446297]
16. Entwistle VA, Quick O. Trust in the context of patient safety problems. *J Health Organ Manag* 2006;20:397–416. [PubMed: 17087402]
17. Clinton HR, Obama B. Making patient safety the centerpiece of medical liability reform. *N Engl J Med* 2006;354:2205–8. [PubMed: 16723612]
18. Hickson GB, Clayton EW, Githens PB, et al. Factors that prompted families to file medical malpractice claims following perinatal injuries. *JAMA* 1992;267:1359–63. [PubMed: 1740858]
19. Rolfé A, Cash-Gibson L, Car J, et al. Interventions for improving patients' trust in doctors and groups of doctors. *Cochrane Database Syst Rev* 2014;3:CD004134.
20. Vincent C, Young M, Phillips A. Why do people sue doctors? A study of patients and relatives taking legal action. *Lancet* 1994;343:1609–13. [PubMed: 7911925]
21. Delbanco T, Bell SK. Guilty, afraid, and alone—struggling with medical error. *N Engl J Med* 2007;357:1682–3. [PubMed: 17960011]
22. Leveille SG, Walker J, Ralston JD, et al. Evaluating the impact of patients' online access to doctors' visit notes: designing and executing the OpenNotes project. *BMC Med Inform Decis Mak* 2012;12:32. [PubMed: 22500560]
23. LaVeist TA, Nickerson KJ, Bowie JV. Attitudes about racism, medical mistrust, and satisfaction with care among African American and white cardiac patients. *Med Care Res Rev* 2000;51:146–61.
24. Gordon HS, Pugach O, Berbaum ML, et al. Examining patients' trust in physicians and the VA healthcare system in a prospective cohort followed for six-months after an exacerbation of heart failure. *Patient Educ Couns* 2014;97:173–9. [PubMed: 25088616]
25. Armstrong K, Putt M, Halbert CH, et al. Prior experiences of racial discrimination and racial differences in health care system distrust. *Med Care* 2013;51:144–50. [PubMed: 23222499]
26. Armstrong K, McMurphy S, Dean LT, et al. Differences in the patterns of health care system distrust between blacks and whites. *J Gen Intern Med* 2008;23:827–33. [PubMed: 18299939]
27. Krupat E, Bell RA, Kravitz RL, et al. When physicians and patients think alike: patient-centered beliefs and their impact on satisfaction and trust. *J Fam Pract* 2001;50:1057–62. [PubMed: 11742607]

28. Walker J, Leveille SG, Ngo L, et al. Inviting patients to read their doctors' notes: patients and doctors look ahead: patient and physician surveys. *Ann Intern Med* 2011;155:811–19. [PubMed: 22184688]
29. Fiscella K, Meldrum S, Franks P, et al. Patient trust: is it related to patient-centered behavior of primary care physicians? *Med Care* 2004;42:1049–55. [PubMed: 15586831]
30. Levinson W, Roter DL, Mullooly JP, et al. Physician-patient communication: the relationship with malpractice claims among primary care physicians and surgeons. *JAMA* 1997;277:553–9. [PubMed: 9032162]
31. Dullabh P, Sondheimer N, Katsh E, et al. Demonstrating the effectiveness of patient feedback in improving the accuracy of medical records Presented to ONC; 6 2014 Washington DC http://www.healthit.gov/sites/default/files/20120831_odrfinalreport508.pdf (accessed 30 Jul 2015).
32. National Patient Safety Foundation. Safety is Personal: Partnering with Patients and Families for the Safest Care. National Patient Safety Foundation's Lucian Leape Institute, 2014 <http://www.npsf.org/?page=safetyispersonal> (accessed 9 Jul 2015).
33. National Patient Safety Foundation. Shining a Light: Safer Health Care Through Transparency. National Patient Safety Foundation's Lucian Leape Institute, 2015 <http://www.npsf.org/shiningalight> (accessed 9 Jul 2015).
34. Institute of Medicine. Improving diagnosis in health care. National Academy Press <http://www.nationalacademies.org/hmd/Reports/2015/Improving-Diagnosis-in-Healthcare.aspx> (accessed 20 Nov 2015).
35. Bell SK, Folcarelli PH, Anselmo MK, et al. Connecting patients and clinicians: the anticipated effects of open notes on patient safety and quality of care. *Jt Comm J Qual Patient Safety* 2015;41:378–84.
36. Bell SK, Mejilla R, Barry M, et al. Partnering with patients for safety: the OpenNotes patient reporting tool Poster presentation at the Annual Meeting of the Society for General Internal Medicine; Toronto; 4 2015.
37. Khullar D Let patients read their medical records. *The New York Times*. 31 3 2016 <http://well.blogs.nytimes.com/2016/03/31/let-patients-read-their-medical-records/Article> (accessed 3 Apr 2016).
38. Dullabh P, Sondheimer N, Katsh E, et al. How patients can improve the accuracy of their medical records. *eGEMs* 2014;2:10.
39. Weissman JS, Schneider EC, Weingart SN, et al. Comparing patient-reported hospital adverse events with medical record review: do patients know something that hospitals do not? *Ann Intern Med* 2008;149:100–8. [PubMed: 18626049]
40. Etchegaray JM, Ottosen MJ, Burrell L, et al. Structuring patient and family involvement in medical error event disclosure and analysis. *Health Aff (Millwood)* 2014;33:46–52. [PubMed: 24395934]
41. Kahn A, Furtak SL, Melvin P, et al. Parent-reported errors and adverse events in hospitalized children. *JAMA Pediatr* 2016;170:e154608. [PubMed: 26928413]
42. Pear R New system for patients to report medical mistakes. *The New York Times*. 22 9 2012 http://www.nytimes.com/2012/09/23/health/new-system-for-patients-to-report-medical-mistakes.html?_r=0 (accessed 10 Jul 2015).
43. Mazor KM, Smith KM, Fisher KA, et al. Speak up! Addressing the paradox plaguing patient-centered care. *Ann Intern Med* 2016;164:618–9. [PubMed: 26857030]
44. The Joint Commission. Speak Up Initiatives. 2008 <http://www.jointcommission.org/speakup.aspx> (accessed 10 Jul 2015).
45. Ginsburg L 'Speaking up' climate: a new domain of culture to measure and explore. *BMJ Qual Saf* 2015;24:661–3.
46. Esch T, Mejilla R, Anselmo M, et al. Engaging patients through OpenNotes: an evaluation using mixed methods. *BMJ Open* 2016;6:e010034.
47. Kahn MW, Bell SK, Walker J, et al. Let's show patients their mental health records. *JAMA* 2014;311:1291–2. [PubMed: 24691603]
48. Kataf M Transparency in doctors' notes helps prevent medical malpractice says malpractice insurance broker. PR Log Press Release Distribution. 6 2 2012 <https://www.prlog.org/11791823->

[transparency-in-doctors-notes-helps-prevent-medical-malpractice-says-malpractice-insurance-broker.html](#) (accessed 12 May 2016).

49. Kachalia A, Mello MM. New directions in medical liability reform. *New Engl J Med* 2011;364:1564–72. [PubMed: 21506746]
50. Mello MM, Gallagher TH. Malpractice reform—opportunities for leadership by health care institutions and liability insurers. *N Engl J Med* 2010;362:1353–6. [PubMed: 20357276]
51. McDonald TB, Helmchen LA, Smith KM, et al. Responding to patient safety incidents: the “seven pillars”. *Qual Saf Health Care* 2010;19:e11.

Table 1

Characteristics of patients who read at least one note (N=4592)

Characteristics	Site 1 N=2451 (%)	Site 2 N=2064 (%)	Site 3 N=77 (%)	ALL N=4592 (%)
Age (years) ^{*†}				
<47	20	27	15	23
47–55	26	25	28	25
56–63	28	22	34	25
>63	26	26	22	26
Sex				
Male	37	41	87	40
Female	63	59	13	60
Race				
White	87	68	78	78
Black/African–American	3	<1	9	2
Other	8	2	10	5
Not specified	2	30	3	15
Education				
HS/GED	5	24	13	14
Some college	19	21	43	20
College/postgraduate	76	25	44	52
Not specified	0	30	0	13
Self-rated health				
Excellent/very good	42	26	45	35
Good	26	32	31	29
Poor/fair	8	11	22	10
Not specified	23	30	1	26
Length of patient–doctor relationship (years) [‡]				
<3.0	15	26	–	21
3.0–4.8	20	18	–	19
4.9–6.5	30	11	–	19
6.6–8.7	13	23	–	19
>8.7	22	22	–	22

The ‘ALL’ column represents average results, accounting for the proportion of respondents at each site.

* Site 1 mean=54 years (SD 12); site 2 mean=55 years (SD 13); site 3 mean=52 years (SD 10).

† Age ranges were defined by quartiles.

‡ Data not available for site 3; mean length of patient–doctor relationship across the two sites was 5.8 (SD 3.0) (site 1 mean=5.7 years (SD 2.6); site 2 mean=5.8 years (SD 3.4)).

Note: Demographic survey questions were optional, missing data indicates non-response from patient respondents.

GED, graduate equivalency diploma; HS, high school.

Table 2

Patient experiences with reading their visit notes (N=4592)

Postsurvey question/statement	Site 1 N=2451 (%)	Site 2 N=2064 (%)	Site 3 N=77 (%)	ALL N=4592 (%)
Reason selected for reading visit notes*				
To know about my health	58	57	71	58
To be sure I understood what the doctor said	55	56	57	55
I was curious	54	41	61	48
To know what my doctor was thinking	49	41	45	45
I have a right to see my record	41	39	53	41
To remember visit	41	35	42	38
To check that the notes were right	32	25	32	29
No particular reason	2	3	1	2
How often did notes accurately describe the visit?				
Always	72	68	66	70
Usually	23	26	30	25
Sometimes	2	3	4	3
Never	<1	<1	0	<1
Do not know	2	2	0	2
How easy was it to understand your notes?				
Very easy	75	73	58	74
Somewhat easy	21	24	32	23
Somewhat difficult	3	2	8	2
Very difficult	<1	<1	1	<1
Do not know	<1	<1	0	<1
Did reading the note change the way you feel about your doctor?				
Much better	17	23	30	20
Somewhat better	17	16	19	17
Do not feel better or worse	65	60	49	62
Somewhat worse	1	<1	1	<1
Much worse	<1	<1	0	<1
Did you ever contact your doctor's office about something in your notes?				

Postsurvey question/statement	Site 1 N=2451 (%)	Site 2 N=2064 (%)	Site 3 N=77 (%)	ALL N=4592 (%)
Yes	8	6	12	7
No	88	90	84	89
Considered but did not	3	2	3	3
Do not know/do not remember	1	2	1	1

The 'ALL' column represents average results, accounting for the proportion of respondents at each site.

* Respondents were permitted to select multiple reasons for reading their visit notes.

Table 3

Patient characteristics associated with report of ‘feeling better’ about their doctor as a result of reading their notes (N=3298) *

Characteristic	% Felt much better/somewhat better	Adjusted RR	95% CI
Age (years) [†]			
<47	32	1	
47–55	35	0.96	0.85 to 1.08
56–63	37	1.07	0.94 to 1.21
>63	42	1.15	1.01 to 1.31
Sex			
Male	42	1.31	1.19 to 1.45
Female	32	1	
Race			
Non-white	44	1.25	1.07 to 1.46
White	35	1	
Education			
HS/GED	44	1.39	1.21 to 1.60
Some college	41	1.33	1.19 to 1.50
College/postgraduate	31	1	
Self-reported health			
Fair/poor	44	1.14	1.00 to 1.30
Good	36	1.01	0.93 to 1.11
Very good/excellent	32	1	
Site			
Site 2	38	1.08	0.99 to 1.19
Site 3	54	1.12	0.089 to 1.40
Site 1	34	1	
Total notes available			
1	31	1	
2	34	1.03	0.90 to 1.18
3	35	1.04	0.87 to 1.25
4	39	1.17	0.96 to 1.43
5	43	1.31	1.15 to 1.50
Notes accurately describe the visit [‡]			
Always/usually	36	1.86	1.21 to 2.85
Sometimes/never	20	1	
Ease of understanding notes [‡]			
Very/somewhat easy	36	1.16	0.94 to 1.42
Very/somewhat difficult	32	1	

* Multivariable logistic regression model including all the predictors shown in the table, controlled for providers and site.

[†] Age ranges were defined by quartiles.

[‡]Derived from postintervention patient survey questions: 'How often did notes accurately describe the visit?' and 'How easy was it to understand your notes?'.

Note: Model excluding patients with missing demographic data.

RR, risk ratio.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 4

Sample patient responses to open-ended survey questions, ‘Did something (good or bad) happened as a result of reading notes?’ (Please describe your experience) and ‘Please briefly tell us about how you used your notes’

Topic	Illustrative patient quote
Trust	‘I saw that my doctor truly listens to what I have to say. I respect, trust and appreciate her even more’
Confidence	‘[Reading the note] gave me insight into the evaluation process my Doctor used and gave me confidence in his abilities’
Collaboration	‘I use my doctor’s notes as a reminder of what she and I agreed that I should do to improve my health. I also see how much my doctor really makes an effort to listen to and address my concerns’
Understanding	‘Reading the notes made it easier for me to understand what the doctor has said and what I need to do...’
Engagement	‘I look at the notes like a report card or a performance review. I can see what I am doing right and what needs improvement’
Confirmation	‘I wanted to check to make sure I left with the correct impression...sometimes so much is happening or you are anxious and you can’t hear it all clearly’
Remember	‘I am more relaxed during the appointments in that I don’t have to remember every detail’
Errors/safety partnership	‘[I] just wanted to confirm accuracy. My husband’s note says he has a 40-year [history of] back pain, but it was actually only a 4-year [history of] back pain. When providers copy and paste, the errors just keep propagating and never get corrected unless we see our notes’

Table 5

PCP perceptions on providing access to visit notes to patients

	Site 1 N=39 (%)	Site 2 N=22 (%)	Site 3 N=38 (%)	ALL N=99 (%)
<i>Preintervention survey question</i>				
Patients will find significant errors in the notes*				
% Agree	3	0	3	2
% Somewhat agree	18	27	29	24
% Somewhat disagree	46	41	50	46
% Disagree	33	32	18	27
Patients will disagree with what I write				
% Agree	5	9	5	6
% Somewhat agree	41	36	37	38
% Somewhat disagree	33	23	37	32
% Disagree	20	32	21	23
<i>Postintervention survey question</i>				
Patients who read their visit notes trust me more as their doctor*				
% Agree	4	27	18	15
% Somewhat agree	37	40	32	36
% Somewhat disagree	17	0	0	6
% Disagree	4	13	5	6
% Do not know	37	20	45	36
Patient satisfaction improved				
% Yes	46	59	58	53
I ordered more tests and/or referrals				
% Yes	0	0	0	0
Based on my experience, making visit notes available to patients online changed my risk for lawsuits				
% Risk decrease	8	9	0	5
% Risk no change	20	45	21	26
% Risk increase	3	0	3	2
% Do not know	69	45	76	67

The 'ALL' column represents average results, accounting for the proportion of respondents at each site.

* Providers unable to provide an estimate of the percentage of their patients who read open visit notes were not asked this question (N=61).

PCP, primary care physician.