

Empowering patients and reducing inequities: is there potential in sharing clinical notes?

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Patients who read their clinical notes via online patient portals ('open notes') report that doing so engages them actively in their care, improves their sense of control over their health and enhances safety.¹⁻³ In several surveys, patients who are older, less educated, non-white or whose first language is not English report even greater benefits than do their counterparts.²⁻⁴ However, for many reasons, persons from these demographic groups are less likely to use health portals than other patient populations.⁵ Drawing on promising preliminary evidence,^{2-4 6} we suggest that open notes may, over time, prove important in the care of patients who are at risk of experiencing healthcare disparities.

OPENING NOTES VIA ELECTRONIC PATIENT PORTALS

Consumers seek convenience, speed and security for their online data. In more than 10 countries worldwide—including Denmark, France, USA and Sweden—growing numbers of patients can now readily retrieve their clinical notes via portals.⁷ Studies suggest that the practice of sharing notes does not produce major disruptions to clinical workflow,¹ and that clinicians with longer-term experience with the practice are more positive about it.⁸ For patients, evidence suggests strongly that the benefits of open notes outweigh the risks. In a recent large US survey conducted across three health systems with over 22 000 respondents, most reported that reading their notes was very important for taking care of their health (73%, 16 354/22 520), feeling more in control of their healthcare (70%, 15 726/22 515) and remembering their treatment plan (66%, 14 821/22 516).² Surveys in Sweden indicate similarly that

many patients feel more empowered and involved in their care as a result of reading their clinical notes.⁹

OPPORTUNITY TO IMPROVE HEALTH EQUITY

Disparities in health outcomes reflect multiple, often interrelated factors. They include environmental, economic, and social determinants, along with issues relating to accessibility and variable quality of the healthcare delivered. When it comes to eHealth innovations, lack of broadband access can be a barrier¹⁰; in the USA, the likelihood of receiving an access code to activate health portals is significantly lower for minorities, the uninsured, non-English speakers and older patients.¹¹ This additional barrier most likely reflects a combination of factors including structural biases in health care system processes, provider biases, differential patient literacy or computer access, broadband access and privacy concerns. Understandably, many have raised concerns about how the digital divide may increase inequalities.^{5 11} Despite the challenges associated with active portal uptake, we hypothesise that the practice of open notes might help address some barriers to care.

Clinician biases and stereotype threat

Implicit associations (unconscious, uncontrollable and automatic processes) of positive and negative attributes with particular social groups can influence clinicians' judgements, leading to harmful stereotyping biases.¹² Research suggests that negative implicit biases can affect the quality of health interactions and are associated with fewer signals of support and empathy towards patients representing some disadvantaged



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demographic groups, including racial and ethnic minorities, low-income, less educated and older patients.¹² A distinct but related cause of communication breakdowns in visits might also be due to stereotype threat, a situational phenomenon that arises when individuals fear explicit and/or implicit stereotyping by others.¹³ Stereotype threat is characterised by a suite of physiological and psychological responses including anxiety, negative cognition and emotions, reduced working memory capacity, diminished effort and compromised performance on tasks. In face-to-face clinical encounters, it is hypothesised that stereotype threat may elevate patient anxiety, reduce participatory behaviour, and lead to delays or failures to follow-up on healthcare.¹³

Open notes might be viewed as extending the visit, potentially thereby elongating and strengthening patient–physician interactions before and after the pressures of the clinical encounter.^{1 3 4} It is reasonable to postulate that this perceived elongation of the visit through online access to notes may reduce anxiety, negative emotions and poor recall associated with stereotype threat.¹⁴ Indeed, a number of studies suggest that open notes may enhance relational aspects of care, especially among vulnerable populations.^{2–4} After a 12-month study, half of physicians surveyed (54%, 53/99) believed that patient satisfaction increased as a result of note access with a similar proportion (51%, 31/61) perceiving that patients trusted them more (36%, 22/61 did not know, and 38 did not respond).¹⁵ In another survey conducted in 2016 involving over 10 000 patients and their families, investigators found that patients who were non-white or less educated reported more benefits than their counterparts: while the numbers are small, 48% (121/253) of black patients and 53% (188/354) of Hispanic patients trusted their provider more after reading their notes, compared with 42% (2826/6763) of white patients (the majority of the remainder reported no change).³ Similarly, 47% (120/253) of black patients and 54% (190/354) of Hispanic patients reported strengthened goal alignment with their clinician after accessing their notes, compared with 39% (2611/6763) of white patients.³ Qualitative research also suggests that reading their clinical notes can help patients feel listened to, validated and understood.¹⁶

Language proficiency

Limited language proficiency is associated with patient-reported communication problems, including frustration, confusion and lower overall ratings of quality of care.¹⁷ Patients experiencing language barriers in clinical visits are at higher risk of treatment non-adherence and adverse reactions to medications, with associated harms that may increase when patients misunderstand why medications have been prescribed.¹⁸

Although some health organisations provide portals in a range of languages, clinical notes are typically offered in one language only. Online machine translation, while improving,¹⁹ is subject to significant error rates, particularly if translating complex syntax and vocabulary in notes. Nevertheless, access to open notes appears to help some patients who speak another primary language by allowing them, or a care partner, to read and recall information.^{2 6} In a recent US survey, among patients whose preferred language was not English, 75% (1064/1420) reported that reading their notes helped them understand the rationale behind prescribed medications, compared with 64% (10 787/16 966) of primary English speakers.⁶ Among patients who did not speak English at home, 77% (357/462) reported reading their notes as extremely important for remembering their care plan, compared with 66% (13 700/20 780) of English speakers.² Similarly, 68% (315/462) of survey respondents who did not speak English at home reported that their notes were extremely important for preparing for clinical visits, compared with 50% (10 466/20 780) of their counterparts.²

Health literacy

It is estimated that, on average, patients do not recall about half of the health information communicated during visits, with this figure likely higher among those with lower levels of health literacy.²⁰ Defined as “the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions”—health literacy is now recognised as a driver of health disparities.²¹ Health literacy depends on many mediating factors, including reading skills, level of education, knowledge about preventive healthcare, and the ability to access and use health information effectively, such as following up on test results and referrals.

By offering patients access to records that document what was discussed during visits, open notes may provide a novel forum for augmenting health literacy among some patients. Surveys show that reading notes is a considerable asset in improving patients’ awareness about medical information, especially among non-white or less educated participants.^{2 3} For example, in a recent survey, 49% (89/181) of black and 55% (138/252) of Hispanic participants reported that reading their notes helped them to understand the reason for tests, compared with 40% (2025/5079) of white respondents.³ Similarly, 40% (72/181) of black and 36% (91/252) of Hispanic patients reported that access to notes helped them remember to get tests done, compared with 23% (1148/5079) of white participants. In addition, among participants with a high school education or less, 48% (459/952) reported

that reading their notes helped them understand the reason for tests compared with 38% (1116/2934) and 21% (610/2934) of patients with a masters or doctoral degree.³ A third (36% (339/952)) of those with high school education or less responded that open notes helped them to remember to get tests done, compared with 21% (610/2934) of patients with a masters or doctoral degree.

Reinforcing these findings, patients describe in qualitative studies how access to their notes improves awareness of their health problems. For example, in a recent qualitative survey involving predominantly minority patients at a safety net clinic, participants reported appreciating reading the detail in their clinicians' notes and described using open notes as a reference for medication information and follow-up plans. As one patient noted: "*I like my summaries because I can go back and revisit them*".¹⁶ While open notes may not help all patients, such as those with very reduced reading skills, they may help some patients with marginal and limited literacy. Moreover, in a large study of patients who read notes, 38% (8588/22 753) reported sharing them with others, predominantly family members.² It is reasonable to postulate that among those with severe literacy or language limitations, sharing access to their open notes with a family member or care partners may prove important in helping them to understand and act on their health information.²²

Limitations

While evidence of the benefits of open notes are promising, current findings are largely dependent on self-report. This can be unreliable, and methodologically robust studies have so far been conducted in only one language and are restricted to a few medical centres and hospitals, limiting the generalisability of results. In addition, surveys may be biased in favour of those participants who may already be more engaged with patient portals and therefore more likely to respond to surveys. Finally, as noted, disadvantaged populations have lower adoption rates, presenting a major residual barrier to harnessing the potential benefits of open notes.⁵

SUMMARY AND NEXT STEPS

Open notes are becoming increasingly common, and preliminary data suggest they may hold particular benefits for vulnerable patient populations (see [box 1](#)). Realising this potential will depend on further exploration into the effects of notes on patients and in tackling the barriers to portal usage faced by disadvantaged patients. We propose several next steps.

First, it is incumbent on health systems to develop strategies that increase the use of electronic patient-facing portals and other eHealth innovations across a wide variety of patient populations, and dedicated healthcare proxies who can

Box 1 Key questions and findings

What is already known about this topic?

- ▶ Growing numbers of patients can now access their clinical notes via online portals ('open notes').
- ▶ Preliminary studies show that open notes can strengthen patient safety, and enhance patient-provider relationships by promoting positive feelings towards clinicians and encouraging patient engagement.
- ▶ Despite challenges associated with lower portal usage among disadvantaged populations, the relational benefits of open notes appear to be especially pronounced among portal users who are older, less educated, non-white and whose primary language is not English.

What are the new findings?

- ▶ Preliminary data suggest that open notes may serve to elongate and strengthen patient-clinician interactions away from the pressures and limitations of face-to-face visits.
- ▶ We hypothesise that inviting patients to access their notes might function as a novel work-around to help address disparities driven by clinician biases and patient and provider stereotype threat, limited language proficiency and low health literacy.
- ▶ Research is needed to explore these hypotheses, and users' experiences of open notes, including cultural and economic barriers to reading notes, demographic differences in eHealth literacy, and the long-term effects of access to visit notes on health disparities including on treatment adherence, outcomes and levels of patient satisfaction.

support vulnerable patients.⁵ To maximise eHealth engagement, patients, including those from diverse backgrounds, should be involved in co-designing portals, and in shaping and delivering outreach initiatives. Health systems should also explore structural improvements, such as making health portals and notes available in multiple languages, reducing the literacy level of note content, and/or providing tooltips, along with readily accessible definitions of medical terms. Relatedly, designing portals to enable willing patients to share some or all of their notes with health literate or multilingual family or friend caregivers might help to empower patients, especially those from disadvantaged populations. Using data cascade metrics—an approach that analyses the effects of sequentially introduced steps of an intervention—may help clarify the most effective ways to influence differential portal usage among different demographic groups.²³

Second, as preliminary evidence suggests, it is possible that open notes may increase trust between patients and clinicians, reduce transmission of bias and increase patient engagement, especially among vulnerable patient populations. By expanding opportunities for online communication, open notes might

provide more instances for providers and patients to communicate in a context in which discrimination is less likely to arise. Web-based courses may help clinicians to write notes that are both more sensitive to patients' needs and also document patients' strengths.²⁴ Open notes might prompt clinicians to include less stigmatising language. This could reduce the transmission of negative biases to other providers who have not yet met the patient. Future research might investigate also whether the content and tone of notes might be adapted to empower patients, especially those at greater risk of inequities.

Third, the co-creation of medical notes holds promise and is currently under investigation.²⁵ Health systems should consider asking patients to report what has occurred since a previous visit and to articulate their priorities for an upcoming visit. Such co-creation of notes might help alleviate burdens on both patients and clinicians. Within time-pressured clinical consultations, this tool might help clinicians to manage cognitive biases more effectively and might also reduce the risk of stereotype threat interfering with patient disclosures. Such an approach might also benefit patients who are not language concordant with clinicians.

A growing body of evidence indicates that hiding clinical notes from patients may obviate opportunities to promote patient safety and enhance trust and engagement—particularly among those most at risk from inequities in care.³ In concert with the growing number of efforts to reduce disparities in care, we suggest that future research should scrutinise the potential of open notes to empower vulnerable patient populations.

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REFERENCES

- 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.
- Walker J, Leveille S, Bell S, *et al.* OpenNotes after 7 years: patient experiences with ongoing access to their clinicians' outpatient visit notes. *J Med Internet Res* 2019;21:e13876.
- Bell SK, Folcarelli P, Fossa A, *et al.* Tackling ambulatory safety risks through patient engagement: what 10,000 patients and families say about safety-related knowledge, behaviors, and attitudes after reading visit notes. *J Patient Saf* 2018. doi:10.1097/PTS.0000000000000494. [Epub ahead of print: 27 Apr 2018].
- Gerard M, Chimowitz H, Fossa A, *et al.* The importance of visit notes on patient portals for engaging less educated or nonwhite patients: survey study. *J Med Internet Res* 2018;20:e191.
- Tieu L, Schillinger D, Sarkar U, *et al.* Online patient websites for electronic health record access among vulnerable populations: portals to nowhere? *J Am Med Inform Assoc* 2017;24:e47–54.
- DesRoches CM, Bell SK, Dong Z, *et al.* Patients managing medications and reading their visit notes: a survey of OpenNotes participants. *Ann Intern Med* 2019;171:69.
- Essén A, Scandurra I, Gerrits R, *et al.* Patient access to electronic health records: differences across ten countries. *Health Policy Technol* 2018;7:44–56.
- Moll J, Cajander Åsa. Oncology health-care professionals' perceived effects of patient accessible electronic health records 6 years after launch: a survey study at a major university hospital in Sweden. *Health Informatics J* 2019;19:146045821988100.
- Moll J, Rexhepi H, Cajander Åsa, *et al.* Patients' experiences of accessing their electronic health records: national patient survey in Sweden. *J Med Internet Res* 2018;20:e278.
- Rodriguez JA, Lipsitz SR, Lyles CR, *et al.* Association between patient portal use and broadband access: a national evaluation. *J Gen Intern Med* 2020;26:1–2.
- Ancker JS, Barrón Y, Rockoff ML, *et al.* Use of an electronic patient portal among disadvantaged populations. *J Gen Intern Med* 2011;26:1117–23.
- FitzGerald C, Hurst S. Implicit bias in healthcare professionals: a systematic review. *BMC Med Ethics* 2017;18:19.
- Burgess DJ, Warren J, Phelan S, *et al.* Stereotype threat and health disparities: what medical educators and future physicians need to know. *J Gen Intern Med* 2010;25:169–77.
- Gerard M, Fossa A, Folcarelli PH, *et al.* What patients value about reading visit notes: a qualitative inquiry of patient experiences with their health information. *J Med Internet Res* 2017;19:e237.
- Bell SK, Mejilla R, Anselmo M, *et al.* When doctors share visit notes with patients: a study of patient and doctor perceptions of documentation errors, safety opportunities and the patient–doctor relationship. *BMJ Qual Saf* 2017;26:262–70.
- Belyeu BM, Klein JW, Reisch LM, *et al.* Patients' perceptions of their doctors' notes and after-visit summaries: a mixed methods study of patients at safety-net clinics. *Health Expect* 2018;21:485–93.
- González HM, Vega WA, Tarraf W. Health care quality perceptions among foreign-born Latinos and the importance of speaking the same language. *J Am Board Fam Med* 2010;23:745–52.
- Karliner LS, Auerbach A, Nápoles A, *et al.* Language barriers and understanding of hospital discharge instructions. *Med Care* 2012;50:283–9.
- Khoong EC, Steinbrook E, Brown C, *et al.* Assessing the use of Google Translate for Spanish and Chinese translations of emergency department discharge instructions. *JAMA Intern Med* 2019;179:580–2.
- Kessels RPC. Patients' memory for medical information. *J R Soc Med* 2003;96:219–22.
- Kindig DA, Panzer AM, Nielsen-Bohlman L. *Health literacy: a prescription to end confusion*. National Academies Press, 2004.
- Chimowitz H, Gerard M, Fossa A, *et al.* Empowering informal caregivers with health information: OpenNotes as a safety strategy. *Jt Comm J Qual Patient Saf* 2018;44:130–6.

- 23 Lala O, Garcia A, Lau J, *et al.* Measuring performance of OpenNotes initiatives to target improvement efforts. *NEJM Catalyst* 2019;5.
- 24 Dobscha SK, Kenyon EA, Pisciotto MK, *et al.* Impacts of a web-based course on mental health clinicians' attitudes and communication behaviors related to use of OpenNotes. *Psychiatr Serv* 2019;70:474–9.
- 25 Mafi JN, Gerard M, Chimowitz H, *et al.* Patients contributing to their doctors' notes: insights from expert interviews. *Ann Intern Med* 2018;168:302–5.