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OBSERVATION: BRIEF RESEARCH REPORT

Patients Managing Medications and Reading Their Visit Notes: A Survey of OpenNotes Participants

Background: As many as half of Americans with chronic illness do not take their medications as prescribed, which contributes to poorer health outcomes and up to \$300 billion annually in avoidable health care costs (1). As patients increasingly read their visit notes through online portals (www.opennotes.org), reports from primary care practices have suggested that patient access to notes may improve adherence to medications (2).

Objective: We examined patients' perceptions of how note reading affects factors related to medication adherence. In addition, we sought to understand their engagement with online medication lists and their willingness to participate in keeping those lists correct and up to date.

Methods: In 2017, we did an online survey of patients in the 3 health systems that participated in the original OpenNotes pilot (3). These 3 systems provide patients with online access to clinical notes throughout most of their ambulatory practices. Eligible patients were aged 18 years or older and in the previous 12 months had logged into the portal at least once and had an ambulatory visit note available.

We sent the survey to all potential participants between June and October 2017. We offered 50 raffle prizes at each site as an incentive for participation.

Results: Of 136 815 patients who received survey invitations, 29 656 (22%) responded (Figure 1). Among the 19 411

Figure 1. Constructing the analytic sample.

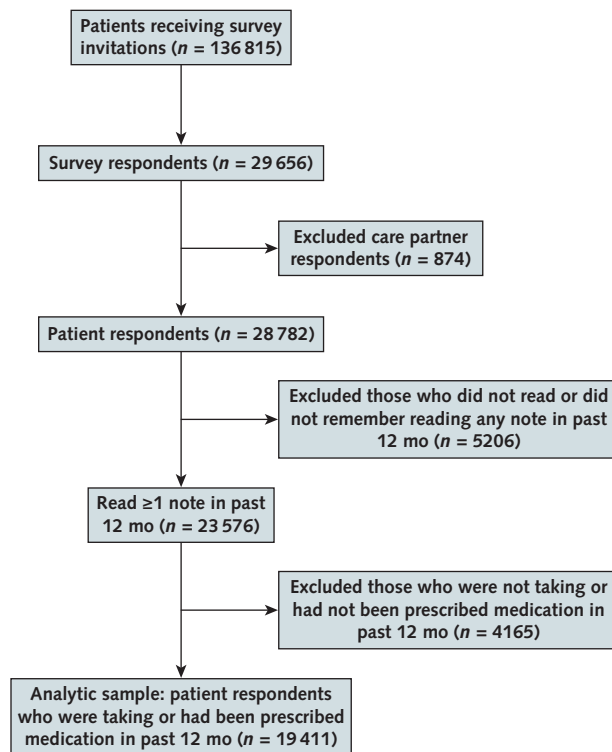
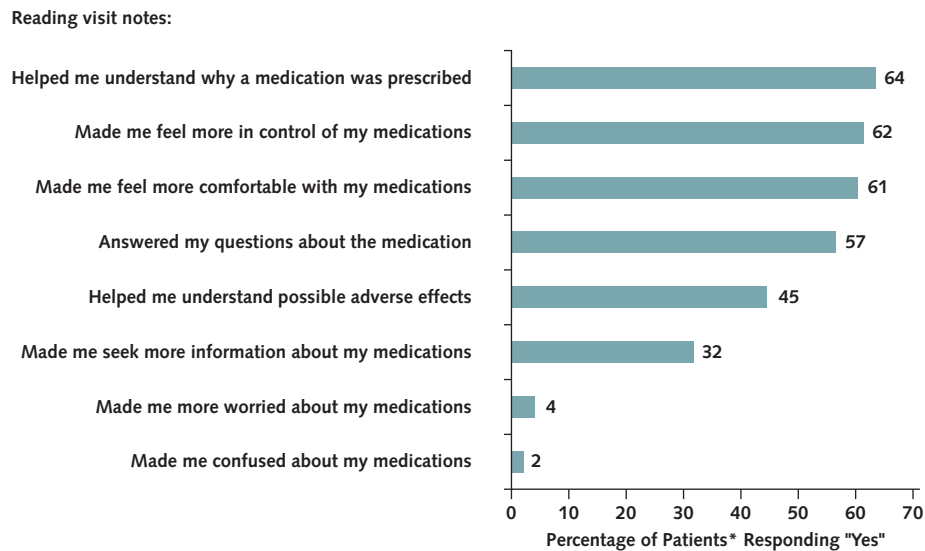


Figure 2. Patient-reported experiences with note reading and medication adherence.

* Patients responding to the survey who received a prescription for or were taking medications and had read a note in the past 12 mo.

patients who had read notes and reported having taking or been prescribed medications in the 12 months before the survey, 14% from practices associated with Beth Israel Deaconess Medical Center and Geisinger reported that reading their notes made them more likely to take their medications as prescribed (86% reported no change). At practices associated with the University of Washington, where the survey used different wording and response categories, 33% of such patients rated notes as extremely important in assisting with their regimens. Most patients at all 3 sites reported that note reading helped them understand why a medication was prescribed, answered their questions, and made them feel more comfortable with and in control of their medications. Very few reported that notes made them feel worried or confused about their medications (Figure 2). Of respondents with a primary language other than English, 1064 of 1420 (75%) reported that reading their notes helped them understand why a medication was prescribed, compared with 10 787 of 16 966 primary English speakers (64%). Among those with a high school education or less, 886 of 1239 (74%) reported that reading their notes helped answer questions about their medications, compared with 6795 of 12 839 college graduates (53%).

Approximately 8 of 10 respondents reported looking at their medication list on the patient portal at least once. Of these, 18% reported that the list was not accurate and 85% wanted to be able to submit corrections to their medication list online.

Discussion: Reading visit notes may be important for sustained improvements in the use of medications over time in ambulatory care. Why might note reading be associated with such differences?

On average, patients remember about half of the information conveyed during a visit (4). Written records of visits can communicate critical information about why a given regimen is recommended and remind patients about additions, changes, and potential adverse effects of medications. Reports of improved

adherence may also reflect increased trust, particularly for patients who identify as racial or ethnic minorities.

Safety risks associated with inaccurate medication reconciliation are well documented (5), and our findings indicate that many patients are willing to participate in ensuring the accuracy of their medication lists. Encouraging them to review their notes and lists and to submit correspondence online between visits when they find errors may enhance safety and improve the efficiency of visits, but efficient mechanisms need to be developed for making corrections without overwhelming clinicians.

Our study has several limitations. The survey generated a modest response rate from a population that was primarily white and highly educated, and the measures of medication adherence were self-reported. Respondents may have been those with the strongest opinions about OpenNotes, and our results may not generalize to other organization types and those whose practice culture does not embrace open visit notes. Nevertheless, as we assess the challenges posed by poor adherence to medications, the data indicate that an important group of patients report benefits, even if its size and specific characteristics cannot be clearly defined by these early results.

Although note sharing means a substantial change in the culture of medicine, the practice of inviting patients to review clinicians' notes online is spreading rapidly. Our survey results suggest that reading notes may help many patients manage and adhere to their medications.

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See Also: Editorial comment (page 64).

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