

# How do older patients with chronic conditions view reading open visit notes?

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## Abstract

**Background:** We examine the experiences with and perceptions of the effect of reading clinical outpatient visit notes on patients with multiple chronic conditions at three healthcare organizations with significant experience sharing clinical notes with patients.

**Methods:** A cross-sectional survey was conducted via patient portals at three diverse healthcare organizations in the United States: Beth Israel Deaconess Medical Center (Boston, MA), UW Medical Center (Seattle, WA), and Geisinger Health System (Danville, PA). Participants were aged 65 and older patient portal users who read at least one clinical note over the 12 months before the survey. We examined the effect of note reading on patient engagement and managing medications.

**Results:** The majority of respondents had read two or more clinical notes in the 12 months before the survey. Patients with more than two chronic conditions were more likely than those with fewer or none to report that reading their notes helped them remember their care plan, take their medications as prescribed, and understand and feel more in control of their medications. Very few patients reported feeling worried or confused about their health or medications due to reading their notes.

**Conclusions:** Older patients with chronic conditions are particularly vulnerable to misremembering and mismanaging their care and medication plans. Findings from this study suggest that these patients and their care partners could receive important benefits from accessing their notes. Healthcare organizations should work to maximize patient's engagement with their health information both through the patient portal and through other methods to ensure that patients and the healthcare systems reap the full benefit of the increased transparency of medical records.

## KEYWORDS

electronic health records, medication adherence, open notes, patient portal, survey

## INTRODUCTION

An estimated 85% of older adults aged 65 and older in the United States live with a chronic condition, and 60% have more than one.<sup>1</sup> Adults with chronic conditions use more and spend more on healthcare services and often experience reduced physical and social functioning.<sup>2-4</sup> Moreover, owing to a range of environmental, economic, and social factors such as systemic racism, racial and ethnic minorities, and low-income patients are at increased risk of developing chronic conditions and doing so sooner than white and higher-income populations.<sup>5</sup> Managing multiple chronic conditions and juggling their various medications can be a time-consuming and frustrating experience for older patients and their care partners.

Many chronic care management models emphasize the need for open communication with informed, activated patients and care partners to better manage chronic illness.<sup>6,7</sup> However, for patients and their care partners to be informed and activated, they need both information and time. Clinic visits can be rushed and stressful experiences, and research suggests that patients misremember, on average, approximately half of what was discussed during a visit.<sup>8</sup> These findings suggest that the clinic visit alone is inadequate for information exchange and retention, and supplemental, asynchronous clinician–patient communication and education methods are needed. Health researchers have proposed that access to online patient portals may be one way to increase engagement; however, until recently, these portals have not offered patients access to the types of information needed to engage in and manage their care.<sup>9</sup>

Beginning on April 5, 2021, U.S. healthcare organizations are legally required to provide patients with electronic access to all information in their electronic health records, including outpatient visit notes.<sup>10</sup> The shift toward greater information transparency for patients may help facilitate patient engagement and communication in managing multiple chronic conditions by providing rapid, convenient access to information. Patients who read their outpatient visit notes (referred to in this article as “open notes”) report feeling more in control of their care, better remembering their care plan, and increased trust in their clinicians.<sup>11,12</sup> Patients reading their notes say they better understand their medications and potential side effects, and there is evidence suggesting that note reading increases the likelihood that patients will take their medications as prescribed.<sup>13,14</sup>

Several smaller studies have examined patients' perceptions of open visit notes within a single chronic condition (e.g., diabetes, COPD) and found similar perceptions of benefits and risks compared with patients without these diagnoses.<sup>15-17</sup> However, patients with multiple chronic conditions may have different experiences. It is possible that note reading may be overwhelming, lead to more

### Key Points

- Older people with chronic conditions report reading their notes is very important for engaging in care, remembering care plans, taking medications.
- Few older people were more worried or confused after reading notes.

### Why Does this Paper Matter?

Sharing notes with patients is now federal regulation. Findings suggest important benefits for older adults with chronic conditions.

confusion or worries for patients with more complex care needs and more contact with the healthcare system.

We examined survey data from three healthcare organizations with up to 7 years of experience, offering patients access to their notes through patient portals. These healthcare organizations shared clinical notes across all ambulatory care settings, with few exceptions (e.g., mental health, pain management). Using the survey data, we examined the experiences with and perceptions of open notes among patients with multiple chronic conditions to understand the perceived benefits and risks of this increased transparency.

## METHODS

### Survey

The details of survey development and field methodology have been previously reported.<sup>11</sup> In brief, the survey instrument relied heavily on previously used questions, with some new content developed with expert input, patient focus groups, and psychometric testing.<sup>11,18</sup> We surveyed patients at three healthcare organizations: Beth Israel Deaconess Medical Center (BIDMC) in Boston, MA; Geisinger Health System, Danville, PA; and UW Medical Center in Seattle, WA. All three sites provide patients with access to their clinical notes through a patient portal across all outpatient care settings with few exceptions (e.g., mental health, pain management). Patients must have a valid email address in order to register for a patient portal account. Patients aged 18 and older with an active online portal account were eligible for the survey if they had at least one open note available

to be read in the past year. We define an “open note” as the clinical note written by a clinician after a clinical visit conducted either in person or via telemedicine, which is accessible to the patient through the organization’s patient portal. Patients were sent a message with a personalized link to the online survey through the patient portal inviting them to participate, and they received a reminder 1 week after the original invitation if they had not completed the survey. In addition, we offered respondents an incentive to encourage participation: a raffle of 50 prizes of U.S. \$25 or U.S. \$50 at each site.

## Analytic sample

To maximize the likelihood that we were examining responses about reading open notes, rather than other information on the patient portal (i.e., imaging reports), we excluded from our analysis respondents whose self-reported note reading in the past 12 months did not match portal tracking data; for example, cases in which a respondent reported reading at least one open note but the tracking data showed they had not. Respondents were asked if they were answering the survey for themselves or another person for whom they helped manage their care. We excluded respondents answering the survey for another person ( $n = 874$ ). Finally, we excluded those under age 65, leaving an analytic sample of true readers aged 65 and over. We then linked respondents’ survey data with administrative data containing diagnosis codes. We obtained all chronic disease ICD-10 codes from the Centers for Medicare and Medicaid Services (CMS) chronic condition algorithm (CCW).<sup>19</sup> We used the top 10 chronic conditions listed by the National Council on Aging to create our chronic conditions flags: hypertension, high cholesterol, arthritis, ischemic heart disease, diabetes, chronic kidney disease, heart failure, depression, Alzheimer’s disease and dementia, and chronic obstructive pulmonary disease (COPD).<sup>20</sup> Using the diagnosis codes for each of these conditions, we identified a patient as having a chronic condition if any of the diagnosis codes for each visit met the criteria specified by the CCW. We aggregated the visits of each patient, and then calculated the summed number of chronic conditions for each patient. Finally, we classified the summed number of chronic conditions as 0, 1–2, and more than 2.

## Analysis

Most items addressing potential benefits and risks asked for ratings on an 11-point scale ranging from 0 (not at all) to 10 (extremely). Responses to these items were collapsed into two categories (0–7) and 8–10 (“top box” scores).

Four-level agreement responses were dichotomized as agree/somewhat agree and disagree/somewhat disagree. We used Chi-square tests to compare differences among chronic condition categories across demographic characteristics. We tested associations between experiences and perceptions of note reading and chronic condition categories using Chi-square tests for categorical variables and ANOVA for continuous variables. Finally, we used Fischer’s exact test for any analyses with an individual cell size of less than 5. All analyses were conducted using SAS software version 9.4 (SAS Institute, Inc).

The Institutional Review Boards approved our study at all three healthcare organizations.

## RESULTS

Of 136,815 patients across the three healthcare organizations invited to complete the survey, 21.7% responded (28,782 patients and 874 care partners). After excluding patients younger than 65 and those answering the survey as care partners, our analytic sample consisted of 7688 respondents, of whom 4190 were female (Table 1) and 4018 were between the age of 65 and 70. The majority of the respondents in our analysis were white (6526), non-Latinx (6993), had at least a high school education (7127), rated their health as at least good (6005), and spoke English as a primary language (6973). Reflecting the eligibility criteria of aged 65 and older, most respondents were retired (5465).

Men were more likely than women respondents to have more than two chronic conditions (26.4% vs 34.7%;  $p < 0.001$ ), as were respondents with less than a high school education as compared with all other educational groups (47.2% high school, 35.5% some college, 29.0% college degree, 24.6% masters or doctoral degree;  $p < 0.001$ ). In addition, although the majority of respondents were retired or not working for another reason (homemaker, unemployed, or unable to work due to a disability), those who reported being employed were significantly less likely to have two or more chronic conditions (retired 31.8% with  $>2$  conditions, homemaker, unemployed, or not working due to a disability 27.6%; employed 31.8%;  $p = 0.003$ ). Finally, respondents reporting their health as fair or poor were more likely than those reporting better health to have more than one chronic condition (45.7% vs 27.0%;  $p < 0.001$ ).

## Experience with note reading

The majority of respondents reported reading notes for a year or more (80.2%), and 52.9% reporting reading four or

TABLE 1 Older patients (aged 65 and older) with chronic conditions by demographic group

Variable	Total (N = 7688)	0 chronic condition n (%)	1 or 2 chronic conditions n (%)	>2 chronic conditions n (%)	p Value*
Age					
65–70	4018	1136 (28.3)	1888 (47.0)	994 (24.7)	<0.001
71–84	3432	700 (20.4)	1528 (44.5)	1204 (35.1)	
85+	237	37 (15.6)	76 (32.1)	124 (52.3)	
Gender					
Female	4190	1095 (26.1)	1988 (47.5)	1107 (26.4)	<0.001
Male	3497	778 (22.2)	1504 (43.0)	1215 (34.7)	
Race					
Asian	181	40 (22.1)	87 (48.1)	54 (29.8)	0.226
Black	86	15 (17.4)	38 (44.2)	33 (38.4)	
White	6526	1625 (24.)	2960 (45.4)	1941 (29.7)	
Other	133	23 (17.2)	63 (47.4)	47 (35.3)	
Multiple races	134	28 (20.9)	67 (50.0)	39 (29.1)	
Ethnicity					
Hispanic/Latinx	89	22 (24.7)	40 (44.9)	27 (30.3)	0.994
Non-Hispanic/Latinx	6993	1712 (24.4)	3183 (45.5)	2098 (30.0)	
Education					
High school or less	561	83 (14.8)	213 (38.0)	265 (47.2)	<0.001
Some college	1562	331 (21.1)	676 (43.3)	555 (35.5)	
College degree	2085	521 (24.9)	959 (46.0)	605 (29.0)	
Masters or doctoral degree	2980	827 (27.7)	1419 (47.6)	734 (24.6)	
Primary Language					
Other	147	35 (23.8)	62 (42.2)	50 (34.0)	0.557
English	6973	1710 (24.5)	3174 (45.5)	2089 (30.0)	
Employment					
Employed/self-employed	1517	412 (27.1)	745 (49.1)	360 (23.7)	<0.001
Homemaker, unemployed, and disabled	192	51 (26.5)	88 (45.8)	53 (27.6)	
Retired	5465	1294 (23.7)	2432 (44.5)	1739 (31.8)	
Health condition					
Excellent/very good or good	6005	1529 (25.5)	2852 (47.5)	1624 (27.0)	<0.001
Fair of poor	1163	226 (19.4)	405 (34.8)	532 (45.7)	
Site					
BIDMC	3993	1061 (26.6)	1863 (46.7)	1069 (26.8)	<0.001
GHS	514	34 (6.6)	197 (38.3)	283 (55.1)	
UW	3180	778 (24.5)	1432 (45.0)	970 (30.5)	

Note: The analytic sample contained true readers with age  $\geq 65$  only.

\*p Value from Chi-square test.

more notes (Table 2). Those with more than two chronic conditions were more likely than other patients to read four or more notes (62.7% vs 52.4% 1–2 chronic

conditions, 41.6% 0 chronic conditions;  $p < 0.001$ ), and more likely than those with no chronic conditions to report reading notes for at least 1 year (81.4% vs 74.9%;

TABLE 2 Experience with note reading among older adults (aged 65 and older)

Variable	Total (N = 7688)	0 Chronic condition	1 or 2 conditions	>2 Chronic conditions	p Value*
Number of notes read					
1	411 (5.4)	151 (8.1)	212 (6.1)	48 (2.1)	<0.001
2 or 3	2773 (36.2)	826 (44.4)	1280 (36.8)	667 (28.8)	
4 or more	4053 (52.9)	774 (41.6)	1825 (52.4)	1454 (62.7)	
Do not know/not sure	424 (5.5)	109 (5.9)	165 (4.7)	150 (6.5)	
How long have you been reading notes?					
A week or less	126 (1.6)	32 (1.7)	58 (1.7)	36 (1.6)	<0.001
> than a week, < than a year	1388 (18.1)	435 (23.4)	557 (16.0)	396 (17.1)	
A year or more	6146 (80.2)	1393 (74.9)	2866 (82.3)	1887 (81.4)	
Talked to a provider in the past 12 months about a note?					
Yes	2671 (35.63)	554 (30.5)	1189 (34.9)	928 (40.9)	<0.001
No	3769 (50.27)	1012 (55.7)	1731 (50.8)	1026 (45.2)	
Do not know/not sure	1057 (14.10)	251 (13.8)	489 (14.3)	317 (14.0)	
Encouraged by provider to read notes?					
Yes	2411 (31.6)	525 (28.4)	1095 (31.6)	791 (34.3)	<0.001
No	3520 (46.2)	910 (49.2)	1566 (45.2)	1044 (45.3)	
Do not know/not sure	1691 (22.2)	414 (22.4)	805 (23.2)	472 (20.5)	
Shared note with someone?					
Yes	3013 (40.2)	682 (37.5)	1343 (39.4)	988 (43.6)	0.002
No	4299 (57.4)	1090 (60.0)	1981 (58.2)	1228 (54.2)	
Do not know/not sure	177 (2.4)	45 (2.5)	82 (2.4)	50 (2.2)	
Who did you share the note with?					
A family member or relative	1987 (66.0)	424 (62.2)	901 (67.1)	662 (67.0)	0.069
A friend	91 (3.0)	23 (3.4)	44 (3.3)	24 (2.4)	
A health care provider	261 (8.7)	77 (11.3)	114 (8.5)	70 (7.1)	
Someone else	13 (0.4)	3 (0.4)	7 (0.5)	3 (0.3)	
More than one person	661 (21.9)	155 (22.7)	277 (20.6)	229 (23.2)	
How important is it to be able to share your visit notes with others?					
% scoring 8–10	2788 (37.5)	653 (36.2)	1253 (37.0)	882 (39.2)	0.116
Have you contacted your provider's office about notes in the past 12 months?					
Yes	1575 (21.1)	370 (20.4)	695 (20.5)	510 (22.7)	0.122
No	5262 (70.6)	1302 (71.8)	2422 (71.3)	1538 (68.5)	
Do not know/not sure	622 (8.3)	141 (7.8)	282 (8.3)	199 (8.9)	
How confusing were the visit notes?					
% scoring 8–10	338 (4.5)	73 (4.0)	156 (4.6)	109 (4.8)	0.458
As a result of reading your visit notes, were you more or less worried about your health?					
Much less or less worried	2176 (29.0)	519 (28.5)	1018 (29.8)	639 (28.2)	0.127
No change	4269 (56.9)	1064 (58.4)	1904 (55.7)	1301 (57.4)	
More or much more worried	312 (4.2)	68 (3.7)	133 (3.9)	111 (4.9)	
Never worried	752 (10.0)	172 (9.4)	364 (10.7)	216 (9.5)	

Note: The analytic sample contained true readers with age  $\geq 65$  only.

TABLE 3 Perceived benefits of note reading among older adults aged 65 and older (% of score 8–10)

Variable	Total (N = 7688)	0 Chronic condition	1 or 2 Chronic conditions	>2 Chronic conditions	p Value**
<i>How important is reading your visit notes for...</i>					
Taking care of your health	5486 (73.7)	1316 (72.9)	2494 (73.7)	1676 (74.4)	0.552
Helping you feel in control of your care	5123 (68.9)	1209 (67.1)	2326 (68.8)	1588 (70.5)	0.060
Helping you to make the most of your visit to your healthcare provider <sup>a</sup>	2002 (65.8)	500 (67.3)	888 (65.2)	614 (65.3)	0.592
Feeling like you have an active role in your medical care <sup>a</sup>	1976 (64.9)	478 (64.4)	884 (64.9)	614 (65.3)	0.939
Remembering the plan for your care	4799 (64.5)	1118 (61.9)	2166 (64.0)	1515 (67.3)	0.002
Preparing for your office visits	3901 (52.5)	945 (52.4)	1718 (50.8)	1238 (55.0)	0.009

Note: The analytic sample contained true readers with age  $\geq 65$  only.

<sup>a</sup>UW only.

\*\*p Value from Chi-square test.

$p < 0.001$ ). Forty percent of respondents with more than two conditions talked to a clinician about a note (40.9% vs 34.9% 1–2 conditions, 30.5%;  $p < 0.001$ ), and those with any chronic conditions were more likely than those without to say a clinician encouraged them to read notes (34.8% >2, 31.6% 1–2, 28.4% 0 conditions;  $p = 0.006$ ). Finally, 43.6% of respondents with more than two chronic conditions shared a note with someone, compared with 39.4% of those with 1–2 conditions and 37.5% of patients with no chronic conditions ( $p < 0.001$ ). Across all three groups, respondents most commonly shared notes with a family member or relative (62.2%–67.0%), and among these respondents, approximately one in five reported sharing notes with more than one person.

Approximately 20% of patients across all groups reported contacting a clinician about something they read in a note. However, few patients found notes confusing (4.0%–4.8%) or reported that reading notes made them more worried about their health (3.7%–4.9%). Finally, 28.5%–29.8% said that note reading made them feel *much less* or *less* worried about their health.

### Perceptions of note reading

Across all respondents, patients perceived benefits from reading their notes (Table 3). Using top box scores (8–10 on a scale of 0–10), 73.7% of patients said that notes were *very important* for taking care of themselves (see Table S1 for the full distribution across all response options). In addition, more than 6 in 10 respondents overall reported that note reading was *very important* for helping them feel in control of their care (68.9%), helping them to make the most of their visit to their healthcare provider (65.8%), feeling like they had an active role in their

medical care (64.9%), and remembering their care plan (64.5%). Finally, 52.5% said that reading notes was *very important for preparing* for office visits. There were no differences in perceptions of the benefits of note reading across the three groups with two exceptions: respondents with more than two chronic conditions were more likely than those with none to report that note reading helped them to remember their care plan (66.1% > 2 conditions, 63.2% 1–2 conditions, 61.9% 0 conditions;  $p = 0.005$ ) and preparing for office visits (55.0% > 2 conditions, 50.8% 1–2 conditions; 52.4% 0 conditions;  $p = 0.009$ ).

### Reading notes and taking medications

Respondents who reported taking or having been prescribed medications in the past 12 months (6264) were asked a series of questions about the perceived risks and benefits of note reading related to understanding and taking their medications (Figure 1). Patients at UW were asked to rate the importance of note reading in taking their medications on a 0–10 scale, whereas those at BIDMC and Geisinger were given a five points scale ranging from very important to not important at all. The UW survey field period was slightly later than that of the other two sites, and the investigators at UW chose to use the alternative wording as part of a battery of survey items. At UW, 50.8% of patients with more than two chronic conditions rated notes as *very important* (scored 8–10 on a scale of 0–10) for helping them with their medications, compared with 42.1% and 45.7% of those with no and 1–2 conditions ( $p = 0.0006$ ). Exactly 16.9% of patients with more than two conditions at Geisinger and BIDMC said they were *more likely* to take their medications as prescribed after reading notes, compared with those with 0 (10.1%) or

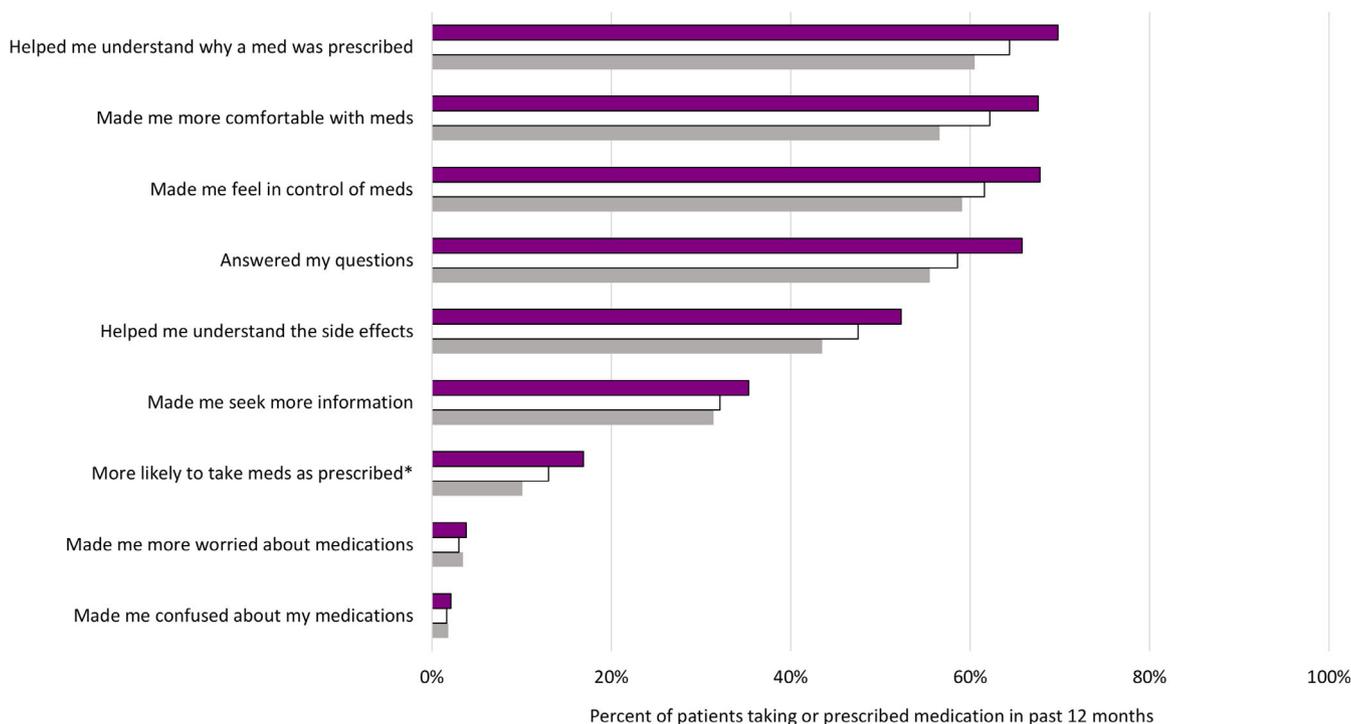


FIGURE 1 Perceived benefits of note reading related to medications among older patients with chronic conditions

1–2 conditions (13.5%) ( $p < 0.001$ ). Similarly, respondents with two or more conditions were significantly more likely than those with fewer conditions to report that reading notes helped them understand why medications were prescribed (69.9% < 2 conditions, 64.4% 1–2, 60.6% 0 conditions;  $p < 0.001$ ), made them feel more comfortable with (67.6%, 62.3%, 56.7%;  $p < 0.001$ ) and in control of their medications (67.8%, 61.6%, 59.1%;  $p = 0.002$ ), answered questions about their medications (65.8%, 58.6%, 55.5%;  $p < 0.001$ ), and helped them to understand the possible side effects of their medications (52.3% vs 47.6%, vs 43.5%;  $p < 0.001$ ).

Very few respondents, regardless of their chronic conditions, said that note reading made them confused (2.1% >2 conditions, 1.6% 1–2, 1.8% 0 conditions;  $p = 0.486$ ) or worried (3.8% >2 conditions, 3.0% 1–2, 3.5% 0 conditions;  $p = 0.056$ ) about their medications. Finally, respondents with more than two conditions were significantly more likely than those with fewer conditions to report looking for additional information about their medications after reading their notes (35.3% >2 conditions, 32.1% 1–2, 31.3% 0 conditions;  $p = 0.028$ ).

## DISCUSSION

In this analysis of the largest survey to date of patients' experiences with open notes, nearly three in four patients aged 65 or over reported that reading notes was very

important for taking care of themselves. Among respondents in this age group, there was no difference between the experiences of patients with chronic conditions and those without; approximately two-thirds of all patients reported that reading their notes was *very important* for feeling in control of their care and helping them to make the most of their visit. Compared with other patients, patients with two or more chronic conditions were also more likely to have read four or more notes and reported that reading their notes helped them better recall their care plan. These patients were also more likely to report that a clinician had encouraged them to read their notes. In addition, respondents with two or more chronic conditions were considerably more likely than other patients to have shared a note with someone else.

Importantly, given the significance of adherence to medications in terms of health and costs to the healthcare system, respondents with two or more chronic conditions were considerably more likely to say that reading notes was very important to helping them with their medications and taking them prescribed. Note reading helped patients with chronic conditions understand why medications were prescribed, made them more comfortable about their medications, helped answer their medication questions, and helped them understand potential side effects of their medications. Finally, few respondents—including those with multiple chronic conditions—reported being *more confused* or *more worried* about their medications after reading their notes. These findings extend current

research showing that, compared with their counterparts, patients who are older and facing multiple chronic conditions experience benefits from reading their open notes. These findings extend the pilot work looking at open notes and other chronic conditions such as diabetes, COPD, cancer, and mental health.<sup>5,15–17,21</sup>

It has been suggested that inviting patients to read their notes via secure online portals may function as a novel visit extender by allowing patients to review information between clinic visits, reduce the pressures and communication limitations associated with face-to-face interactions, and enhance recall of information.<sup>22</sup> Building on this perspective, we underline that persons with multiple chronic conditions interact with the healthcare system more frequently and must remember a greater amount of information during visits. Moreover, many of these patients are likely to be older and possibly experience a decline in short-term and working memory. Although these patients may not themselves access portals, millions of Americans with chronic conditions manage their health with the involvement of care partners—family, friends, and others who are not part of the formal care delivery system.<sup>23</sup> Our research and others suggest that online access to patient information through portals is desired by patients and valued by families.<sup>11,24–26</sup> Among this patient population, open notes may serve to enhance recall and supplement continued understanding, which may include support from informal care partners.

Respondents' reports of increased medication adherence are especially notable. In the United States, it is estimated that around half of all patients with chronic conditions fail to take their medications as prescribed, leading to increased rates of hospitalization, worse patient outcomes, and incurring healthcare costs of approximately \$300 billion annually.<sup>27</sup> With an aging population, the prevalence of chronic conditions is predicted to rise dramatically in the forthcoming decades, placing even greater pressure on health providers.<sup>28</sup> The results of this study suggest that sharing open notes with older patients with multiple chronic conditions presents a significant innovation with the potential to improve adherence to medications and health engagement.

This study has several limitations. First, this is a cross-sectional study examining patients' self-reported experiences from only three regions of the United States, and results may not be generalizable to other regions or practices. Second, the response rate was modest, although it was similar to the response rate in a recent Consumer Assessment of Healthcare Provider and Systems survey.<sup>29</sup> Although there were some demographic differences between responders and nonresponders, these differences were small, and the size of the sample analyzed gives further weight to the findings. Third, it is very

possible that the survey respondents were those most enthusiastic about open notes. Finally, the literature on the impact of portals on patients is often confused by lack of specificity about different functionalities. A strength of our study is that we took several steps to make sure patients had experience in reading notes and were reporting on reading visit notes, rather than on other information available on their portals.

In this study, the respondents were majority white and female, had at least a high school education, were retired, and English speakers, and the majority had no more than two chronic conditions. Although survey data were representative of the health systems, the overall lack of diversity among respondents limits our ability to draw inferences for minority, low income, or less educated patient populations who are already marginalized by the 'digital divide' in health care. In addition, it is difficult to draw firm conclusions about the benefits to non-English speakers because the survey was only offered in English; subsequent surveys could be administered in other languages and explore issues of health literacy. However, in multiple surveys, compared with other patients, non-white, less educated, older patients, or those whose preferred language is not English report better remembering their care plan, better engagement in their care, and trusting their clinician more as a result of reading their notes.<sup>11,30</sup> This suggests that targeted efforts to encourage patients with chronic conditions from backgrounds traditionally under or poorly served by the healthcare system could help address disparate outcomes.

## CONCLUSION

Findings from this study suggest that older patients with chronic conditions may reap important benefits from accessing their notes, including fostering greater adherence to medications and better understanding and recall of their medication and treatment plans. The new federal rules prohibiting information blocking facilitate easier access to patient's health information, and open notes are increasing worldwide.<sup>31</sup> However, we underscore that these benefits will not be harnessed unless patients or their care partners can actually access this information and that it is in a usable and useful format. Although, overall, our respondents had education levels beyond high school and may have had fairly high levels of digital literacy, this is often not the case among older adults with chronic conditions.<sup>32,33</sup> Studies show that older patients are less likely to be offered information about patient portals, and when offered, they are less likely to register for and use them.<sup>34</sup> Providing personalized health information, both through patient portals and on paper, that is

appropriate to lower literacy levels, such as clinical notes in layperson terms, perhaps facilitated by natural language processing, could be helpful in engaging patients. Although access to online information offers promise to patients, health systems should strive to ensure that all older patients have access to appropriate information in a format that is most usable and useful for them.

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## CONFLICT OF INTEREST

The authors have no conflict of interest relevant to this work to disclose.

## AUTHOR CONTRIBUTIONS

Catherine M. DesRoches was responsible for obtaining funding for this work and participated in the data collection. Catherine M. DesRoches and Zhiyong Dong conducted the statistical analysis and interpreted the results. Catherine M. DesRoches, Zhiyong Dong, Liz Salmi, and Charlotte Blease participated in drafting and revising the manuscript.

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The funders did not play a role in any of the following activities related to this research: survey development, data collection, data analysis and interpretation, and writing and revising the manuscript.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

**Table S1.** Full distribution of “top-box” scores shown in Table 3.

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