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Ophthalmology patients' interest in online access to clinic notes at three US clinics

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Abstract

Purpose: This study aimed to understand patients' perceptions about potential benefits and harms of accessing their own ophthalmology clinic notes via an electronic patient portal as part of the OpenNotes initiative.
Methods: The authors conducted a cross-sectional, in-person survey of ophthalmology patients at three US eye clinics. The paper survey was self-administered or administered with assistance from study staff before or after patients' clinical visits. The authors used descriptive statistics to summarise patient characteristics and patient attitudes about accessing their ophthalmology notes online. Chi-square and *t*-tests were performed to assess differences in patient responses between clinic locations.
Results: Four hundred and fifty-one patients responded (response rate 65%). Most patients thought that accessing doctors' notes online was a good idea (95%), wanted to view their clinic notes online (94%), and agreed online access would increase their understanding of their eye problems (95%) and help them better remember their care plan (94%); 14% said online access would increase their worry; 43% had privacy concerns; and 96% indicated they would show or discuss their notes with at least one other person. Non-white patients were more likely than white patients to perceive online clinic notes as a useful tool, but they were also more likely to worry and to express greater privacy concerns.
Conclusions: Patients at three US eye clinics were strongly in favour of online access to ophthalmology notes and were optimistic this access would improve their understanding and self-care. Ophthalmologists should consider offering online access to their notes to enhance doctor-patient communication and improve clinical outcomes.

Introduction

Although ophthalmology is subject to the same regulatory framework as any other field within medicine, the profession is sometimes slow to adopt electronic medical records (EMR).[1] However, the US Health Information Technology for Economic and Clinical Health (HITECH) Act, which initially encouraged providers to implement EMR with incentives, also mandated penalties for non-adopters beginning in 2015.[2] HITECH is designed to integrate with the Health Insurance Portability and Accountability Act (HIPAA), which not only governs the security of health information in the US but also grants patients the right to review and obtain a copy of their medical records.[3]

Other factors over the past 15 years have additionally shaped current US medical practice. In 2001, the influential Institute of Medicine report *Crossing the Quality Chasm* listed six areas for improvement, with transparency being a

'necessary' element for achieving the aim of patient-centred care.[4] Patients also now heavily utilise the Internet to find health information, including information about eye health.[5] With increased awareness of the need for transparency, patients' legal right to review their records, and greater use of EMR, some healthcare providers began providing patients with online access to their clinic notes through secure patient portals as part of OpenNotes, an initiative that invites patients to review clinic notes written by their doctors, nurses, or other clinicians. Over 12 million US patients currently have access to their EMR, and additional providers and health systems continue to add access each year in the US and internationally.[6,7]

The initial OpenNotes survey in 2011 reported that over three-quarters of patients in three different primary care settings felt EMR access helped them better understand their medical conditions, better remember their care plan, feel more in control of their care, and improve their medication adherance.[8] Fewer than 5% of participating doctors in the original survey felt visits took longer, and the effect on clinical practice was smaller than expected in the pre-intervention survey. Over 85% of primary care doctors at each site felt access to their EMR 'was a good idea.'[8]

To date, there are few published studies of patient attitudes and beliefs about access to ophthalmology clinic notes. One 2013 report described the results of focus groups gauging enthusiasm and preferences of 71 glaucoma patients for personal health records in either electronic or paper format.[9] However, to our knowledge, there has been no research specifically studying the implementation of EMR in ophthalmology, making this not only a larger study (n = 451 patients) than the glaucoma focus group study but also the first study to report a broad range of ophthalmology patients' attitudes toward accessing their eye clinic notes online.

Methods

Setting and study design

At the time of this study, University of Washington (UW; Seattle, WA, USA) patients had access to a secure patient portal through UW's software vendor, EPIC (Verona, WI, USA: www.EPIC.com). That portal included problem lists, medication records, and laboratory and radiology reports, but not doctors' clinic notes. Patients from three UW ophthalmology clinical sites that used EPIC were surveyed prior to the implementation of OpenNotes to determine their baseline perceptions of potential benefits and harms of accessing their eye clinic notes online. The Eye Institute at Harborview Medical Center was the largest attending physician clinic site, the Eye Center at UW Medical Center was a smaller attending physician clinic site, and the third site was the resident ophthalmology clinic at Harborview Medical Center. One month after survey data were collected, patients were offered access to their full medical record, including access to their ophthalmology clinic notes, for the first time as part of the OpenNotes initiative.

Survey content and design

The patient survey included 28 questions on self-reported health, patient-doctor communication, privacy concerns, demographics, and the potential impact of access to their EMR on health behaviours, such as medication adherence, self-care, and preparation for clinical visits. Most (21 of 28) survey questions were the same as those used in primary care clinics during the original OpenNotes study and were based on validated, previously published surveys.[10–13] The remaining seven survey questions were specific to eye health or Internet usage. The survey is available as an online Supporting Information.

Participant recruitment and enrolment

Patients were invited to complete the baseline survey during a 4-week period from August 2014 to September 2014. Survey staff spent 3 weeks in the Harborview Eye Institute and 1 week in each of the other two clinics. The three clinics provide comprehensive eye care, as well as specialty care for glaucoma, corneal diseases, vitreoretinal diseases, orbit and nerve diseases, neuro-ophthalmology, and cataract and refractive surgeries. All patients who had clinical visits at the eye clinics during the recruitment period were prescreened by front desk staff for survey eligibility. Only patients who were aged 18 years or older, not cognitively impaired, had not previously taken the survey, and were able to read and/or understand English were eligible to participate. Eligible patients who were interested in participating completed a consent form and the survey. Study staff assisted patients with reading the consent and survey if desired (e.g., in the case of patients whose treatment included pupil dilation). A $25 gift card was raffled for incentive.

Analysis

Descriptive statistics (means and standard deviations for continuous data, and frequencies or percentages for categorical data) were used to summarise baseline patient characteristics—age, gender, self-reported ethnicity, education, and the number of hours spent online. Comparison of respondent and non-respondent characteristics could not be conducted due to the lack of clinical information on non-respondents.

The five-point Likert scales for measuring patients' interest in or concerns about access to their online eye clinic

notes were collapsed into binary outcomes of 'agree/somewhat agree' and 'disagree/somewhat disagree.' The 'don't know' category was excluded from the analysis. The proportion of missing values was less than 5% for most questionnaire items, thus we did not adjust or impute for missing values.

Pearson's chi-square test (χ^2) was performed for categorical variables and *T*-tests for continuous variables to assess possible differences between clinic locations in regard to patient baseline characteristics, interest or concerns about access to EMR, and patient confidence in doctors. When expected frequency values were <5, the Fisher Exact test was used. Normality was assessed using Q–Q Plot and the Shapiro–Wilk test. For statistical tests, the significance level was set at a probability value <0.05. All reported *p* values and confidence intervals are two-sided. Statistical analyses and data management were conducted using Statistical Package for the Social Sciences (SPSS) Version 21.0 for Windows (IBM Corporation, Armonk, NY).

Human subjects protection

All participants gave their informed consent prior to inclusion in the study, and all study procedures were approved by the UW Institutional Review Board.

Results

Data collection occurred at three clinic sites over a period of 20 days (*Figure 1*). A total of 1429 patients were seen in the clinics during the study period: 1162 at the two attending physician clinic locations and 267 at the resident clinic location. Of those patients, 412 (29%) were not eligible and 328 (23%) were not approached, usually because there were too few survey personnel available for the number of patients at that time in clinic. Of the remaining 689 eligible patients, 238 (35%) declined to take the survey, and 451 (65%) completed the survey.

The majority of respondents came from the main faculty practice site, the Harborview Eye Institute (n = 397, 88%), with an additional 16 (4%) responding from the faculty Eye Center at the UW Medical Center (which only has one attending physician each day), and the remaining 38 (8%) responding from the resident ophthalmology clinic at Harborview Medical Center. The mean age was 58 years old (S.D. 16, range 18–97), and 54% of respondents were female; 73% of respondents were white, 10% Asian, 8% black, and 4% Hispanic/Latino; 29% attended some college or were 2-year college graduates, 23% were college graduates, and 33% attended graduate school or had a masters or doctoral degree (*Table 1*).

Most patients agreed that making eye clinic notes available online to patients was a good idea (95%) and said they would like to be able to view their notes online (94%). Most (80%) also reported that they might share their eye clinic notes with a family member, whereas 46% indicated they might share their eye clinic notes with another doctor or health care provider; only 4% did not think they would show or discuss their eye clinic notes with anyone else.

Patients also were asked what concerns they had about access to their EMR and what benefits they anticipated (*Figure 2*). Although 14% said they would worry more if they could read their doctors' notes, the majority (86%) disagreed that they would worry more. Fewer than half (44%) agreed that access to their EMR would make them concerned about privacy. Most felt that OpenNotes would help them be more likely to take their eye medications as prescribed (77%), take better care of themselves (84%), be better prepared for visits (89%), feel more in control of their eye care (90%), better remember their eye care plan (94%), and better understand their eye conditions (95%).

Patients generally expressed confidence in understanding and communicating with their eye doctors. Patients rated their ability to understand ophthalmology notes at 7.5 on a 10-point scale, from 1 (not at all confident) to 10 (extremely confident). Over half (55%) were 10/10 confident they could get their doctor to take their chief eye health concern seriously, and 63% were 9/10 or 10/10 confident in their ability to make the most of their visit. Patients also expressed high confidence levels in their doctors, with 56% rating confidence in their doctor as 10/10 and an additional 24% rating their confidence as 9/10.

No patient demographics or health characteristics were associated with patients' belief about whether access to their EMR was a good idea. Only self-described Internet usage was associated with whether or not participants reported that they would look at their electronic ophthalmology notes. Compared to patients who use the Internet 2–16 h per week, patients who use the Internet fewer than 2 h per week were less likely to say they would like to look at their ophthalmology clinic notes on a secure Internet website ($p < 0.001$) and were also less likely to say access to their EMR would make them better prepared for visits ($p = 0.002$). Patients who use the Internet fewer than 2 h per week were more likely to say they would be concerned about their privacy ($p = 0.02$).

Patient attitudes about OpenNotes were the same regardless of age or gender, except that older patients reported less concern about privacy ($p = 0.001$), and more women than men stated that access to their EMR would make them feel more in control of their eye health (94% vs 86%, $p = 0.009$). However, ethnicity was a significant variable for four questions. Non-white patients were more likely than white patients to say that access to their EMR would help them take better care of themselves (90% vs 81%, $p = 0.039$) and take their eye medications as prescribed

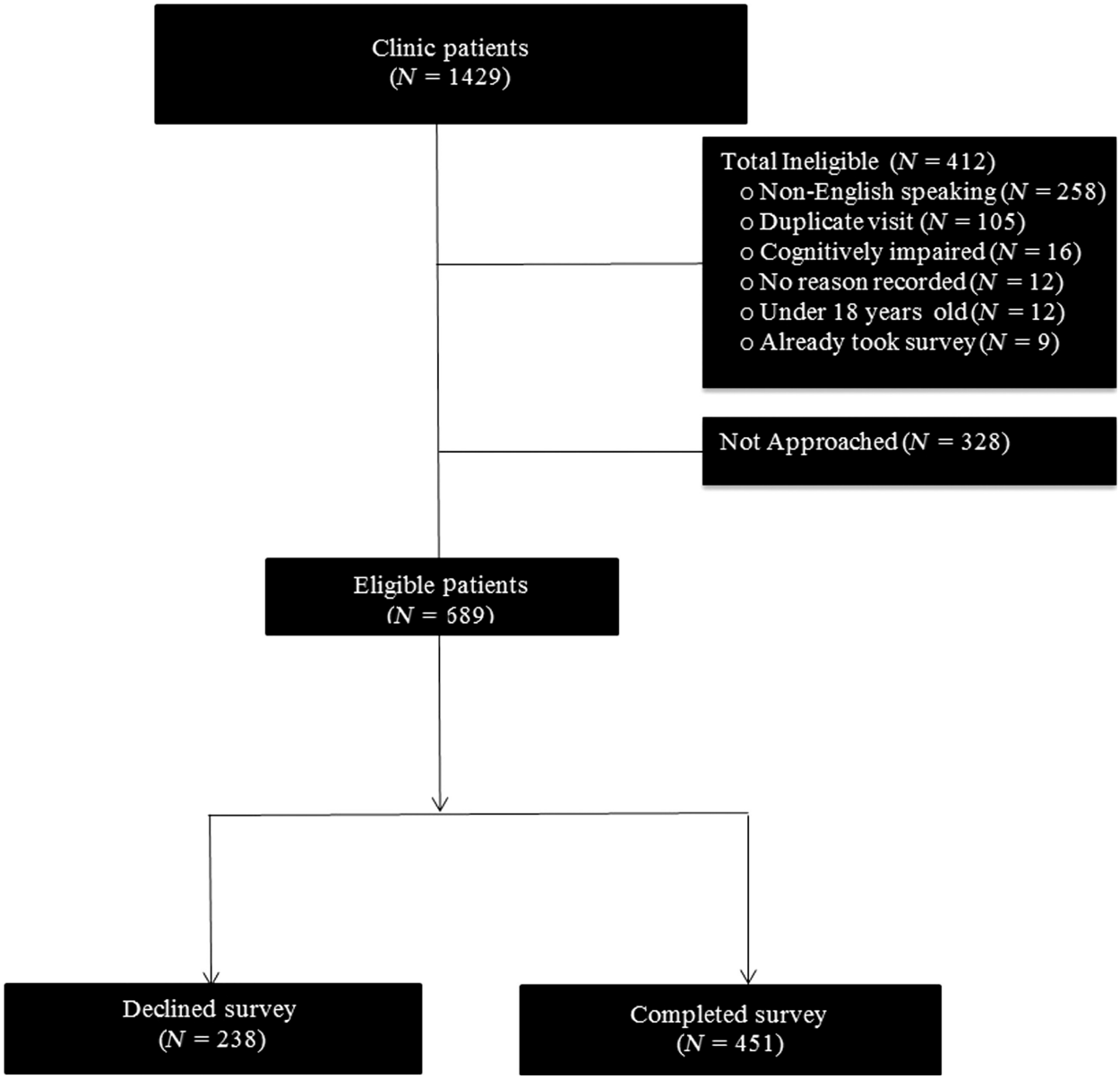

Figure 1. Survey population for the 20 clinic days in the study period.

(85% vs 74%, $p = 0.02$). However, non-white patients were also more likely to express worry (28% vs 13%, $p < 0.001$) and were more concerned about their privacy (55% vs 38%, $p = 0.001$). Education was not significantly associated with patient attitudes except for one question: patients who had at least some college were less likely to say that access to their EMR would make them worry more ($p < 0.001$).

Self-reported general health status was not a statistically significant variable for any of the attitudes surveyed. However, compared to those with good or excellent vision, those with worse self-reported vision status (fair/poor/very poor) were less likely to agree that access to their EMR would help them better understand their eye problems (97% vs 92%, respectively; $p < 0.02$) and more likely to say that access to their EMR would make them worry more than those with good or excellent self-reported vision (9% vs 19%, respectively; $p = 0.005$).

Subgroup analysis

The participants seen at the Harborview resident clinic were demographically different from the other two sites, being statistically significantly more likely to be younger (53 vs 59 years old, $p = 0.001$); male (79% vs 43%,

Table 1. Characteristics of ophthalmology clinic patients who responded to the survey about upcoming patient access to online clinic notes (n = 451)[a]

Patient characteristic	*n* (%)
Age	
18–39	63 (15)
40–49	48 (11)
50–59	83 (19)
60–69	129 (30)
≥70	108 (25)
Gender	
Women	235 (54)
Men	201 (46)
Ethnicity[b]	
White	327 (73)
Black or African American	36 (8)
American Indian or Alaskan Native	12 (3)
Asian	44 (10)
Native Hawaiian or Pacific Islander	7 (2)
Other	22 (5)
Spanish/Hispanic/Latino ethnicity	
Yes	19 (4)
No	418 (96)
Highest grade of education completed	
8th grade or less, some high school, did not graduate	15 (4)
High school graduate or GED	47 (11)
Attend college but didn't graduate	76 (18)
2-year degree graduate	50 (12)
4-year college graduate	101 (23)
Some graduate school	29 (7)
Masters or doctoral degree	114 (26)
Average no. hours per week spent online, excluding e-mail	
<1	82 (18)
1–2	61 (13)
2–5	88 (20)
5–10	72 (16)
10–15	57 (13)
≥16	85 (19)
Self-reported health status	
Excellent	39 (9)
Very good/good	310 (72)
Fair/poor	84 (19)
Self-reported vision status	
Excellent/good	204 (47)
Fair/poor/very poor/blind	228 (53)

[a]Numbers do not add up to n = 451 for all categories due to missing values.The number of patients with missing data on specific variables was as follows: age = 20; sex = 15; Latino ethnicity = 14; education = 19; no. hours spent on online = 6; self-reported health = 18; self-reported vision status = 19.
[b]Multiple responses allowed.

$p < 0.001$); non-white (47% vs 26%, $p = 0.04$); and less educated ($p < 0.01$). In addition, patients in the Harborview resident clinic were significantly more likely to be excluded because they did not understand English (43% vs 14%, $p < 0.001$). There was no significant difference in self-reported Internet usage, health status, or vision status among survey participants at the three sites.

Compared to the other respondents, the patients in the Harborview resident clinic were significantly less likely to agree that OpenNotes was a good idea (83% vs 96%, $p = 0.001$) or that they would like to look at their notes (82% vs 95%, $p = 0.03$). They were also less likely to say they might show their notes to a family member (61% vs 81%, $p = 0.003$) or another doctor (32% vs 59%, $p = 0.001$), as well as less likely to show or discuss their notes with anyone (16% vs 7%, $p < 0.05$). Despite this relative lack of enthusiasm at this clinic, these patients did not express greater concerns about privacy or worrying more due to EMR access. The Harborview resident clinic patients also rated their ability to understand ophthalmology notes lower (6.6 vs 7.6 out of 10, $p = 0.04$).

Discussion

To our knowledge, this is the first survey to gauge the interest of ophthalmology patients in obtaining online access to their clinic notes and to describe patients' perceptions of the potential clinical usefulness of receiving online access to their EMR. Ophthalmology patients were enthusiastic about online access to their doctors' notes and expressed hopes that this access would improve their eye health.

The eye clinic patients in this study showed remarkably similar enthusiasm to those in OpenNotes surveys of primary care patients.[14] In the original OpenNotes pre-implementation survey, around 95% of primary care patients (compared to 95% of eye clinic patients in this survey) said access was a good idea. For other survey questions about possible benefits, the ophthalmology patients in this study had identical or slightly more positive attitudes about access to their EMR.

Patient concerns were also similar to the original OpenNotes survey, with about 14% of primary care patients also saying they would worry more (compared to 14% of eye clinic patients). Slightly more ophthalmology patients were worried about privacy (42% vs 34–38%), which might reflect the number of recent highly-publicised breaches of patient information.[15] Moving forward, the impact of both potential benefit and possible harms of patients' viewing their medical records needs to be further studied. For instance, patients who are able to view pathology or radiology reports without appropriate counselling may become confused by these reports as well as by clinic notes.

Although non-white patients expressed more concern about possible difficulties arising from access to their EMR than white patients, they also were more likely to view this access as a tool to improve their self-care and medication compliance. In eye care research, non-white racial identification has been associated with less adherence to

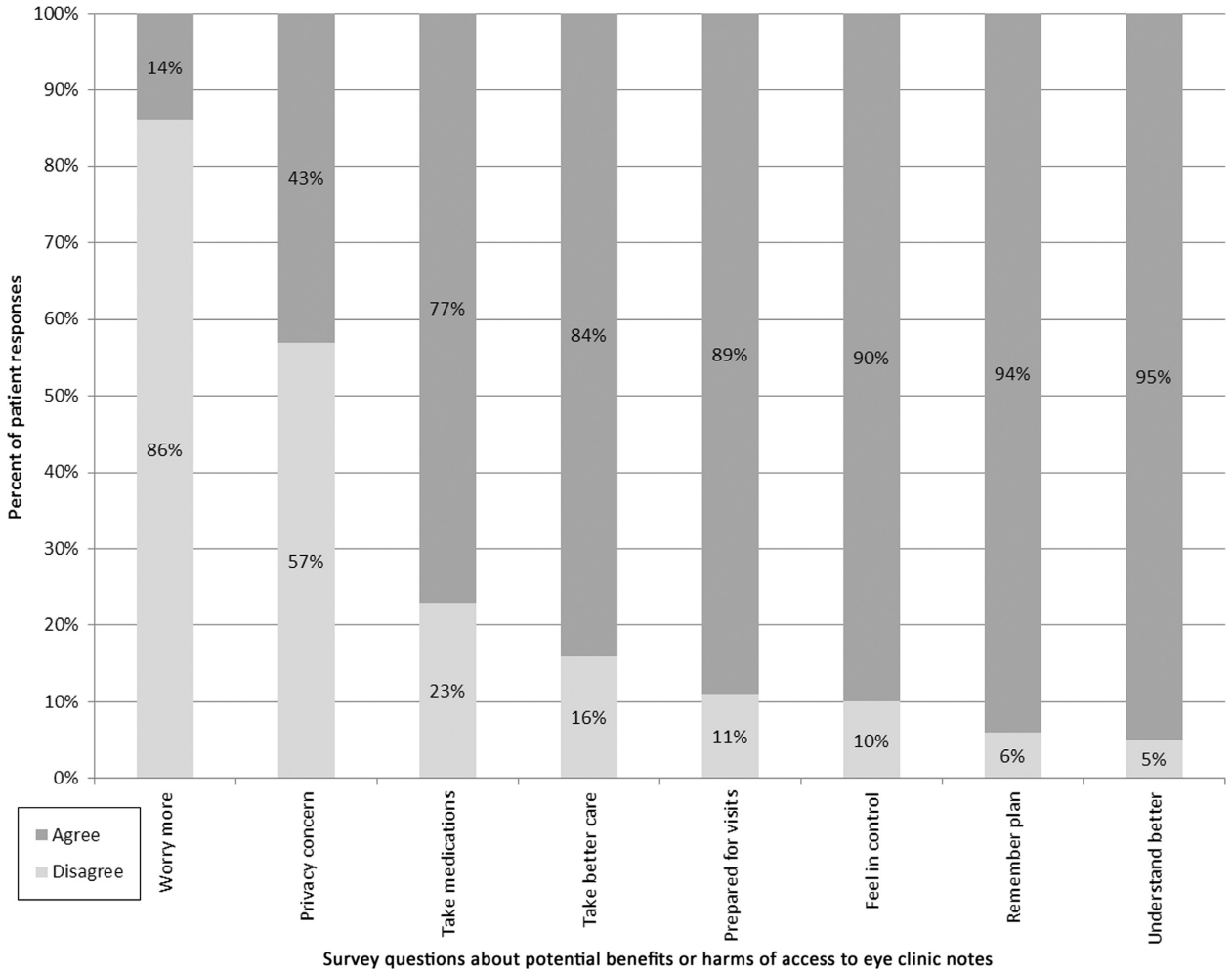

Figure 2. Patients' perceived benefits and harms of accessing their eye clinic notes.

medications and follow-up care.[16,17] Previous studies have also reported that a high percentage of non-white patients perceive racism in their doctor-patient interactions and that many non-white patients view their interaction with their doctor as less participatory than white patients.[18,19] Therefore, the optimism that non-white patients express for EMR access as a tool to improve their eye self-care is encouraging, especially given the higher prevalence of ocular hypertension and glaucoma in Latino populations[20] and in populations of African origin.[21.]

Prior studies concerning shared decision-making have shown that female patients ask their doctors more questions, get more information, and have more patient-centred interactions than male patients.[22] This may explain why women in our study were more likely to believe that access to their EMR would help them feel more in control of their eye care.

The ophthalmology patients from the Harborview resident clinic showed less enthusiasm for viewing their online EMR, even when excluding non-English speakers. However, patient portals to online EMR still may be a valuable way to increase engagement given that greater than 80% of participants in the resident clinic thought EMR access was a good idea and expressed interest in seeing their ophthalmology notes. Since the medical records are in English, non-English speakers were excluded from this survey. Therefore, other ways of increasing eye care education and engagement in non-English speaking populations are necessary, such as offering an embedded translation function into online clinic notes or providing caregivers access to the portal.

Limitations of the study include that this was a self-reported survey, included three academic eye clinics from the same institution, and involved ophthalmology patients with a high level of pathology.

Future studies should determine how often patients actually access their eye clinic notes and how useful they and their caretakers find them. We have previously studied

patients signed up for the EMR patient portal in our overall health system that includes all primary care and specialty outpatient clinics. We found that 60% of our patients viewed laboratory results online when they became available; 51% of patients viewed a new radiology report when it was available online; and 34% of patients viewed a new clinic note when it became available.[23] It would also be helpful for future studies to survey providers to see what effects—if any—providing patients online access to their EMR has had on their practice and the content of the clinic notes. In our healthcare system, we have noted a reduction in use of abbreviations and other efforts to simplify and better organise the clinical records.[24.]

This survey shows for the first time that a demographically diverse spectrum of ophthalmology patients has great interest in reading their eye clinic notes online. Patients increasingly expect transparency, and more healthcare providers have begun taking the initiative to provide patients online access to their EMR. In this survey, most ophthalmology patients across a range of demographic groups thought that such access would be beneficial.

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Disclaimer

OpenNotes (www.opennotes.org) is not a software program; it is a national initiative that invites patients to review their own clinic notes.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Data S1 Open Notes Survey