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Engaging patients through open notes: an evaluation using mixed methods

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ABSTRACT

Objectives: (A) To gain insights into the experiences of patients invited to view their doctors' visit notes, with a focus on those who review multiple notes; (B) to examine the relationships among fully transparent electronic medical records and quality of care, the patient-doctor relationship, patient engagement, self-care, self-management skills and clinical outcomes.

Design: Mixed methods qualitative study: analyses of survey data, including content analysis of free-text answers, and quantitative-descriptive measures combined with semistructured individual interviews, patient activation measures, and member checks.

Setting: Greater Boston, USA.

Participants: Patients cared for by primary care physicians (PCPs) at the Beth Israel Deaconess Medical Center who had electronic access to their PCP visit notes. Among those submitting surveys, 576 free-text answers were identified and analysed (414 from female patients, 162 from male patients; 23–88 years). In addition, 13 patients (9 female, 4 male; 58–87 years) were interviewed.

Results: Patient experiences indicate improved understanding (of health information), better relationships (with doctors), better quality (adherence and compliance; keeping track) and improved self-care (patient-centredness, empowerment). Patients want more doctors to offer access to their notes, and some wish to contribute to their generation. Those patients with repeated experience reviewing notes express fewer concerns and more perceived benefits.

Conclusions: As the use of fully transparent medical records spreads, it is important to gain a deeper understanding of possible benefits or harms, and to characterise target populations that may require varying modes of delivery. Patient desires for expansion of this practice extend to specialty care and settings beyond the physician's office. Patients are also interested in becoming involved actively in the generation of their medical records. The OpenNotes movement may increase patient activation and engagement in important ways.

Strengths and limitations of this study

- This study uses rigorous qualitative methodology and descriptive quantitative measures to understand the experience of patients who both utilise health services frequently and read their primary care physician's visit notes online.
- It compares free-text survey responses from samples of patients who frequently read their encounter notes to responses from those who made little use of this option.
- It draws on face-to-face interviews with an information-rich, purposive sample of patients who had read notes from many visits. The results suggest that patients who read their notes are actively engaged in their care and have a better understanding of their health and care, but the generalisability of the findings is limited because patients who were cared for in a single institution differed from a majority of patients nationally by virtue of having registered on secure electronic patient portals.

INTRODUCTION

Easy access to personal health information has long been on the 'wish lists' of patients and their advocates,[1–5] and modern health information technology, the Internet, and secure patient portals have dramatically increased the possibilities for patients.[6–9] In the USA, the Health Insurance Portability and Accountability Act (HIPAA), enacted in 1996, affords patients the right to access their clinical information and medical records, except in rare circumstances primarily involving major mental disorders. However, until recently, it has been difficult for patients to gain access, and only rarely do they review the notes their clinicians write following encounters, both in the ambulatory setting and on hospital wards. Today, electronic health records (EHRs), coupled to patient-facing, secure Internet portals, facilitate access if providers decide to offer it, and such portals are spreading rapidly, partly in response to federal incentives.[10–13] More than five million patients in the USA are now registered on portals that offer ready and secure access electronically to their clinicians' notes.

Many argue that EHRs should support transparent clinical communication with patients,[14–16] but the practice remains controversial.[17–24] Doctors worry about disturbances to their workflow and fear frightening some patients. At a time when electronic information breaches are widely publicised, some worry that general concern about loss of privacy may lead patients to withhold information or refrain from visiting doctors when care may be indicated. On the other hand, easy access to records may encourage underserved populations to engage more actively with the healthcare system.[25 26]

Secure electronic patient portals offer the opportunity to improve patient education,[27 28] the management of chronic conditions[29 30] and efficiency of care[31] by shifting care from a prime focus in the doctor's office towards more integrated perspectives that include patients' daily lives, homes, caregivers and families.[32–35] Transparent hospital records may promote more information sharing in clinician–patient communication.[36 37] Overall, information gaps may be narrowed, thereby facilitating better continuity and integration of care.[38–40] Patients appear to value the convenience of easy and flexible access,[41] and individuals with poor health status may, in particular, benefit by being able to share their information with family members and other informal caregivers.[42 43]

OpenNotes, a rapidly expanding national movement in the USA that encourages clinicians to offer patients ready access to their encounter notes, began as a demonstration and evaluation study in 2010, with 105 volunteer primary care physicians (PCPs) and 19 000 of their patients in Boston, rural Pennsylvania, and the Seattle inner city.[44–47] Notified automatically via a secure email message when a note was signed, patients were invited to review their doctors' notes, and they were again encouraged to do so prior to a next scheduled visit. Results from the 1-year evaluation were striking and attracted considerable attention from professional groups and consumers.[48] Four of five patients read their note(s); two-thirds of those surveyed a year after the experiment started reported potentially important clinical benefits; 99% of the patients completing surveys wanted the practice to continue, whether or not they chose to read the notes; and 85% indicated that access would be important for their future choice of a provider or system. Perhaps most strikingly, at the end of the study, no doctor chose to discontinue the practice. Since this study, the findings have been replicated in several other settings, including hospitalised patients,[49–51] and today the entire Veterans Administration health system, many major academic health centres, large health systems and increasing numbers of smaller institutions in urban and rural settings in the USA are adopting the practice (http://www.myopennotes.org). Although percentages of patients reading their notes may differ, study results indicate that patients both value and benefit from online access to clinical notes, and adherence for some medications may indeed improve.[52]

Patients can read their notes at home or wherever they want, that is, asynchronously and repeatedly, and can readily share their notes with people of their choice by downloading them and forwarding them, or by inviting others to read them on a computer, tablet or smartphone. Some users now have 5 years of experience with open notes, and many patients have become frequent users. We decided to revisit this 'expert' population and to gather further insights through a systematic analysis of free-text comments offered in the patient surveys, and through in-depth interviews with individuals with a heavy burden of illness who reviewed their notes frequently.

Objectives of this study

1. To characterise the patient experience with open notes and, in particular, to identify and describe themes that emerge from patients making primary care visits and reading their notes with high frequencies;
2. To examine whether and how open encounter notes are linked to patient engagement;
3. To evaluate from the frequent user's perspective how open encounter notes/transparency relates to self-care/self-management, patient outcomes, quality of care and the patient–physician relationship.

METHODS

This study used a mixed methods research design (figure 1). We examined free-text responses and patient characteristics from the Beth Israel Deaconess Medical Center (BIDMC) survey respondents participating in 2010–2011, with the quantitative findings published in 2012.[48] Baseline surveys (n=4545) were collected to examine the preintervention study population characteristics and expectations before exposure to open notes.[45 46] Patients were eligible if they had been registered on the patient Internet portal for at least 1 year before the start of the study, and if their PCPs agreed to offer them electronic access to their office notes. Patients were surveyed online before and after the intervention. To permit comparisons between preintervention expectations and actual experiences, postintervention surveys were based largely on the baseline surveys. Postintervention data collection occurred after approximately 1 year of exposure to open notes. At BIDMC, 10 355 patients finished the intervention with 6678 providing postintervention surveys. With this original data pool of preintervention and postintervention surveys, we started our evaluation by probing for note availability/reading frequencies (figure 2). Besides free-text examination in the original survey data set, we also interviewed individual BIDMC patients who had read multiple notes during and after the original study period. For our study, we applied several qualitative methodologies and standards: grounded theory formation/grounded hermeneutic approach, crystallisation/immersion techniques, content analysis and multiple triangulation measures including member checking on various levels.[53–63]

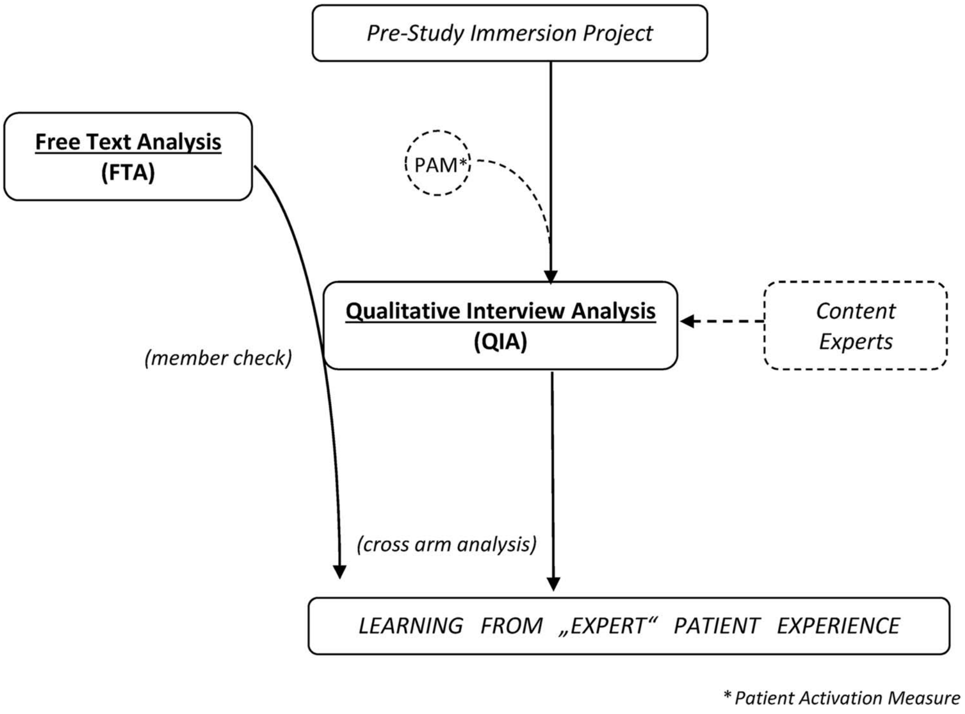

Figure 1 Study design—Data analysis and triangulation sequencing. Approach: mixed methods—qualitative. Left side illustrates the survey arm of the study (analysis of OpenNotes survey data: free-text analysis); centre/right side depicts the interview arm of the study (analysis of qualitative interviews with OpenNotes 'experts'); both arms interact (inform) and finally merge into each other—for further explanation, see text. Abbreviations: FTA, free-text analysis; QIA, qualitative interview analysis.

We began with a prestudy immersion project[64] (see online supplementary appendix 1). We developed a list of 100 questions to derive key points for exploration. The immersion project yielded the structure for the interview guide.

Our study contained two arms, an analysis of the free-text survey responses (FTA) arm and an evaluation of the qualitative interviews (QIA) arm (figure 1). Seeking insights into patients' expectations and experiences, in the FTA arm, we examined patients' free-text responses

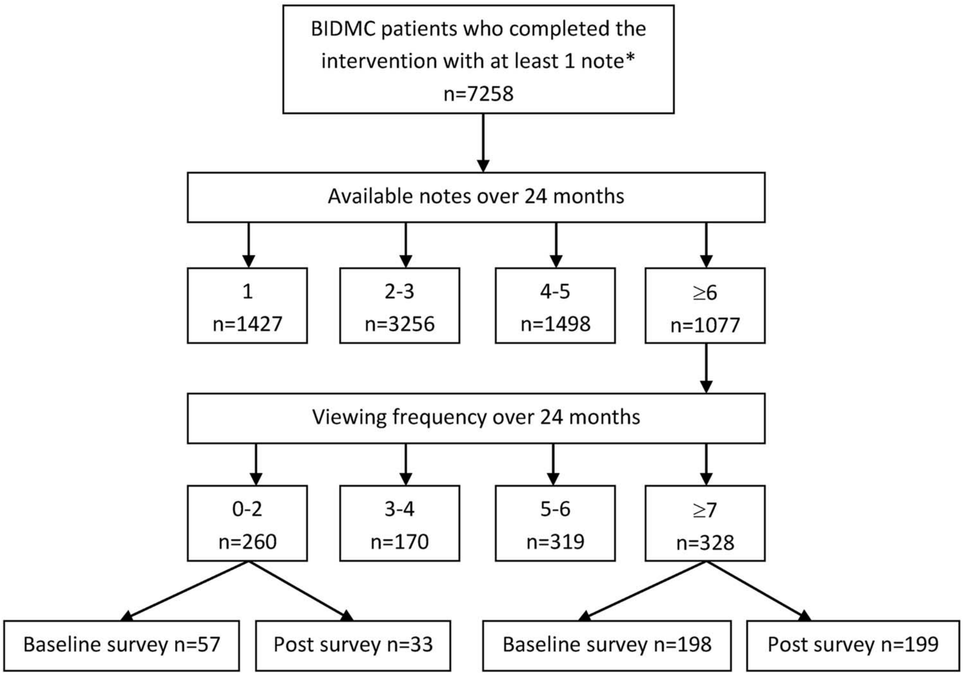

Figure 2 Patient/Survey flow—free-text analysis project (FTA). *Totals include only initial note and progress note (other notes/contacts such as telephone or letter not counted). Abbreviation: BIDMC, Beth Israel Deaconess Medical Center (Boston).

both in baseline (expectations) and postintervention (experiences) surveys collected before and after the original study period (see online supplementary appendix 2). We included responses from patients who had access to at least six notes from the start of the OpenNotes intervention until 1 year after its completion (24 months). Among patients with ≥6 notes available, we included comments from both those who had read at least 7 notes and those who had read 0–2 notes (figure 2). We iteratively analysed these comments and created a codebook using inductive methodology and constant content analysis ('analytic induction').[65, 66] During this process, we kept baseline and postintervention data separate, as well as data from low and high-frequency users, and started our analyses with baseline data, then going through the various data subsets (low and high-frequency users at pre- and at postintervention, respectively). Once the codebook was formed and stable, following various iterative cycles of data examination (starting with all portions of data subsets, then examining the entire data at a stretch), we again analysed and then coded the complete data set, thereby creating a comprehensive picture of the free-text survey content. In order to still allow for distinct views and comparisons, for example, between low to high users and pre to post data, we set up a quantitative descriptive analysis of code counts and frequencies in the various subgroups. For this analysis, we used Atlas.ti, V.7.

In the qualitative interview analysis (QIA) arm, we conducted semistructured, in-depth, face-to-face interviews with English-speaking 'heavy user' patients, defined as those who read at least 8 notes in a 24-month period. We recruited these patients as information-rich key informants[67] by sequential inclusion from a purposive sample (figure 3). We stopped these interviews when we reached thematic saturation. The interviews focused on engagement and self-care, and each patient completed the patient activation measure (PAM-13) survey.[68, 69] All interviews were conducted in 2014 (February–March) in Greater Boston and were recorded and transcribed verbatim using a transcription service. Additional field notes were taken during the interviews.

The QIA and FTA were followed by a data consolidation/reconciliation phase (figure 1). This cross-arm analysis combined the two arms as we searched for a richer understanding of key themes.

TE and BP performed the data analysis and coded independently, using different styles for each target population and research objective (eg, immersion/crystallisation, editing and template). We used multiple measures of triangulation to ensure credibility, dependability, transferability and reflexivity. We asked three PCPs (2 female, 1 male, age 44–56) with extensive OpenNotes experience (working with it for >40 months, independent of the research team) to serve as content experts (figure 1).

In an attempt to avoid 'socially desirable' comments in favour of the OpenNotes initiative, the interviewer (TE) stressed his neutrality and independence at the start of each interview session. In addition, to avoid 'framing effects', he provided no inside information (such as scientific data or recent or unpublished evidence).

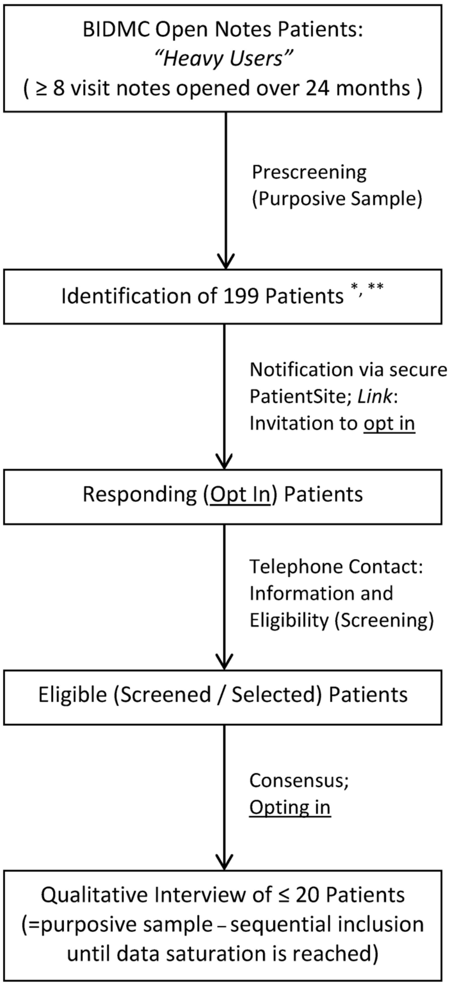

Figure 3 Recruitment chart for qualitative interview analysis project (QIA). *Median notes available=10 (IQR: 9, 12). **Median notes viewed=9 (IQR: 8, 11). Abbreviations: BIDMC, Beth Israel Deaconess Medical Center (Boston); QIA, qualitative interview analysis.

All study procedures were approved by the institutional review board (IRB) of the Beth Israel Deaconess Medical Center, Boston.

RESULTS

Themes from the survey arm (FTA)

A total of 487 patient surveys met our inclusion criteria (figure 2), and these were analysed for free-text content. The number of utilisable free-text answers was 576 (female: 414, male: 162; age: 23–88 years), with a word range of 2–416; the majority of answers ranging from 50 to 150 words. During our analysis, we identified 1980 codes that then populated the codebook that emerged in the iterative analytic process (see online supplementary appendix 3). We made adjustments to the codebook until we achieved saturation. Inter-rater reliability was 0.977 after the first round, and 1.0 after the second round of reconciliation. A third independent coder, who was prepared to step in in case of unsettled incongruities, was not mobilised.

Five themes were identified: understanding, relationship, quality, self-care and improvements for the future, with up to 15 distinct codes in each domain (figure 4). The most frequently cited codes addressed the use of clinical notes for refreshing memory, improved understanding of one's own health information, and confirmation of one's understanding (figure 5). Patients also frequently reported improved trust in the physician–patient relationship and better quality through using the notes as a reference. Adherence and compliance were also reported as enhanced due to improved clarity of health information. In the self-care domain, increased patient-centredness and a greater sense of control (reduced helplessness) were most frequently cited. Finally, regarding future improvements, a wish for more or all doctors to participate in the OpenNotes movement was predominant.

Quantitative-descriptive analysis (table 1, online supplementary appendix 4) demonstrated that more experience with open notes correlated with fewer concerns and more perceived benefits. Compared to those who had read 0–2 notes, high users (those who had read at least 7 notes) reported less confusion or fewer safety and privacy concerns, along with an increase in trust, motivation and feeling of control. Female patients differentiated themselves from male patients by more frequently mentioning better understanding of their doctor's work (and higher appreciation of their skills), together with an increased ability to refresh memories of visits as a benefit of reading notes. Patients with mental disorders (defined as 2 visits with a diagnosis of psychosis, depression, anxiety or substance abuse; or one visit with a prescription for a psychiatric medication) wrote more frequently about better communication with their doctors, better care coordination, and increased ability to self-manage and self-coordinate (including decreased feelings of stress/challenge or distraction during visits) than did patients without mental disorders. Compared to those in better health, people who reported fair/poor health more frequently described better care coordination as a result of reading notes. Activation and engagement as general aspects of the patient experience with open notes were mentioned in particular by those who had reported fair/poor health conditions prior to the actual experience (at study baseline), in addition to those who reported good health at the end (compared to excellent/very good or fair/poor at this point). Non-white patients more often reported better clarity of health information, higher motivation about their health and increased confidence and encouragement.

Themes from the interview arm (QIA)

Thirteen patients were interviewed (table 2). The average length of interviews was 40 min. We administered the PAM questionnaire at the end of each patient interview; it took an estimated additional 7 min.

Analysis of the transcripts confirmed the codebook and its themes (see online supplementary appendix 5).

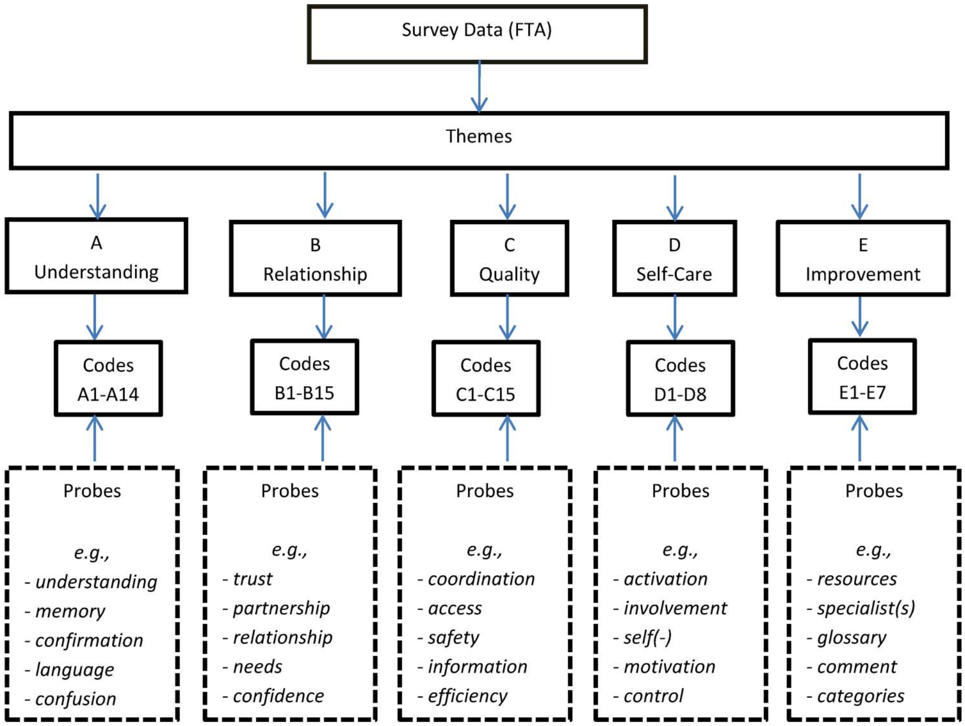

Figure 4 Overview of theme and code structure (theme-code identification).

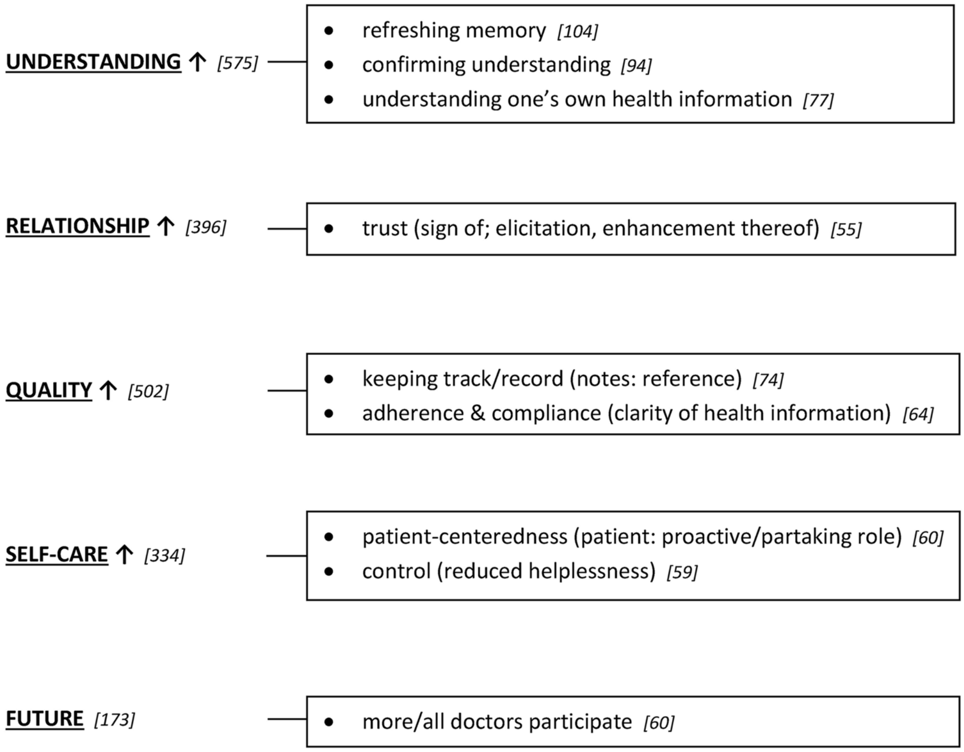

Figure 5 Overview of frequency analysis. Most frequently checked codes from codebook—results from free-text answers/survey data (FTA), organised on per domain/theme basis. Left side= themes (domains); right side= codes. Numbers depicted in square brackets reflect the numbers of identified codes (with the numbers on the left side—following each theme—expressing sum scores=absolute numbers of identified codes per theme; the numbers on the right side—following each depicted code—expressing how often a specific code was identified). Note: Arrows behind each theme indicate the overall direction of reported effects (in this case: improvements/increase in all domains following/in view of OpenNotes practice).

Table 1 Overview of quantitative-descriptive analysis* results

These patients	More often described these impacts	Than these patients
With experience (at study end)	Seeing/reporting more benefits Less concerns	Without experience (at baseline)
Read ≥7 notes	More reassurance/confirmation Feeling that the doctor understands the patient better Decreased confusion Better trust in the doctor Patient–doctor relationship strengthened Increased experience of transparency (as a quality indicator) Fewer safety/privacy concerns Better keeping track of health information Feeling more engaged Feeling more motivated about their health Feeling more in control	Read 0–2 notes
Women	Better refreshment of memory (of visits)	Men
With Mental Health problems	Better communication with doctors Experiencing higher coordination of care More self-management and self-coordination Feeling less challenged/distracted during visits	Without Mental health problems
Fair/poor health	Experiencing higher coordination of care More self-care	Good to Excellent Health
Non-white	Increased confidence, feeling secure/well-cared for More clarity of health information, adherence/compliance Feeling more motivated about their health Feeling actively encouraged	White

Summary of key findings from free-text answers/survey data (FTA).
*Quantitative analysis was performed with support of Atlas.ti software (V.7)—see Methods section.

Among these high users, few reported safety and privacy concerns (two of 13 interviewees), and four reported sharing their notes with others. Some expressed the possibility of withholding information during visits because of worries about others gaining undesired access. The overall patient experience was characterised with terms of transparency, trust, easy access, efficiency, health benefits, harm avoidance, more involvement and feeling in control. Patients wanted more interactivity of notes, for example, the option to comment on notes or give input to have errors corrected. High users usually read single notes once or twice. The idea of an 'embargo' or delay in releasing notes was mentioned frequently, either for protecting patients from reading notes that could be overwhelming at a given moment, or to make sure that they would not accidentally read 'bad news' online before seeing their doctor in person.

High-use patients appeared strongly motivated, involved, active and engaged in their care. This group had a positive attitude towards self-care; at least 75% of the codes from the self-care domain of our codebook were met (checked) in all 13 interviews, and a third of them explicitly matched with 100%. However, this finding was not always consistent with the PAM-13 scores (Table 2). For example, patients could conform to eight of eight self-care codes but still be placed in lower PAM ranges. Data analysis revealed that current medical condition (eg, facing chronic disease) and education (eg, professional academic background) are examples of factors that may have exerted influence on PAM scores: agreement with activation measures (as measured by PAM) did not in every case correspond to individual engagement reports and self-care approval (eg, interview analysis suggested higher activation scores for some participants).

Themes from cross-arm analysis

We performed a structured examination 'across-methods' to gain a more detailed and robust picture.

Overall experience, individual use and constraints

Frequent users of open notes were strongly in favour of an open, transparent and candid communication style, with easy access and high availability for them, but they still wanted to have personal and individual face-to-face time with their doctors as the primary means of communication. Patients wanted their doctors to tell them of serious or potentially stressful information and expressed caution towards 'automated' openness that might antedate contact with the doctor ("I guess my concern would be reading something at a time where you are physically not prepared to deal with what actually happened."). Patients described also how they felt 'empowered' or 'reassured' and used open notes in particular to refresh their memories of particular medical encounters, or generally as a 'memory aid' to track their health information ("I look at OpenNotes as a reassuring memory aid.").

Trust

Enhanced trust—regarded as a key part of an improved patient–physician relationship—was frequently reported ("I think it's important to know that I'm trusted as part of this relationship. And it helps me trust the doctor as well."). This was particularly true for female patients, patients without mental health problems and older patients. Self-rating of fair or poor health was also correlated with higher trust.

Clarity, error detection and correction

Better clarity of health information (reading notes resulted in better clarity) was often mentioned, particularly by patients with mental health problems, older patients and non-white patients. Clarity included clear—or clarification of—instructions, possibly improving adherence to and compliance with medications. In addition, almost all interviewed patients mentioned the experience of detecting errors in the notes, mostly non-medical or minor, and they usually did not contact the

Table 2 Descriptive data/study population—Characteristics of Interview Participants (QIA)

Participant ID	PAM score (level)	Age	Gender	Education	SR H
004	45.3 (1)	87	F	+c	OK
018	55.6 (3)	82	F	+c	OK
011	60.6 (3)	75	M	+c	Excellent
014	60.6 (3)	58	F	–c	OK
009	63.1 (3)	67	F	–c	OK
010	63.1 (3)	66	F	–c	OK
012	63.1 (3)	66	M	+c	Excellent
003	65.5 (3)	66	F	+c	OK
005	65.5 (3)	67	M	+c	Poor
016	65.5 (3)	69	F	+c	OK
017	75.0 (4)	60	F	+c	Excellent
013	84.8 (4)	73	F	+c	Excellent
006	90.7 (4)	77	M	+c	OK

PAM scores are depicted on a theoretical 0–100 point scale, with 4 possible levels—1 being lowest, 4 being highest (ranges following algorithm provided by PAM authors; rounded, from 0–47, 48–54, 55–70, to 71–100, respectively).+c, college education; –c, no college education; PAM, patient activation measure; SR H, self-rated health status.

doctors about errors, at least not before a next visit. Nearly all interviewed patients reported that reading notes led them to correct their therapeutic regimen in some way, with most changes focusing on medication intake. As examples, patients mentioned correcting wrong dosages or times of medication intake as a result of reading their notes. Patients frequently mentioned the OpenNotes initiative as having health benefits by possibly helping them avoid harm and improving the quality of their care. While virtually all patients found notes containing errors in documentation or medical instructions, they found them only on occasion (happening, as patients reported, only once or twice over the 2 years). As examples: "I discovered that the doctor has misunderstood something I said.", "It … sometimes clarifies my need and use of medications.", "I was [online] and happened to see that I was taking the wrong amount of prescription.", "The biggest benefit I see is being able to … double check."

Sharing, coauthoring notes and withholding information

The majority of frequent note users in our analyses did not share their notes, using them primarily for their own record-keeping. When sharing occurred, this often happened with health professionals within the (extended) family. Some patients mentioned the possibility of actively withholding information during a visit because of the chance of other people reading it, especially when visits included discussions about their spouses or family. Some noted that open notes could produce more efficient and structured, yet less 'private' visits, and views differed on whether this represented a loss or gain. Frequent users seemed eager to comment on notes, or have parts changed/adjusted ('customised'). While some desired an option to approve a note, coauthoring of notes was not their first choice. "I just don't want anyone to share it. … That's my own personal thing.", "I had it in writing for extended family to see also.", "The patient should have an opportunity to comment, and the doctor give feedback."

Self-care, control and engagement

These high users reported feelings of control and reduced helplessness, as well as active encouragement (feeling encouraged through reading the notes to take care of oneself or reflect on a visit and ask self-reliant questions). Control came up particularly for patients with mental health problems, with poor or fair health, and for men. These patients also referred to their ability to self-coordinate through the use of open notes. Patients described open notes as a stimulus or tool for helping them understand the importance of their playing an active, part-taking ('patient-centered') role in their own care. Member checking through individual interviews, however, revealed a distinction between patient-centredness as a 'whole person' (feels that the 'system' is built around the individual patient) and the actual experience of 'being at the centre of concern', which referred more to the actual problem that a patient presented, and how it was addressed. For the frequent users, their personal engagement seemed linked to the actual use of this tool. However, frequent users were not 'obsessive' about reading their notes; reading each note usually occurred once or twice. Additionally, frequency of reading was not correlated with self-rated health of patients. Overall, patients who felt more in control, more motivated, and had better understanding of their health, may have translated these sentiments into better self-management abilities. Quotes: "I take an active role … that's a tool to make that happen.", "It made me feel … proactive … and not just reacting.", "I want to know what's happening. I want to be right at the forefront.", "I am at the center of concern. I am not powerless."

DISCUSSION

Not surprisingly, frequent users of open notes reported positive experiences, with commentaries that suggest that patient activation and engagement may be fostered in important ways. Drawing on free-text commentary and detailed encounters with patients who have used open notes frequently over a couple of years, our analyses suggest that as patients reflect on the experience, their thoughts fall into five themes (domains) that focus on understanding, relationships, quality, self-care and hopes for the future. Within these themes, understanding came up most frequently, with emphasis on using doctors' notes for refreshing memory and improving or confirming understanding of one's own health information. In addition, patients pointed to increased trust, improved management of medications, and a stronger sense of control, and they hoped that easy access to doctors' notes would become more widespread.

These findings complement other studies. Earnest *et al*[70] reported that of all medical record components offered online, patients with congestive heart failure accessed their visit notes the most and felt empowered by this option. Patients in studies by Bjoernes *et al*[41] and Pagliari *et al*[31] were positive about experiences with open medical records, reporting improved communication and trust between patients and professionals, confidence in self-care, compliance and accuracy of records (also see Pyper *et al*,[71] Honeyman *et al*,[72] Woods *et al*,[49] Nazi *et al*[50]). In addition, Pyper *et al* attributed transparent clinician–patient interaction through personal health records to enhanced patient responsibility, participation and knowledge, overall health and quality of life, improved accessibility and relationships with health professionals, better care collaboration, and decreased errors and costs.

Two-thirds of the high-use patients in our study chose not to share notes with others. Despite multiple office visits, these patients were well enough to complete online surveys and to be interviewed. Perhaps reading notes is particularly important to those who, despite high utilisation, manage their own health without support from other caregivers. This population of high users also demonstrated high affinity towards self-care and active engagement. Code frequency analysis in the self-care domain and individual interviews revealed that this subset of patients is strongly motivated, active and engaged in their care.

Importantly, this finding was not always reflected in the PAM-13 scores, leading to the hypothesis that for a patient with chronic illness and debilitating limitations, a positive attitude towards self-care may need to be distinguished from actual ability to be active and self-engaged. Physical or situational factors, above and beyond engagement and activation formally assessed by PAM, may be of prime importance in this context. However, Mosen *et al*[73] tested PAM among adults with chronic conditions and found that patients with high scores were more likely to perform self-management behaviours or report high medication adherence, compared to patients with the lowest scores. This needs to be examined more thoroughly in future studies.

Another aspect that deserves more attention in future research is the applicability of open notes to target groups. Previous studies[48] found, for example, that about one-third of the overall study population had privacy concerns, but this was not reflected in the subset of high users examined in our study (about 15%), suggesting that ongoing use of open notes might decrease privacy concerns over time. Patient comments in interviews also support this view. Some researchers, however, assume underreporting of safety or privacy concerns in the context of EHR use.[74] Despite some patients truly experiencing challenges, they, in general, seem to value, benefit from and report predominantly positive experiences with health record transparency and the open sharing of notes.[49 50] The area of privacy and a possible relation to frequency of use, or burden of illness, needs further study.

Our findings are primarily hypothesis generating, and they are clearly limited in terms of generalisability, but we believe they carry some weight. We approached the research questions from multiple perspectives, combining different study arms and techniques. With formally developed design and measures, including prestudy explorations to support the construction of interview guides, our goal was both to reflect and refer to the full body of existing literature and knowledge in the field. In addition, we combined analyses of free-text survey data with qualitative interviews in which purposefully selected information-rich study participants offered insights on the patient experience. We were guided by the standards of data triangulation, analysis and legitimation and tried to minimise biases.

Despite all these efforts, the possibility of biased conclusions persists. Participants in the study differed from a majority of patients nationally by virtue of having registered on secure electronic patient portals. Moreover, we included patients from only one health system (BIDMC). This may also have caused health literacy and educational biases, which should be more thoroughly addressed in future studies. Since the interviewer (TE) was a doctor, patients may have offered responses different from what might have been elicited by a non-medical interviewer. Finally, attitude towards ‘their’ hospital, or ‘their’ doctor, or the use of the secure patient portal in general, or EHR use, may have affected responses (halo effects should be considered in both directions).

Our results highlight some areas for additional consideration. Some patients reported withholding information to avoid the chance that others might see it. Some wanted delayed access in order to allow time for bad news to be relayed by their doctors before reading it in the note. Some wanted to comment on notes or to correct them. To the best of our knowledge, portals and electronic medical records cannot currently handle individual patient preferences such as who can see what, or interactivity allowing commentary or other input from patients. We will need to develop these capabilities to be responsive to engaged and activated patients.

The OpenNotes movement has now spread to a growing number of organisations around the USA and has extended beyond primary care to include medical and surgical specialists, professionals focusing on mental disorders, nurses, physical therapists and other clinicians.[75 76] As the practice spreads, both consumers and health professionals have called for open notes to become the standard of care.[47 77] In ‘traditional’ practice (not providing patients with online access to their notes), 50% of patients may leave office visits without an adequate recall or understanding of what the physician has told them.[78] The American College of Physicians now expects increased transparency through open notes and improved clinical documentation, also calling for broad-based efforts for patient education, explaining, for example, that a good medical note should be accurate but brief, and not a verbatim transcript of clinical interaction.[79] Also, in examining missed and inappropriate diagnoses, the Institute of Medicine has recently recommended the adoption of open notes, in an attempt to mobilise patients and their families as active witnesses and evaluators of care.[80]

CONCLUSIONS

Open notes may increase patient activation and engagement in important ways. Patients in this evaluation suggest that reading notes helped improve their understanding of health information, fostered better relationships with doctors, improved the processes of care, and helped with self-care. They are also interested in becoming involved more actively in the generation of their medical records. As the use of fully open and transparent medical records spreads, it is important to gain a deeper understanding of the possible benefits or harms, and to characterise target populations that may require varying modes of delivery. Studying and exploring these aspects more deeply in the future will be important for developing a richer understanding of the effects of fully transparent records. However, for now, comments from one of the patients seem sensible:

"I do think that transparency is key and is quality of care. I think it's important for patients to understand truthfully what their situation is and how they can help themselves and be educated enough to be able to ask the right questions to physicians. Every patient has that right … and I think that OpenNotes helps that."

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Contributors TE, JW and TD conceived the study. TE, JW and TD were involved in designing the study and developing the methods. TE, JW and TD obtained funding. TE coordinated the conduct of the study and conducted the interviews, and together with BP read the survey and interview data (transcripts), developed the analytical framework/coding, and codebook, as well as performed the primary qualitative, and quantitative analyses with technical support of Atlas.ti software. RM was involved in statistical analyses and, together with MA in study administration, including patient recruitment and steering. TE led the secondary and final analysis, with substantial contributions from JW and TD, including data interpretation, organisation of findings. TE, JW, and TD drafted the manuscript. All authors critically revised the manuscript. TE, JW and TD are guarantors. All authors had access to the data. The lead author (TE) affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; no important aspects of the study have been omitted; no discrepancies from the study as planned occurred.

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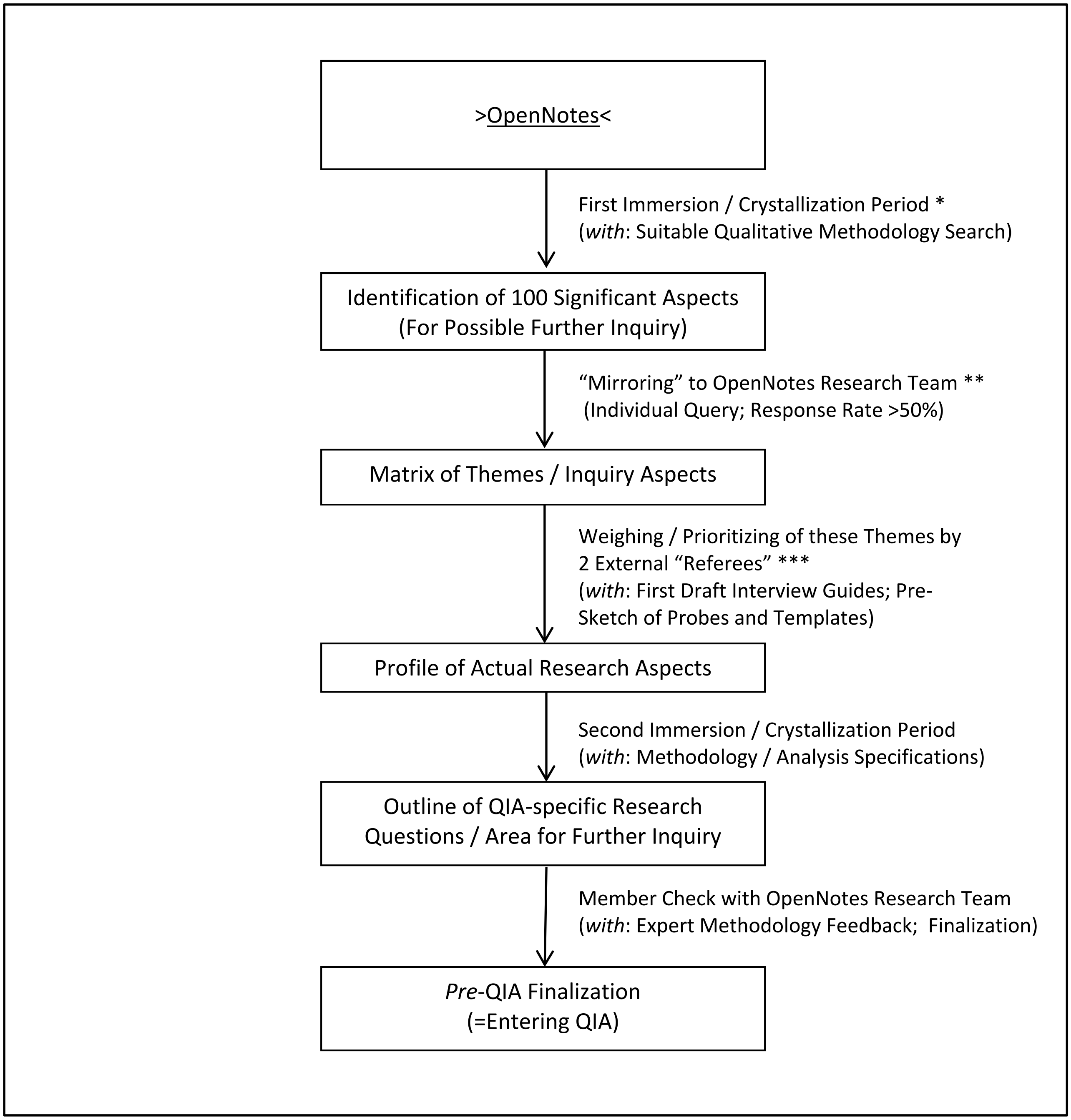
Appendices

Appendix 1 [Figure]: Pre-QIA Study Immersion Project – *Project Flow (Iterative Cycles)*



** Following comprehensive literature search in the field, and field observations, conversations with qualified scholars [colloquy] and with OpenNotes participating physicians, as well as non-participating physicians and patients*

*** "Colleague inquiry" (study team survey)*

**** Independent of OpenNotes team, knowledgeable; expert 1: patient perspective (PharmD), expert 2: physician perspective (MD)*

<u>Abbreviations:</u> QIA= Qualitative Interview Analysis

Appendix 2 [Table]: Free Text Questions in OpenNotes Patient Questionnaires (Surveys)

Baseline Survey Questions	
Text in Q.18	"If you have any comments about being able to read your visit notes online, please write them here:"
Text in Q.40	"If there is anything else that you would like us to know about you, or other comments you would like to make, please write them here:"
Post Survey Questions	
Text in Q.4	"Please tell us more about why you didn't read your doctor's notes."
Text in Q.18	"Please briefly tell us how you used your notes. We would appreciate any examples you have to help us understand."
Text in Q.32	"Did something happen as a result of reading your notes?"
Text in Q.54	"Do you have any other changes or suggestions about open notes?"
Text in Q.60	"Is there anything else that you would like us to know about you, or other comments you would like to make, please write them here."

Appendix 3 [Table]: Codebook (FTA)

Theme (No.)	**Theme**	**Subtheme (Code)**	**Code (No.)**	**Sentiment** **+**/supportive **-**/concerned (negative) **o**/neutral	**[Focus]** PAT PCP BON	**Examples / Quotes** (with reference number = no. of patient comment/statement)
A	**UNDERSTANDING**	understanding (and appreciating) doctor's work, skills	A1	+	PCP	"[Reading the notes] reinforced my already great appreciation for my doctor's caring and skills" (164)
		understanding processes and (doctor's) plan; understanding doctor's 'thinking'	A2	+	PCP	"[I used the notes] to gauge my doctor's thoughts after-the-fact" (221)
		understanding one's own health information	A3	+	PAT	"It does help me understand better what is going on with my health" (173)
		refreshing memory (of visit)	A4	+	PAT	"Sometimes I can't remember everything we spoke about, so the notes come in handy" (176)
		reassuring, confirmation (of patient's understanding)	A5	+	PAT	"[I used them to] confirm my understanding of his instructions and advice" (262)
		helping others to understand (e.g., share of understanding)	A6	+	BON	"The notes [...] allow my family to understand" (296)
		making sure doctor understands patient	A7	+	PCP	"I used the notes to make sure my Dr. understands me" (172)
		detecting different perceptions (e.g., of what is important; of patient's needs)	A8	+	BON	"[Notes were] clearing up perceived differences in what occurred in the office visit" (477)
		detecting mistakes, due to misunderstanding	A9	+	BON	"I discovered that the doctor had misunderstood something I said" (203)
		lack of non-verbal communication (possible consequences: worries, fear of misunderstanding)	A10	-	PAT	"The emphasis of a word or phrase is not conveyed so there can be angst created when reading the notes" (137)
		language, terminology difficulties	A11	-	PAT	"Certain terms may not be understood by 'laymen'" (63)
		more confusion [anxiety, worries] (due to impaired/lack of understanding, or actual note content)	A12	-	PAT	"What is written [...] can be very confusing or alarming to patients" (16)
		less confusion [anxiety, worries] (due to improved/clear understanding)	A13	+	PAT	"It saves my being confused and unsure" (37)
		learning opportunity (educational: patient more knowledgeable, well-informed; better prepared)	A14	+	PAT	"I view this option as an excellent learning opportunity" (85)
B	**RELATIONSHIP**	trust (sign of; elicitation, enhancement thereof)	B1	+	BON	"I have a great doctor. He treats me as a person and friend as well as a patient" (575); "I trust him" (104)
		connection - between visits (bridging, bonding of information and communication participants)	B2	+	BON	"I can plug into [the notes] as needed in between my office visits – I think that is a very valuable" (273)
		patient perceives/experiences ongoing (steady) support	B3	+	PAT	"The notes are experienced as being another level of my doctor's ongoing support" (273)
		open and transparent communication (experience)	B4	+	BON	"Reading his notes confirmed to me that he was not holding anything back" (348)
		better communication (overall; interactivity)	B5	+	BON	"Communication improves markedly" (381)
		partnership ('same page'; share 'in' information)	B6	+	BON	"I am able to work with my doc as a partner" (353)
		participation, patient as a 'team member'; collaboration/collaborator in care	B7	+	PAT	"I think this is a wonderful idea and allows the patient to be a [...] member of the team" (39)
		relationship strengthened (also: better mutual 'understanding' - sympathy, empathy)	B8	+	BON	"Having the notes available has strengthened the relationship between my primary care doctor and myself" (363)
		needs of patient addressed, (better) met	B9	+	PAT	"[Notes enable patient] to address needs that might arise without having to make separate appointments" (115)
		doctor as 'policeman' (coordinator, safe-guard for patient)	B10	+	PCP	"I realized that [...] the PCP was like a policeman directing traffic" (336)
		increased confidence (notes put patient at ease, reduce anxiety; feeling of security, being well-cared for)	B11	+	PAT	"Reading the notes made me feel more confident in my Drs." (355)
		patient's curiosity satisfied (gets insight; 'no' secrets)	B12	+	PAT	"Satisfied my curiosity" (245)
		threatened when inaccuracies occur (are perceived)	B13	-	BON	"[The error] is still in that report that others read, despite my protests" (424)
		fear of/concern over putting extra strain/burden on doctor's (staff) time budget, work flow, resources	B14	-	PCP	"Concerned about extra work this would make for MD" (96)
		informed, participating patients use less of doctor's (practice) resources	B15	+	PCP	"I feel that my doctor's job would be a little easier. [...] I would not have to bother him with e-mails" (42)
C	**QUALITY**	coordination: coordination of health information and care (e.g., managing complex cases; information integration)	C1	+	PCP	"Open Notes [...] help in coordination between specialist" (433)
		information transfer: flow of information, exchangeability, general mobility and permeability; easier to share, discuss	C2	+	PAT	"I had it in writing for extended family to see also" (301)
		access: keeping health information for patients accessible and available (ease of access); lowering threshold, barriers	C3	+	PAT	"The notes are put in system and always available if needed" (303)
		transparency (as standard or requirement, quality indicator); information not exclusive, restricted (knowledge sharing)	C4	+	PAT (BON)	"The more good information, the better" (61); "this [...] only adds to the quality of my health care" (85)
		ownership of notes (health information): sign of and advocacy for patient or consumer rights	C5	+	PAT	"I have a right to know, good or bad" (382)
		patient protection: safety, confidentiality and privacy concerns	C6	-/o	PAT	"I am concerned about breech of privacy" (45)
		record: keeping track of health information (chronicle, summary); notes as reference, ('complete') overview	C7	+	PAT	"The notes [...] now keep a running chronicle for me" (252)
		staying up-to-date ('tuned') with care, health information	C8	+	PAT	"Reading the notes kept me abreast of what was happening" (412)
		clarity of information: general sign and facilitator of clarity	C9	+	BON	"I feel it attributes to a much clearer and concise form of health care" (462)
		clarity of health information: adherence and compliance facilitated; e.g., due to clear instructions, medication (etc.)	C10	+	PAT	"It [...] sometimes clarifies my need and use of medications" (191)
		clarity of information: concerns over lack of it (e.g., too confusing or too much of information, lack of critical facts)	C11	-	PAT	"The visit notes might be too much information in a form we can't appropriately process" (46)
		concerns about fragmentation, incompleteness or poor coordination (disintegration) of notes/health information	C12	-	PCP (BON)	"I often receive conflicting answers [in notes] even from people within the same department" (564)
		concerns about candor, veracity/truthfulness, accuracy, and reliability of notes (when opened); e.g., 'filtering' by doctor?	C13	-	PCP	"I think that it might inhibit the doctor's ability to write frankly" (57)
		quality of documentation: error avoidance (procedural); 'quality check' of doctor by patient ('double-checking')	C14	+	PCP	"The biggest benefit I see is being able to [...] double check" (66)
		efficiency: using time and other resources more efficiently	C15	+	PCP (BON)	"I feel it [...] will continue to help me use the time I spend with my [primary care physician] more effectively" (552)
D	**SELF-CARE**	generally facilitating self-engagement and involvement; patient activation and empowerment	D1	+	PAT	"It allows me [...] to be more active in my treatments" (296); "I feel that I am more involved with my care" (351)
		reinforcing self-care and self-management skills, abilities to self-coordinate, to function on his/her own	D2	+	PAT	"I feel better equipped" (302); "I feel more sympathetic about having to coordinate my care myself" (375)
		motivation (e.g., for making and/or keeping healthy lifestyle changes; for complying with agreements or shared advice)	D3	+	PAT	"Being able to read his notes [...] has motivated me to lose weight and watch what I eat" (184)
		patient-centeredness (sign of; tool for); patient has a proactive and part-taking role	D4	+	PAT	"It made me feel [...] proactive [...] and not just reacting" (210)
		control: patient feels more in control; reduced helplessness	D5	+	PAT	"The notes [...] gave me better ways to cope with many of the difficulties I face" (344)
		active encouragement (e.g., to continue taking care of oneself, or reflect upon/prepare visits, ask self-reliant questions)	D6	+	PAT	"Having [...] notes available [...] helped to guide and inform new questions in each visit" (299)
		notes serve to monitor health and self-care options	D7	+	PAT	"It [shows] [...] what actions I can take to improve my health" (37)
		patients less challenged, distracted during visit: can work over their health information at home (themselves, with s.o.)	D8	+	PAT	"By reading the notes I was able to study them at length in the privacy of my home" (225)
E	**FUTURE REFINEMENT (IMPROVEMENTS)**	sustainability: providing resources, allocating financial funds, or capital; keep this ('extra'?) service/make it permanent	E1	o (+)	BON	"I hope that after the study that it will become permanent!!!" (86)
		including (involving) specialists; more/'all' doctors (providers) should participate	E2	o (+)	PCP	"More of my Doctor's should put notes on-line for me" (289)
		offering online dictionary/lexicon, or glossary (tool-box); add standard explanations, FAQs, etc.	E3	o (+)	PAT	"I have sometimes wished I could easily access a 'dictionary' of medical abbreviations used" (422)
		patient can add/comment/approve/work on note; possibly: joint notes (note preparation); continuous, shared document	E4	o (+)	PAT (BON)	"I like the idea of adding my own comment" (433)
		different types and categories of notes	E5	o (+)	BON	"I would suggest having different categories of notes" (113)
		[explicit statement: 'continue as it is' - changes/suggestions for improvement negated]	E6	+	PAT (BON)	"OpenNotes is perfect the way it is" (420)
		[difficulties accessing/finding notes (reason unclear)]	E7	- (o)	PAT	"I looked everywhere but could not find any notes available" (139)

__Abbreviations:__ PAT= patient; PCP= primary care physician; BON= both or neutral (other)

Appendix 4 [Table]: Quantitative Descriptive Analysis (FTA)

Themes / Codes	Imported Survey Data (N=576)	Baseline (n=138)	Post (n=438)	Low-User (n=39)	High-User (n=537)	Female (n=414)	Male (n=162)	MH Condit+ (n=175)	MH Condit- (n=401)	Age Cat A ['young'] (n=278)	Age Cat B ['old'] (n=298)	College+ (n=357)	College- (n=218)	White (n=509)	Non-White (n=61)	SRH/P-E/VG (n=158)	SRH/P-G/OK (n=187)	SRH/P-F/P (n=186)	SRH/B-E/VG (n=128)	SRH/B-G/OK (n=180)	SRH/B-F/P (n=172)
A UNDERSTANDING																					
a01: understanding (and appreciating) doctor's work, skil	6,1%	5,8%	6,2%	2,6%	6,3%	7,5%	2,5%	5,1%	6,5%	6,5%	5,7%	7,8%	3,2%	6,1%	6,6%	6,3%	8,6%	3,8%	11,7%	6,1%	4,7%
a02: understanding processes and (doctor's) plan; unders	8,0%	5,1%	8,9%	5,1%	8,2%	7,2%	9,9%	9,7%	7,2%	9,0%	7,0%	8,7%	6,9%	8,3%	6,6%	5,1%	10,7%	9,1%	6,3%	9,4%	8,7%
a03: understanding one's own health information	**13,2%**	13,0%	13,2%	10,3%	13,4%	13,5%	12,3%	9,1%	15,0%	14,7%	11,7%	13,7%	12,4%	13,2%	13,1%	10,1%	17,1%	11,8%	15,6%	11,7%	12,8%
a04: refreshing memory (of visit)	**17,0%**	12,3%	18,5%	12,8%	17,3%	19,1%	11,7%	17,7%	16,7%	21,2%	13,1%	14,3%	21,6%	16,9%	16,4%	20,3%	16,0%	18,3%	17,2%	16,7%	13,4%
a05: reassuring, confirmation (of patient's understanding	**15,8%**	7,2%	18,5%	7,7%	16,4%	15,9%	15,4%	16,0%	15,7%	18,7%	13,1%	13,2%	20,2%	16,1%	13,1%	18,4%	17,1%	15,6%	18,8%	16,1%	14,0%
a06: helping others to understand (e.g., share of underst	1,6%	0,7%	1,8%	0,0%	1,7%	1,9%	0,6%	1,1%	1,7%	1,4%	1,7%	1,7%	1,4%	1,8%	0,0%	0,6%	1,1%	3,2%	1,6%	0,0%	1,7%
a07: making sure doctor understands patient	8,9%	8,7%	8,9%	0,0%	9,5%	8,5%	9,9%	14,3%	6,5%	9,4%	8,4%	9,0%	8,7%	9,0%	8,2%	7,0%	11,8%	8,6%	7,8%	10,6%	8,7%
a08: detecting different perceptions (e.g., of what is impo	1,9%	0,0%	2,5%	2,6%	1,9%	1,7%	2,5%	4,0%	1,0%	1,8%	2,0%	1,4%	2,8%	2,0%	1,6%	1,3%	1,6%	3,2%	1,6%	1,7%	2,9%
a09: detecting mistakes, due to misunderstanding	4,0%	2,2%	4,6%	5,1%	3,9%	3,9%	4,3%	6,3%	3,0%	4,0%	4,0%	5,0%	2,3%	4,3%	1,6%	3,2%	4,8%	4,3%	5,5%	2,8%	5,8%
a10: lack of non-verbal communication (possible consequ	1,4%	2,2%	1,1%	0,0%	1,5%	1,4%	1,2%	1,7%	1,2%	2,2%	0,7%	1,7%	0,9%	1,4%	0,0%	1,9%	1,6%	0,5%	2,3%	1,1%	1,2%
a11: language, terminology difficulties	2,4%	4,3%	1,8%	2,6%	2,4%	2,7%	1,9%	2,3%	2,5%	1,8%	3,0%	2,8%	1,8%	2,6%	0,0%	5,1%	2,1%	0,5%	3,9%	1,7%	2,3%
a12: more confusion [anxiety, worries] (due to impaired/	3,6%	8,7%	2,1%	12,8%	3,0%	3,6%	3,7%	1,1%	4,7%	4,3%	3,0%	4,5%	2,3%	3,7%	1,6%	4,4%	3,2%	2,7%	5,5%	3,9%	2,9%
a13: less confusion [anxiety, worries] (due to improved/c	5,0%	5,1%	5,0%	5,1%	5,0%	5,3%	4,3%	6,3%	4,5%	5,4%	4,7%	4,2%	6,4%	5,3%	3,3%	2,5%	5,9%	7,0%	4,7%	3,9%	7,0%
a14: learning opportunity (educational: patient more knc	7,6%	5,8%	8,2%	7,7%	7,6%	8,7%	4,9%	5,1%	8,7%	7,2%	8,1%	7,3%	8,3%	8,4%	0,0%	7,0%	9,6%	6,5%	7,0%	5,6%	8,7%
B RELATIONSHIP																					
b01: trust (sign of; elicitation, enhancement thereof)	**9,0%**	5,1%	10,3%	2,6%	9,5%	10,6%	4,9%	8,6%	9,2%	8,6%	9,4%	10,1%	7,3%	8,4%	14,8%	6,3%	10,2%	11,3%	11,7%	7,2%	11,0%
b02: connection - between visits (bridging, bonding of inf	2,4%	4,3%	1,8%	2,6%	2,4%	2,4%	2,5%	2,3%	2,5%	2,2%	2,7%	2,0%	3,2%	2,4%	1,6%	1,9%	2,1%	1,6%	1,6%	4,4%	1,7%
b03: patient perceives/experiences ongoing (steady) supp	3,6%	4,3%	3,4%	5,1%	3,5%	3,9%	3,1%	4,6%	3,2%	4,7%	2,7%	3,1%	4,6%	3,1%	6,6%	2,5%	3,7%	4,3%	4,7%	2,8%	4,7%
b04: open and transparent communication (experience)	3,5%	4,3%	3,2%	7,7%	3,2%	3,4%	3,7%	2,3%	4,0%	2,9%	4,0%	3,9%	2,8%	3,5%	3,3%	3,8%	5,3%	2,2%	3,1%	6,1%	2,3%
b05: better communication (overall; interactivity)	7,3%	10,1%	6,4%	10,3%	7,1%	7,0%	8,0%	13,1%	4,7%	6,8%	7,7%	8,4%	5,5%	7,9%	3,3%	7,6%	10,2%	3,2%	8,6%	8,9%	7,0%
b06: partnership ('same page'; share 'in' information)	4,3%	4,3%	4,3%	5,1%	4,3%	3,9%	5,6%	5,1%	4,0%	2,9%	5,7%	3,9%	5,0%	4,5%	1,6%	4,4%	4,8%	2,7%	4,7%	5,6%	4,1%
b07: participation, patient as a 'team member'; collabora	3,1%	2,9%	3,2%	5,1%	3,0%	2,7%	4,3%	3,4%	3,0%	2,5%	3,7%	3,4%	2,8%	3,3%	1,6%	3,8%	2,7%	1,6%	4,7%	2,8%	4,1%
b08: relationship strengthened (also: better mutual 'und	**7,6%**	5,8%	8,2%	2,6%	8,0%	8,2%	6,2%	8,0%	7,5%	8,3%	7,0%	8,7%	6,0%	7,3%	11,5%	5,7%	9,1%	8,1%	8,6%	8,3%	8,1%
b09: needs of patient addressed, (better) met	2,4%	3,6%	2,1%	0,0%	2,6%	2,9%	1,2%	3,4%	2,0%	3,2%	1,7%	2,8%	1,8%	2,4%	3,3%	1,3%	2,7%	3,8%	1,6%	2,2%	4,7%
b10: doctor as 'policeman' (coordinator, safe-guard for pa	1,4%	1,4%	1,4%	2,6%	1,3%	1,2%	1,9%	0,6%	1,7%	1,1%	1,7%	2,0%	0,5%	1,6%	0,0%	0,0%	0,5%	3,2%	0,8%	0,6%	3,5%
b11: increased confidence (notes put patient at ease, red	**7,6%**	4,3%	8,7%	10,3%	7,4%	9,2%	3,7%	8,6%	7,2%	9,4%	6,0%	8,4%	6,4%	6,7%	14,8%	5,7%	10,7%	7,5%	10,2%	5,0%	8,7%
b12: patient's curiousity satisfied (gets insight; 'no' secret	3,1%	2,2%	3,4%	7,7%	2,8%	3,4%	2,5%	2,3%	3,5%	3,6%	2,7%	2,8%	3,7%	2,8%	4,9%	5,7%	3,7%	1,1%	3,9%	3,9%	1,2%
b13: threatened when inaccuracies occur (are perceived)	3,6%	4,3%	3,4%	5,1%	3,5%	4,1%	2,5%	2,3%	4,2%	3,2%	4,0%	4,8%	1,8%	3,9%	1,6%	4,4%	0,5%	4,8%	5,5%	2,2%	4,7%
b14: fear of/concern over putting extra strain/burden on	5,4%	11,6%	3,4%	5,1%	5,4%	6,3%	3,1%	2,9%	6,5%	6,5%	4,4%	7,0%	2,8%	5,7%	3,3%	7,0%	4,3%	3,8%	6,3%	3,9%	7,6%
b15: informed, participating patients use less of doctor's	2,6%	3,6%	2,3%	2,6%	2,6%	3,1%	1,2%	4,0%	2,0%	4,0%	1,3%	2,2%	3,2%	2,9%	0,0%	2,5%	3,2%	2,2%	2,3%	2,8%	2,9%
C QUALITY																					
c01: coordination: coordination of health information an	6,6%	8,7%	5,9%	5,1%	6,7%	7,5%	4,3%	10,3%	5,0%	6,8%	6,4%	7,8%	4,6%	7,3%	0,0%	3,8%	2,1%	12,9%	4,7%	2,8%	13,4%
c02: information transfer: flow of information, exchangea	5,2%	3,6%	5,7%	5,1%	5,2%	5,6%	4,3%	6,3%	4,7%	4,7%	5,7%	5,6%	4,6%	5,5%	1,6%	3,8%	4,8%	7,5%	3,1%	5,0%	4,7%
c03: access: keeping health information for patients acce	5,9%	8,0%	5,3%	7,7%	5,8%	6,5%	4,3%	7,4%	5,2%	6,1%	5,7%	5,0%	7,3%	6,3%	3,3%	7,0%	4,8%	5,4%	7,8%	5,6%	6,4%
c04: transparency (as standard or requirement, quality in	**7,6%**	13,0%	5,9%	2,6%	8,0%	9,2%	3,7%	8,0%	7,5%	8,3%	7,0%	8,1%	6,9%	7,7%	6,6%	6,3%	5,3%	8,6%	6,3%	6,7%	10,5%
c05: ownership of notes (health information): sign of and	3,1%	3,6%	3,0%	2,6%	3,2%	3,4%	2,5%	1,1%	4,0%	3,6%	2,7%	4,5%	0,9%	3,1%	3,3%	1,9%	2,7%	4,8%	1,6%	1,1%	6,4%
c06: patient protection: safety, confidentiality and privac	5,4%	15,9%	2,1%	10,3%	5,0%	5,3%	5,6%	4,6%	5,7%	5,8%	5,0%	6,4%	3,7%	5,3%	6,6%	5,1%	5,3%	4,3%	6,3%	3,3%	7,0%
c07: record: keeping track of health information (chronicl	**12,2%**	5,8%	14,2%	5,1%	12,7%	12,8%	10,5%	9,1%	13,5%	15,5%	9,1%	12,3%	11,9%	12,0%	14,8%	12,7%	11,2%	14,5%	10,2%	12,8%	11,0%
c08: staying up-to-date ('tuned') with care, health inform	6,3%	2,2%	7,5%	5,1%	6,3%	6,5%	5,6%	6,3%	6,2%	8,3%	4,4%	6,4%	6,0%	5,7%	9,8%	6,3%	7,5%	5,4%	4,7%	6,1%	5,2%
c09: clarity of information: general sign and facilitator of	4,3%	4,3%	4,3%	2,6%	4,5%	5,1%	2,5%	6,9%	3,2%	4,7%	4,0%	3,9%	5,0%	4,9%	0,0%	3,2%	4,8%	5,4%	6,3%	3,3%	5,2%
c10: clarity of health information: adherence and complia	**10,9%**	7,2%	12,1%	7,7%	11,2%	11,1%	10,5%	12,0%	10,5%	11,9%	10,1%	10,6%	11,5%	10,4%	16,4%	8,2%	12,8%	12,9%	7,8%	11,1%	12,2%
c11: clarity of information: concerns over lack of it (e.g., t	2,8%	5,1%	2,1%	0,0%	3,0%	2,9%	2,5%	2,3%	3,0%	2,9%	2,7%	3,9%	0,9%	2,9%	1,6%	3,8%	1,1%	3,2%	4,7%	1,7%	4,1%
c12: concerns about fragmentation, incompleteness or pe	1,4%	1,4%	1,4%	2,6%	1,3%	1,7%	0,6%	1,1%	1,5%	1,1%	1,7%	2,2%	0,0%	1,6%	0,0%	1,9%	0,5%	1,6%	2,3%	0,6%	2,3%
c13: concerns about candor, veracity/truthfulness, accura	2,3%	8,0%	0,5%	5,1%	2,0%	2,7%	1,2%	0,6%	3,0%	2,5%	2,0%	2,8%	1,4%	2,6%	0,0%	2,5%	2,1%	1,1%	3,1%	1,7%	3,5%
c14: quality of documentation: error avoidance (procedu	7,5%	4,3%	8,4%	2,6%	7,8%	7,2%	8,0%	9,7%	6,5%	5,0%	9,7%	8,4%	6,0%	7,7%	4,9%	7,6%	7,5%	7,5%	7,8%	8,3%	7,6%
c15: efficiency: using time and other resources more effic	2,8%	2,2%	3,0%	0,0%	3,0%	3,6%	0,6%	4,6%	2,0%	3,6%	2,0%	2,8%	2,8%	3,1%	0,0%	1,9%	3,2%	3,8%	1,6%	2,2%	5,8%
D SELF-CARE																					
d01: generally facilitating self-engagement and involveme	7,8%	6,5%	8,2%	0,0%	8,4%	8,2%	6,8%	8,0%	7,7%	8,3%	7,4%	8,1%	7,3%	8,1%	6,6%	5,7%	11,2%	7,0%	6,3%	5,6%	12,2%
d02: reinforcing self-care and self-management skills, abi	7,8%	7,2%	8,0%	10,3%	7,6%	8,2%	6,8%	12,6%	5,7%	8,6%	7,0%	9,0%	6,0%	7,9%	8,2%	5,7%	10,7%	7,0%	9,4%	5,6%	9,9%
d03: motivation (e.g., for making and/or keeping healthy	4,9%	1,4%	5,9%	0,0%	5,2%	5,1%	4,3%	5,1%	4,7%	5,0%	4,7%	5,6%	3,7%	4,3%	9,8%	3,2%	7,0%	4,8%	5,5%	5,0%	5,8%
d04: patient-centeredness (sign of; tool for); patient has	**10,2%**	8,7%	10,7%	10,3%	10,2%	11,1%	8,0%	11,4%	9,7%	11,9%	8,7%	10,9%	9,2%	10,6%	8,2%	10,8%	9,1%	10,2%	14,1%	7,2%	13,4%
d05: control: patient feels more in control; reduced helpl	**9,7%**	10,9%	9,4%	5,1%	10,1%	10,6%	7,4%	12,0%	8,7%	12,2%	7,4%	9,5%	10,1%	10,0%	4,9%	6,3%	10,2%	12,4%	7,8%	6,7%	15,7%
d06: active encouragement (e.g., to continue taking care	9,0%	5,1%	10,3%	7,7%	9,1%	9,2%	8,6%	9,1%	9,0%	12,6%	5,7%	9,2%	8,7%	8,3%	16,4%	8,9%	11,2%	8,1%	10,2%	5,6%	10,5%
d07: notes serve to monitor health and self-care options	3,0%	1,4%	3,4%	0,0%	3,2%	3,1%	2,5%	2,3%	3,2%	2,9%	3,0%	3,1%	2,8%	2,9%	3,3%	2,5%	3,2%	3,8%	0,8%	2,2%	2,9%
d08: patients less challenged, distracted during visit: can	3,6%	4,3%	3,4%	2,6%	3,7%	4,6%	1,2%	6,3%	2,5%	4,7%	2,7%	2,5%	5,5%	3,7%	1,6%	5,7%	2,1%	3,8%	4,7%	2,8%	3,5%
E FUTURE REFINEMENT (IMPROVEMENTS)																					
e01: sustainability: providing resources, allocating financ	4,2%	1,4%	5,0%	0,0%	4,5%	3,6%	5,6%	4,6%	4,0%	4,0%	4,4%	4,5%	3,7%	4,1%	4,9%	3,8%	4,8%	4,3%	2,3%	4,4%	5,2%
e02: including (involving) specialists; more/'all' doctors (p	**10,2%**	6,5%	11,4%	5,1%	10,6%	10,6%	9,3%	11,4%	9,7%	9,0%	11,4%	10,4%	10,1%	10,2%	11,5%	8,2%	8,6%	14,0%	7,0%	11,1%	11,6%
e03: offering online dictionary/lexicon, or glossary (tool-b	1,6%	0,7%	1,8%	0,0%	1,7%	1,4%	1,9%	0,6%	2,0%	1,8%	1,3%	1,7%	1,4%	1,8%	0,0%	2,5%	1,6%	1,1%	0,8%	2,2%	1,7%
e04: patient can add/comment/approve/work on note; p	2,3%	2,2%	2,3%	0,0%	2,4%	2,4%	1,9%	2,3%	2,2%	1,4%	3,0%	2,8%	1,4%	2,6%	0,0%	1,3%	2,1%	3,8%	1,6%	1,7%	3,5%
e05: different types and categories of notes	1,4%	2,9%	0,9%	0,0%	1,5%	1,7%	0,6%	0,6%	1,7%	2,2%	0,7%	2,0%	0,5%	1,6%	0,0%	0,6%	1,6%	1,6%	0,8%	0,6%	2,9%
e06: [explicit statement: 'continue as it is' - changes/sugg	**9,5%**	0,0%	12,6%	0,0%	10,2%	8,5%	12,3%	8,0%	10,2%	9,0%	10,1%	8,7%	11,0%	9,0%	14,8%	8,9%	12,8%	9,1%	8,6%	10,6%	8,1%
e07: [difficulties accessing/finding notes (reason unclear)	0,3%	0,0%	0,5%	5,1%	0,0%	0,0%	1,2%	0,0%	0,5%	0,4%	0,3%	0,3%	0,5%	0,4%	0,0%	0,6%	0,0%	0,0%	0,0%	0,0%	0,0%

Abbreviations (Legend): MH Condit+= mental health condition ‘positive’ (i.e., either having had 2 visits with a ICD-9 diagnosis out of: psychosis, depression, anxiety or substance abuse; or 1 visit in combination with a mental health drug prescription; criteria had to be fulfilled at baseline and throughout trial); Age Cat A= age category A (‘young’ – age ≤59); Age Cat B= age category B (‘old’ – age ≥60); College+= college education or higher; College-= less than college education; SRH= self-rated health; SRH/P= self-rated health at post; SRH/B= self-rated health at baseline; E/VG= excellent or very good; G/OK= good or OK; F/P= fair or poor

Note: Printed in bold (see first column with code frequencies/percentages, on the left) are the top 3 codes per domain/theme (in domains with ≥14 codes), or top 2 codes (in other domains) – for general overview (all survey data included); marked in yellow are most frequently checked codes in each column, on per domain/theme basis.

Quantitative analysis was performed with support of Atlas.ti software (Version 7) – see Methods

Appendix 5 [Table]:
Results QIA: Identified Themes and Referring Quotes

Aspect / Theme (Sample)	**Related / Referring Patient Quote (Sample)**
Member checking →FTA codebook (themes) confirmed; e.g.:	
- Improved understanding	*“It improved my understanding” (Daniel, 77)*
o Understanding one’s own health	*“It improves my understanding of my own health” (William, 66)*
o Confirming understanding	*“What was important to me was the confirmation of what went on at the visit” (J. Marie, 82)*
o Refreshing memory	*“I look at Open Notes as a reassuring memory aid” (William, 66)*
- Better relationship	*“By having Open Notes, I feel that we have a better relationship because some of the clouds are gone. We're not talking through a fog” (David, 75)*
o Higher trust	*“It brings the doctor and the patient closer together” (Elaine, 66)*
o Better communication	*“Trust is a big thing. And it does relate to Open Notes, I feel. […] Because I can read her notes […], I trust her more” (Cheryl, 58)*
o Higher confidence (comfort, ease)	*“I think it’s important to know that I’m trusted as part of this relationship. And it helps me trust the doctor as well” (Beverly, 67)* *“With Open Notes being there, communication got better” (Hanna, 87)* *“I feel that she really cares about me. I read the notes and I get reassured” (Elaine, 66)* *“[Open Notes] makes me feel more confident” (J. Marie, 82)*
- Better quality	*“Transparency […] is a quality indicator” (Hanna, 87)*
o Transparency as indicator of quality	*“It’s a continuing reference. It’s an archive. […] I can always refer back to it if need be” (David, 75)*
o Keeping track of information	*“[Reading the notes] clears things up for me” (Cheryl, 58)*
o Adherence/compliance (clarity)	*“I can better conform to what she is recommending me to do” (Mary B., 60)*
o Health benefits/harm avoidance	*“I was [online] and happened to see that I was taking the wrong amount of prescription” (Cheryl, 58)*
o Efficiency	*“I think it makes the whole interaction […] more effective. More efficient” (David, 75)*
- Strengthened self-care	*“Having the […] records online […] helped me definitely be more engaged. [Open Notes] supplemented that” (Beverly, 67)*
o Engagement	*“[It] engages me” (William, 66)*
o Activation (proactive role)	*“I take an active role […]. That’s a tool to make that happen” (Mary B., 60)*
o Involvement	*“You’re more involved in your medical care – by having that note. […] Doctors are more involved, and patient is” (Linda, 69)*
o Patient-centeredness	*“I want to know what’s happening. I want to be right at the forefront” (Ellen G., 73)*
o Feeling in control (less helpless)	*“I feel I’m more apt to talk to her about different things” (Cheryl, 58)*
Few safety/privacy concerns	*“I don’t see any safety concerns” (Cheryl, 58)*
Limited sharing of notes	*“I just don’t want anyone to share it. […] That’s my own personal thing” (Ellen G., 73)*
Withholding of information	*“I think it takes away from the visit when you can’t be honest. […] I definitely would not want it read by anybody else” (J. Marie, 82)*
More interactivity (in the future) - Want to respond/comment on notes - Want to have errors corrected - Little desire to co-generate notes	*“Would be good if at the end of the notes: ‘Is there something here that you see as not correct or something?’” (Ellen, 66)* *“The patient should have an opportunity to comment, and the doctor give feedback” (Mary B., 60)* *“There should be a few check boxes where you could say, understood, will do, confused, or something” (David, 75)* *“I think there needs to be a mechanism for requesting corrections” (Beverly, 67)* *“I think that the doctor’s note should be the doctor’s note” (Mary B., 60)*
Putting some notes under an ‘embargo’ - Caution against ‘automated openness’ - Like to have personal conversation, individual face-to-face time with doctors (direct communication)	*“That is the question of embargo. […] I would not want to read that I have cancer, nakedly on the screen. […] I want this to be told to me in person by a medical professional whom I trust. […] Conditions with fatal outcomes, I think, need to be mediated by a human being!” (Hanna, 87)* *“I guess my concern would be reading something at a time where you are physically not prepared to deal with what actually happened” (Mary B., 60)* *“Openness […] needs to be done with sensitivity to the emotional impact of different kinds of news. […] There is no reason to hide that from me. But I don’t want to see it [in the record/notes] before a conversation” (William, 66)*
⇨Characteristic (indicative) ‘summarizing’ statements	*“Expand it; include specialists, and almost everybody who is involved in [my] care. And expand the system and make it more inclusive” (Elaine, 66)* *“I do think that transparency is key and is quality of care. I think it’s important for patients to understand truthfully what their situation is and how they can help themselves and be educated enough to be able to ask the right questions to physicians. Every patient has that right. […] And I think that Open Notes helps that” (Mary B., 60)*