

Data, analysis, perspectives | No. 3, 2020

OpenNotes

Online access to visit notes activates patients
and strengthens mutual trust

- **Digital access to records in the United States:** In the last ten years, clinicians have provided more than 50 million patients online access to their notes; as of April 2021, this access will be mandated by law.
- **Visit notes as part of EHR:** Patients in some Scandinavian countries can also read the visit notes found in their electronic health records
- **Visit notes in Germany:** Patients in Germany have to request to review their medical files. They then usually receive a paper copy. 66 percent would read their visit notes if these were accessible online
- **Positive findings in the Witten pilot project:** Access to visit notes leads to improved information exchange, patient activation and greater clinician-patient trust

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For many years now, patients in several countries have called for easier access to their health information. This includes the visit notes regarding their particular case history. Thanks to the development of digital information technology, this need can today be more easily met. The increasing spread of electronic health records and the new internet-based patient portals provided by clinics, physicians' networks and health insurance companies offer a wide range of possibilities for such access.

As a result of Germany's Patient Rights Act of 2013, patients in the country have had the right to access and read their files, including visit notes, for seven years (see infobox "The right to inspect medical records in Germany"). A recent Bertelsmann Stiftung-commissioned representative survey showed that nine out of ten citizens (87%) are aware of this right. However, accessing their personal information – diagnoses, laboratory reports, referrals and also visit notes – is not necessarily a straightforward matter.

In Germany, the open and transparent handling of visit notes (e.g., case-history information, steps to be taken, patient preferences, agreements made) is rather rare. To exercise their right, patients can place a request for access to their files to their physician; 41 percent of those surveyed in Germany have already done so. However, should they insist on this right, this often ends in conflict. Nearly 44 percent of patients' right cases handled by Germany's UPD – an independent agency tasked with patient advocacy – involve questions regarding a patient's access to medical files. This topic is thus the most frequently addressed issue by the UPD. In recent years, refusals or delays in accessing medical records, as well as a patient's wish to have a diagnosis corrected or deleted from his or her record – a request which does not require physician approval, even when the request is erroneous – have become ongoing issues.

Changing this situation involves bringing about a cultural shift in physician-patient relationships – toward more openness and strength-

The right to inspect medical records in Germany

Patients' rights in Germany have been written into the Civil Code (Bürgerlichen Gesetzbuch, BGB) since February 2013. The right to "inspect medical records" is found in § 630g: "The patient is on request to be permitted to inspect the complete medical records concerning him/her without delay to the extent that there are no considerable therapeutic grounds or third-party rights at stake to warrant objections to inspection. [...] The patient can also request electronic duplicates of the medical records. He/she shall reimburse to the treating party the costs incurred."

The need for physicians to maintain medical records and associated documentation is stated in § 630f: "The treating party is obliged to record all measures in the medical records which are relevant in medical terms for the current and future treatment and its results, in particular the establishment of the medical history, diagnoses, examinations, results of examinations, findings, therapies and their effects, procedures and their impact, consent and information. Physicians' letters must be included in the medical records." Medical records can be held in either physical or electronic form.

ened mutual trust. How might we achieve this, and what are the potential consequences? The Bertelsmann Stiftung has published a study on these issues in which Prof. Dr. med. Tobias Esch reports on the current state of research in the field of OpenNotes. This initiative, which began in the United States, is one of the research priorities of Prof. Dr. Esch, a physician at the University of Witten/Herdecke. With his pilot project underway since 2019, the physician is the only person in Germany testing the concept (see box on OpenNotes). The study also features the results of a

OpenNotes

The OpenNotes movement started in the United States in 2010 by general practitioners in Boston, Pennsylvania and Seattle. The basic idea behind the project is to have physicians agree to make their notes available to patients. OpenNotes thus follows the idea of “everyone on the same page”. The use of OpenNotes took place on portals provided by physicians or hospitals, which patients in the United States have usually access to for billing purposes. In nearly ten years’ time, more than 50 million patients in more than 300 organizations now have access to their visit notes via patient portals. In addition to general practitioners, specialists in various fields now use OpenNotes. Increasingly, inpatient facilities are also participating. Similar systems are now available outside the United States – in Denmark, Sweden, Norway, Estonia and Canada.

qualitative study involving patients and staff at that university outpatient clinic in Witten that was conducted by Dr. Next GmbH. Through two guided focus groups, they shared their initial impressions and experience in working with OpenNotes. Key findings for both studies are presented in this issue of Spotlight Healthcare.

More than 50 million patients in the United States can review visit notes

In the German healthcare system, physicians share medical information about patients with each other, but usually paper based and rarely with the patients themselves. Starting in 2021, patients can request physicians to save medical documents in their new patient electronic health record (ePA) and, for example, be able to review their medication plans (see Figure 1). However, despite the Patients Rights Act and the growing desire among patients to review visit notes, to date, there are no plans to technically enable saving visit notes in the new ePA.

The disjuncture between the theoretical right to review and actual opportunities to do so was also prevalent in the United States for many years. However, things began to change once the OpenNotes pilot project was launched in the United States in 2010. Since then, large numbers of patients with access to patient portals provided

What kind of data files can be stored in the electronic patient health record (EHR) in Germany?

Legal requirements:

As of 2021:

- › Data on emergency treatment
- › Medication plan
- › Findings
- › Diagnoses
- › Treatment reports
- › Referrals
- › Screening test data
- › Data on implemented and scheduled therapies
- › Self-reporting health data

As of 2022:

- › Vaccination record
- › Preventive dental care pass
- › Maternity record
- › Child health record
- › ePrescriptions

So far no legal requirements:

- › Visit notes
- › Links to general health information provided by Germany’s national health portal

Figure 1 | Sources: www.bundesgesundheitsministerium.de, www.gematik.de, Legislation on the protection of electronic patient data in the telematics infrastructure (Patient Data Protection Act)

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by their clinic or physician can also access visit notes, which their physicians have voluntarily cleared for review in advance. As of April 2021, access to visit notes will even be required by law.

Scandinavian countries are even further ahead

In some Scandinavian countries, being able to review one’s medical records is even more widely implemented than in the United States. In Norway and Sweden, visit notes are seen as part of the overall set of personal health data that patients can regularly access through their electronic health record.

In three out of four regions in Norway, patients can access their EHR via the patient portal helsenorge.no. Hospital patients and those seeing a specialist can view all of their personal documentation – including visit notes – within 24 hours of a physician’s clearance. According to recent survey findings, nearly 97 percent of patients in Norway are very satisfied with this situation. Patients with complex or chronic conditions in particular benefit from this option.

In Sweden, all citizens aged 16 and over have, in principle, access to their health-related information, which includes visit notes. Patients in the country can log in online to their electronic medical records through the national patient portal 1177.se and review their notes. Because having access to one's records is viewed in Sweden to be an integral aspect of physician-patient interaction, it is not treated as an additional service or named as such. Physicians as well as patients in the country have a deep appreciation for the fact that visit notes can be viewed in one's electronic medical record. Since the national patient portal is widely known among the Swedish population, its population-related login and usage figures are even much higher than those recorded for OpenNotes in the United States.

OpenNotes improve healthcare provision

U.S. studies have shown that the disclosure of notes from medical consultations (OpenNotes) in particular leads to patients being more actively involved in their care, increases their satisfaction with care and promotes a cultural shift towards greater openness and deepened trust. U.S. patients report that they now have a better understanding of their medical information. They also report finding it helpful to be able to re-read their medical records. In addition, the studies show that opening up notes fosters a more trusting physician-patient relationship as well as patients' improved ability to manage their medication and treatment.

The first pilot study on OpenNotes in the United States, which included 19,000 patients



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Two questions for the founders of the OpenNotes initiative, Janice Walker and Tom Delbanco

Where did you get the idea for OpenNotes?

Tom Delbanco: "I have spent much of my life in academic general internal medicine trying to break down invisible walls that can separate patients (and often families) from the health professionals working to care for them. Janice and I knew from personal experience and from research literature that patients often forget what happens in clinical encounters. We agreed that the information in notes could be very valuable for patients. From there, it seemed a logical next step was to invite patients to review what we write about them."

What has surprised you most since introducing OpenNotes?

Janice Walker: "The biggest surprises continue to be how much patients indicate they benefit from reading these notes, coupled with how little the doctors and nurses feel that their lives change as a result. [Patients] tell us repeatedly that they understand their medications and their importance more clearly, and that they actually take them more faithfully. They look things up and often ask their questions of friends in the health professions. They respect how busy their own clinicians are and, generally speaking, only get in touch with them when they feel it is very important. Sometimes they find a mistake that both they and their doctor feel important to correct before a harm occurs."

How did you convince physicians in the beginning to participate in OpenNotes, and how do you do that now?

Tom Delbanco: "Overall, we have a simple recommendation for our clinical colleagues: Don't write something down that you feel you cannot share with a patient! If I suspect depression, I tell the patient, and that can be the first step toward recovery. In primary care, half of the issues we address have more to do with the psyche than with the heart, lungs, or abdomen."

What are your recommendations for German health policy decision-makers when introducing OpenNotes?

Janice Walker: "Be brave! Transparent records and communication carry far more benefit than risk. In the near future, patients will download their records and carry them with them on their secure cellular devices, allowing them to share their records with doctors, nurses, and psychotherapists anywhere! Culture change is not easy; this level of transparency will seem difficult at first, particularly for clinicians. But there's no going back; transparency in nearly all sectors of our society is here to stay. Experimenting with open notes and records now will give you invaluable early experience, and gratitude from your patients! So, get started ... Everyone will benefit."

and 105 general practitioners in private practice, showed that after just one year, four out of five patients had read the notes written by their physician. Some 99 percent of the study's participants expressed a desire for OpenNotes to be continued, while 85 percent stated that this kind of access would prove important for them when choosing a physician in the future. Remarkably, none of the participating practitioners chose to stop using OpenNotes after the study came to an end. Even today – ten years after the pilot study – three-quarters of the approximately 1.600 physicians still find the concept useful for involving patients in their treatment, and 61 percent would recommend it to their colleagues (see Figure 2).

As a result of the many advantages associated with OpenNotes, the initiators have taken a further step with a new pilot project. Through OurOpenNotes, patients can enter information into their file online between visits to the clinic. This can include updates on their case history, self-measured values such as blood sugar levels and their three most urgent questions for the physician at their next visit. Physicians can use this information to better prepare for the upcoming appointment and also copy and place it into the patient's medical file. This applies in particular to the preparation for video consultations, which have also increased considerably in the USA since the outbreak of the corona pandemic.

Pilot project in Germany confirms international experience

The qualitative studies conducted with OpenNotes participants at Witten/Herdecke University (see box on pilot project) confirm the positive findings seen in the United States. The qualitative evaluation of the two guided focus groups showed that both groups – patients and medical staff – saw the greatest added value of OpenNotes in the improved communication between physician and patient, but also between a practice's staff and patients.

Increased trust in the physician

Patients at the university outpatient clinic in Witten report that the provision of visit notes in the health portal and the open access to them helps not only in terms of preparing for their consultation, but also with questions and adjustments. Furthermore, patients sometimes feel so

Experiences of US-American physicians with OpenNotes

Physicians who use OpenNotes:

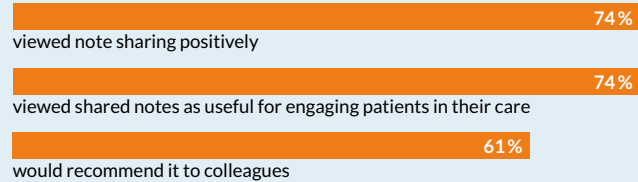


Figure 2 | Source: DesRoches, C. et al. (2020): doi: 10.1001/jamanetworkopen.2020.1753, n=1.628.

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The pilot project OpenNotes at the university outpatient clinic Witten/Herdecke

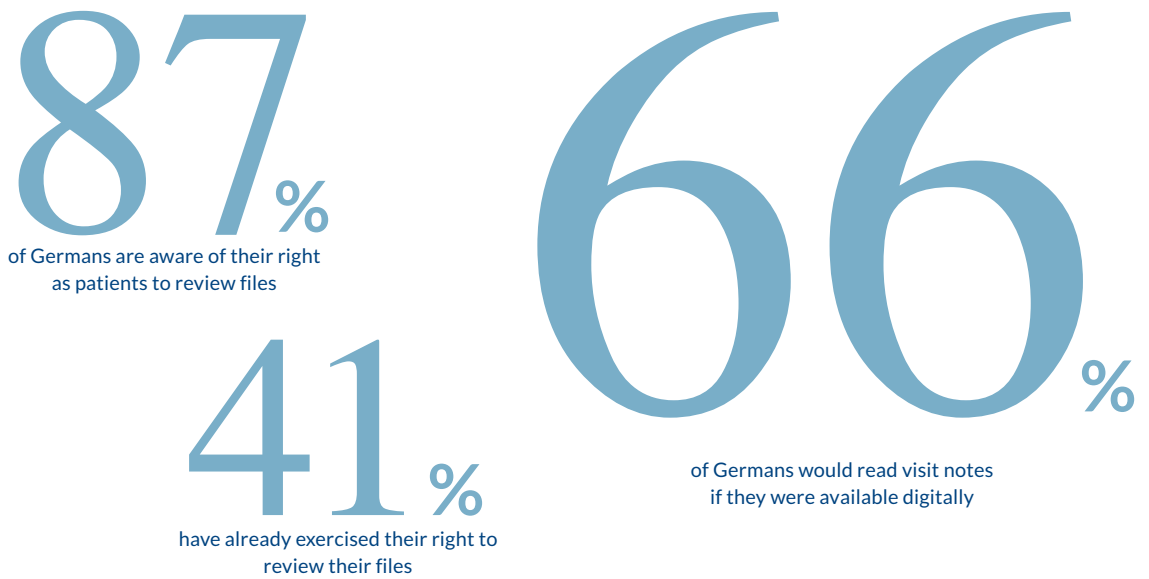
The first German pilot project with OpenNotes was initiated by Prof. Dr. Tobias Esch, who was a member of the OpenNotes team in Boston. The project was launched in early 2019 at the new university outpatient clinic for integrative healthcare and naturopathy in Witten. Physicians and medical staff at this primary care facility, which is part of the University of Witten/Herdecke, now share all relevant treatment reports with patients through an in-house electronic health portal, as well as the notes taken during interactions with patients. After each appointment with a physician or therapist, patients can review and download a digital copy of notes regarding their treatment online through the outpatient clinic's portal. Patients automatically receive an email notification as soon as new entries are added to their file. Patients without online access can receive notes in the form of paper printouts. Patients can also add their own documents. Physicians are then notified of such additions through the practice management system. As of September 2020, nearly 800 patients have signed up to participate in the program.

well-informed that they no longer feel the need to consult the internet (i.e., Dr. Google) for additional health information.

From their point of view, being able to review visit notes improves the relationship between physician and patient. They state that they have more confidence in the physician because of the transparency that OpenNotes creates. This is also true if they discover an error in the notes.

“ I can forgive a doctor if he has written something down incorrectly, because I have the opportunity to talk to him about it. ”

Patient



In the future, some patients would even base their decision to see a specific physician depending on whether he or she would make his or her notes available for online review. However, they would not drop a trusted physician or specialist for another one if he or she did not use OpenNotes.

OpenNotes lowers the burden on medical staff

Physicians and medical staff report a qualitative improvement to their documentation thanks to OpenNotes. Some say that they now consider more carefully how they choose to formulate things. They just needed more time to do so, at first. They report that the transparency created by OpenNotes leads to a flattening of hierarchies between them and their patients, which improves physician-patient relationships.

Another major advantage is that OpenNotes provides a new means of activating patients and thus relieves physicians of certain pressures. Physicians report that creating transparency around notes leads to patients becoming more involved in their treatment. Patients who are able to re-read recommendations or agreements can prepare themselves more properly for future appointments because they have a better understanding of the information they might need to give their physician.

“I found the thought [of opening up notes] simply a good idea. That is, [the patient] sitting at home can [...] track how things were before, look at their current values, what they discussed with the doctor, and what the next steps involve. Honestly, I found that to be a good thing.”

Medical staff

The pilot project OpenNotes was started one year ago at the university outpatient clinic for general medicine in Witten / Herdecke. The physicians and staff surveyed noted the need to optimize the current technical solution and the processes associated with it. In their view, implementing OpenNotes throughout Germany would require documentation and communication training to ensure that notes are formulated and explained in a manner understandable to laypersons. In addition, they believe it is important to integrate several physicians into a treatment network so that patients and physicians alike benefit even more from the transparency surrounding notes.

Physicians in Germany are likely to be skeptical

The physicians and medical staff involved in the Witten pilot project suspect that German physicians in particular are likely to be skeptical of using OpenNotes. This presumably has in part to do with concerns of having to lay bare the thinking behind their decisions.

“The fear, really, is the thought [among physicians] that I could be sued for this.”

Medical staff

These concerns are confirmed by individual court cases in which physicians have insisted that their notes are their property and are therefore not part of a patient’s file. Regardless of the legal context and the patients’ right to access their file, OpenNotes is based on physicians voluntarily making their records available to patients. Witten pilot project participants have also stated that they would like to see physicians who are skeptical of the idea reconsider their position.

“This requires a change in thinking, even among doctors. It involves tackling concerns. This approach can deliver advantages – it has more advantages than it does disadvantages.”

Medical staff

The OpenNotes pilot projects in the USA, Canada and Sweden also had to do with the initial skepticism of the medical profession. However, this skepticism often turned into enthusiasm. In the USA, no physician has withdrawn his participation in OpenNotes.

Accessing and reviewing files through EHR

On January 1st, 2021, the electronic patient health record (ePA) will start in Germany. One important requirement here, however, is that patients be able to understand, assess and use the information they retrieve from their ePA. To this end, physicians are well advised to voluntarily provide their patients full access to the file, including the notes from a consultation. A majority of the pop-

Methodology

There are four components to our analysis of file review.

Literature review: Prof. Dr. Tobias Esch compiled and summarized the current research literature on file access and review in the United States and Germany, and on OpenNotes.

Focus group interviews: In autumn 2019, Dr. Next GmbH surveyed ten patients and seven medical staff employees at the university outpatient clinic in Witten/Herdecke on their expectations regarding OpenNotes and inquired of their experiences with it so far. The quotes featured in this SPOTLIGHT HEALTHCARE come from these interviews.

Phone survey: Through the use of Computer-Assisted Telephone Interviewing, Kantar surveyed 1,030 people aged 18 and over on the subject of file access and review. The sample is representative of the population for the period of May 13 – 14, 2020.

International research and interviews: In May 2020, Dr. Cinthia Briseño carried out research on the application of OpenNotes in an international environment and conducted interviews with experts from Estonia, Norway, England and Sweden.

ulation in Germany would welcome this approach: Although 58 percent of the population have yet to actively request access to their files, 66 % say they would review their own patient files and notes if they could do so digitally.

To ensure that many people can benefit in the short term from viewing visit notes, practice software systems should be equipped with user-friendly functions for physicians so that they can save their notes as a document in the patient’s ePA. The German ePA will have the technical capability to store visit notes in file format from the very beginning. In the long-term, the potential of open doctor-patient communication should also be enhanced in the ePA by enabling interactive applications like OurOpenNotes.



The report “Akteneinsicht – Chancen und Umsetzung von OpenNotes in Deutschland” (Accessing medical records – implementing OpenNotes in Germany and the opportunities this entails) is available free of charge and only in German at www.patient-mit-wirkung.de

Recommended actions

Simplify access to health records – Strengthening the culture of trust

A physician's voluntary offer to share visit notes helps patients to better understand and remember the contents of a treatment conversation and thus to better handle their own illness. OpenNotes improves the relationship between doctor and patient. In order to promote the cultural change towards more openness and mutual trust, the following measures should be taken:

Offer to access health records

- › The advantages of an open approach to the visit notes were shown in other countries, when this was started voluntarily. Physicians in Germany could already offer their patients a printout or copies of their visit notes, so that they can better understand their disease and better remember conversations.

Enable digital access to health records through the German ePA

- › International examples show that the EHR (in Germany ePA) is the right place where doctors can give their patients an insight into their notes. The ePA which starts in Germany on January, 1st 2021 would be technically able to receive and save note files generated from the various practice management systems. But this requires a standardization of the note files. Moreover, a corresponding function needs to be set up in the practice management systems.

Creating favorable conditions

- › If the technical requirements for saving visit notes in the ePA are met, physicians should receive appropriate remuneration for the voluntary saving of the note documents in the patient's ePA. In addition, medical training courses should be offered on how to formulate visit notes in a way that can be understood by laypersons.

Promote digital information exchange

- › OpenNotes unfolds its great added value as an interactive application on a digital platform, as it is done for example in Sweden. Then patients can not only read the visit notes, but also comment or add to them by themselves. Such an interactive application should be considered and implemented in the further development of the German ePA.

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Further information at www.bertelsmann-stiftung.de/en/our-projects/patients-with-impact (in English), www.bertelsmann-stiftung.de

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