

Insights from the Implementation of Open Notes in Sweden

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Abstract. The implementation of Open Notes in Sweden, granting patients access to their clinical records, has been a complex and nuanced endeavor, marked by regional variations in strategy and challenges arising from the diverging needs of healthcare providers and patients. This paper presents an interview study with managers about the implementation process in five of the 21 regions in Sweden. The aim of this study is to explore the experiences and strategies of these managers in navigating the implementation challenges. The study sheds light on the prevalent theme of uncertainty throughout the implementation journey and the strategies used to balance conflicting perspectives. The findings contribute to our understanding of Open Notes implementation and offer policymakers and healthcare organizations insights about enhancing the implementation process to optimize patient care.

Keywords. Electronic health record, online record access, open notes

1. Introduction

Open Notes is here defined as patients' access to their clinical records including test results, referrals, diagnoses, and notes from visits. This access might create transparency, promote empowerment, and provide better consultation preparation for patients. It may also cause uncertainty and distress [1,2]. For healthcare providers, the new audience for medical records introduces new considerations about record content. These include whether patient access to records may interfere with treatment or cause some clinicians to leave clinically relevant content out of records to avoid harm [3–5]. This concern has especially been raised for psychiatric patients [6,7].

Giving Swedish patients access to their clinical records is possibly one of the nation's most vital infrastructural and cultural changes of healthcare. However, the shift did not happen quickly and easily. In 1997, Region Uppsala started a project to give patients online access to their health records, and 21 years later, in April 2018, the last of

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Sweden's 21 regions connected their Electronic Health Records (EHR) system to the national Open Notes solution. Agreeing on a national regulatory framework was challenging [8]. Different regions in Sweden adopted different strategies to deal with conflicting needs and requirements from healthcare providers and patients. Moreover, the implementation has varied widely across the regions [7,9,10]. Some variations are due to technical reasons, such as access to vaccination records, and others are due to disagreements about what it is appropriate to show patients and when. We know little about the strategies and experiences of the different implementation project group members when implementing Open Notes in Sweden. Hence, this paper presents an interview study with managers from five regions in Sweden about their experiences with implementing Open notes.

2. Methods

We did semi-structured interviews with 14 project group members who had worked with the implementation of Open Notes. Participants were recruited using purposive sampling through the National Organization for eHealth Services, INERA. The interview template included questions regarding respondents' biographies, work-life, implementation strategies, and experiences related to conflicts in the project. All interviews were audio-recorded and transcribed, and participants were treated confidentially (Table 1). A thematic analysis was conducted on the transcribed interviews to identify key themes and patterns related to the implementation experiences and strategies of the project group members.

Table 1. Participant profile

Region	Gender and age	Role in Project	Background
1	F, 40-45	Project leader	Caregiver/developer
1	M, 65-70	Team-member	Physician
2	F, 55-60	Project leader	Care admin./ manager
2	M, 55-60	Sub-project leader	IT Engineer
2	F, 55-60	Team-member	Caregiver/ manager
2	F, 45-50	Team-member	Care admin./developer
3	F 45-50	Project leader	Caregiver/ manager
3	M, 60-65	Sub-project leader	Physician
4	M, 55-60	Project leader	Caregiver/ manager
4	F, 45-50	Team-member	Physician
5	M, 55-60	Project leader	IT Engineer
5	F, 40-45	Sup-project leader	Caregiver/ manager
5	M, 45-50	Sub-project leader	Physician
5	F, 45-50	Team-member	Care admin./ manager

Ethical approval was not sought, as the study did not involve sensitive personal information as defined by Swedish laws. However, ethical standards were followed.

3. Results

3.1. Uncertainty

The most common experience in the interview data was feeling uncertain. One interviewee described the initial phase of the project, expressing uncertainties and

repeated concerns: *"There have been, there has been anxiety and all that, and it has been a bit. You come to a... it's the same questions /related to anxiety/ all the time."* The interviewee also acknowledged the intensive risk analysis by commenting that *"The risk analysis we conducted has been screamingly red."* However, as the project progressed, the fears seemed to subside, suggesting that the perceived risks were not as severe as anticipated: *"And then it did not become as serious as anticipated when it finally started."*

Another interviewee described their journey by stating that they were initially unfamiliar with Open Notes: *"I did not know what Open Notes was when I got the assignment."* This quote emphasizes the lack of prior knowledge and the unexpected nature of their role in the project. Furthermore, they highlighted the shift in perspective brought about by the implementation process: *"Open Notes has been, well, what should I say, a sacred, a holy grail almost. Or whatever you want to call it. We have now dared to release something to those it's really about."*

One interviewee discussed the unexpected complexities and the under-preparedness of healthcare professionals: *"I thought healthcare providers were more prepared for this than they actually were."*

3.2. Balancing the Healthcare Providers' and the Patients' Perspectives

The interviewees highlighted healthcare professionals' fear of patients receiving too much information or being unable to handle it effectively: *"I heard more concerns from the doctors /.../: 'What will we do now when the patient gets this information? Will they get it before we do? I want to be able to explain to the patient what it means when they read it.'"*

A fundamental aspect of Open Notes that resonated with patients was the transparency it offered. Some interviewees viewed access to their medical records as the patient's right, allowing them to be well-informed about their health condition and treatment plans. Some interviewees recognized, however, that certain circumstances, such as critical care situations or psychiatric care, might warrant temporary restrictions on access to sensitive information. Nevertheless, often, the overarching sentiment was a strong belief in their right to access their medical data: *"So, it's a major shift in mindset, and sometimes I still find it difficult... that now when a patient is in a critical care phase, we want to hide the information for a period so the patient cannot see it. I still believe it is important that we sometimes have that possibility. Especially in psychiatry."*

According to the interviewees, patients with chronic conditions expressed a strong desire to access their test results promptly through Open Notes. For them, timely access to test results had significant implications for managing their chronic illnesses. This emphasized the practical benefits of electronic health records in improving patient care: *"And I have also seen and heard information about patients who very much want Open Notes, especially those with some form of chronic illness and who depend on test results"*.

Psychiatric care emerged as a specific context where concerns about patients accessing their health information were raised in the interviews. Healthcare providers in psychiatric settings expressed heightened fears regarding patient vulnerability and the potential for misinterpretation of sensitive information. They stressed the need for careful consideration when granting access to certain psychiatric records and ensuring that patients can understand and interpret the information appropriately.

The implementation of Open Notes revealed the need for extensive learning and adaptation for healthcare providers and patients. The implementation project in the regions initially underestimated the preparations required for the implementation and the

amount of resistance encountered. The project required addressing technical complexities and engaging in discussions to ensure appropriate documentation practices. The implementation process was a learning experience, bridging the gap between technology and healthcare practices. The successful implementation of Open Notes required extensive learning, preparation, and adaptation by healthcare personnel. This extended adjustment period highlights the considerable effort invested in the transition: *"So, it was quite a long learning period."*

3.3. Conflicts Encountered

Conflicts were a prominent theme in the interviews. One interviewee described the project journey, expressing initial resistance to the new ideas: *"From almost being against... very resistant to opening up for new ideas, both within our organization and the healthcare system."* This quote highlights the challenges faced in introducing and obtaining acceptance of the implementation of Open Notes.

Another interviewee discussed technical issues encountered with the communication protocols between the local system, Cosmic, and the national service platform, which serves as the central hub for transmitting information to Open Notes: *"There were technical problems with the communication protocols between Cosmic and the national service platform, which is like the spider in the web and sends the information to Open Notes."* This quote emphasizes the difficulties experienced due to technical inadequacies and suboptimal implementation practices.

Furthermore, conflicts arose in interactions with different groups of stakeholders, in particular physicians. One interviewee contrasted the attitudes of different groups of physicians, highlighting the challenging dynamics depending on experience and specialty. The interviewees described the need for ongoing dialogue and engagement to address the physicians' concerns and obtain project acceptance.

4. Discussion

The introduction of Open Notes in Swedish healthcare has acted as a disruptive technology [12], catalyzing a shift in many healthcare providers' professional identities, perceptions of hierarchical structures, and engagement with patients [5]. This implementation journey—far from being a mere technical deployment—became the stage for a drama of change, conflict, and eventual understanding. For some, the disruption triggered a backfire effect, a clinging to traditional practices where professional authority went unquestioned and patient roles were more passive [3,5]. However, as knowledge about the system deepened and the diverse perspectives of other stakeholders became apparent, these initial conflicts often dissolved into constructive dialogue.

The implementation of Open Notes also imposed a substantial emotional toll on the regional implementation teams in Sweden. These teams, consisting of individuals with diverse professional backgrounds [11], were at the forefront of a cultural shift. They became the bridge between Open Notes' innovation and the reluctant healthcare providers, mitigating concerns, aligning expectations, and promoting confidence.

The study focused on understanding the experiences of 14 project group members involved in the implementation, prioritizing individual narratives over generalizable outcomes. The sample was purposively selected to capture diverse perspectives, but the

participants' specific characteristics may limit the findings' transferability to other contexts. Despite these limitations, the insights generated can be transferable to similar projects, offering valuable perspectives and considerations.

5. Conclusions

In summary, implementing Open Notes in Sweden illustrates the transformative potential for patient empowerment and the challenges of aligning healthcare practices with digital innovation. Through interviews with project group members, this study highlights the critical balance between transparency and healthcare provider concerns, revealing a journey of adaptation and conflict. The experiences captured underscore the necessity of thoughtful strategies that prioritize both technological advancements and the nuances of patient-provider dynamics. As healthcare continues to evolve, the insights from Sweden's journey with Open Notes offer valuable lessons for integrating patient access to clinical records to foster engagement while maintaining care quality.

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