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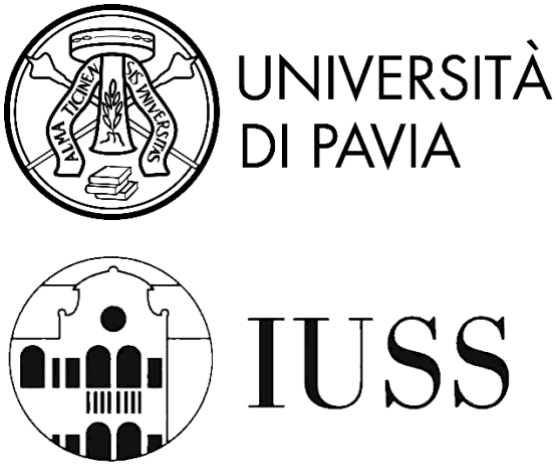

Open Notes in General Health Care Settings: A Scoping Review of Stakeholder Experiences. Implementation Challenges and Implications for Clinical Practice

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خورشیدِ می ز مشرق ساغر طلوع کرد
گر برگِ عیش می‌طلبی، ترک خواب کن

Il sole del vino è sorto dall'oriente della coppa;
se cerchi la provvista della gioia, rinuncia al sonno.

— Ḥāfiẓ of Shiraz (14th c.)

Acknowledgments

I would like to begin by expressing my deepest love and gratitude to my mother and father — Maman, Baba, everything begins and ends with you.

There are no words in any language that can fully capture what I feel for you, but let me try. Leaving your arms to build a life and a future far away was the hardest thing I have ever done. Some nights the distance felt unbearable, and I would have given anything just to sit beside you, to hear your voice in the next room, to be home. Yet even oceans apart, you never once let me feel alone. Your love reached me across every mile, in every phone call, every worry you tried to hide, every prayer you sent my way.

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Table of Contents

Abstract

Open notes—patients' electronic, portal-based access to the narrative documentation clinicians produce within electronic health records (EHRs), has moved from an experimental practice to a legal and policy reality, exemplified by the United States' 21st Century Cures Act and comparable national initiatives across Europe. By transforming the clinical note from a professional artifact into a shared medium of communication, transparent documentation reconfigures the patient–provider relationship, yet no synthesis has previously mapped its effects across all healthcare specialties and stakeholder groups. Building on an earlier mental-health-specific review, this thesis aimed to map the breadth of empirical evidence on how patients, families, and clinicians experience open notes across general healthcare settings, examining patient and family experiences, clinician responses and documentation practices, note-related factors, and the organizational conditions shaping implementation. A scoping review was conducted following the Joanna Briggs Institute methodology and the PRISMA-ScR reporting guidelines. Five databases were searched, records were screened in duplicate against a pre-registered protocol, and data from 79 included studies were charted and consolidated into 17 unified measurement domains, which were synthesized narratively by domain and by clinical setting. The evidence concentrated on clinician documentation concerns and patient informational outcomes, with comprehension and recall emerging as the most consistently documented benefits. Patients reported improved engagement, self-management, empowerment, and trust, while adverse emotional responses clustered around sensitive, prognostic, or stigmatizing content. Clinicians' anticipated workload, patient distress, and dissatisfaction were consistently higher before implementation than after, though documentation adaptation varied by specialty. Privacy concerns and inequities in note access were most pronounced in mental health, pediatric, and underserved populations. Overall, open notes deliver meaningful benefits when implementation attends to documentation quality, patient preparation, clinician training, governance, and equitable access.

Keywords: open notes; patient access to records; electronic health records; scoping review; patient–provider communication; clinical documentation; health equity

Chapter 1: Introduction

1.1 Open Notes: Definition, Origins, and the Shift Toward Transparency

The term *open notes* refers to providing patients with electronic, portal-based access to the narrative documentation clinicians produce during or after medical encounters within Electronic Health Records (EHRs). These notes contain detailed clinical observations, diagnostic reasoning, treatment plans, medication changes, future recommendations, and clinicians' professional assessments of a patient's physical or psychological state. What distinguishes open notes from other patient-accessible health information, such as laboratory results or discharge summaries, is their unfiltered, contemporaneous character: they reflect the same documentation clinicians produce for professional purposes, including clinical language, working hypotheses, and interpretive statements historically restricted to the healthcare team (Delbanco et al., 2012; Fossa et al., 2018).

The conceptual foundations of open notes are rooted in the broader evolution of patient-centered care, shared decision-making, and medical transparency. For much of the twentieth century, clinical paternalism meant patients were routinely excluded from access to their own medical records; open notes emerged as a direct counter to this paradigm (Esch et al., 2016). The ethical argument for patient access to clinical information, grounded in autonomy and respect for persons, received growing scholarly attention as healthcare systems transitioned toward more participatory models of care (Beauchamp & Childress, 2019). By the 1990s and early 2000s, clinicians, scholars, and ethicists increasingly questioned the rationale for withholding clinical documentation from the people it described, laying the intellectual groundwork for formal note-sharing initiatives (Delbanco et al., 2012).

The transition from theoretical discussion to practical implementation began with the landmark OpenNotes project, launched in 2010 across three major United States healthcare institutions: Beth Israel Deaconess Medical Center, Geisinger Health System, and Harborview Medical Center. Led by Dr. Tom Delbanco and colleagues, the project evaluated the feasibility, perceived risks, and potential benefits of routinely sharing clinical notes with patients. Over the course of one year, more than 100 primary care physicians and nearly 20,000 patients participated in a quasi-experimental study in which patients were invited to access their visit notes through secure online portals (Delbanco et al., 2012). The findings were consequential: most patients

reported feeling more informed, more engaged, and more in control of their care, while physicians reported minimal effects on their workload or documentation practices. These results provided the first large-scale empirical support for open notes and catalyzed broader adoption and international attention (Leveille et al., 2012; Walker et al., 2015).

1.2 Global Expansion and Policy Context

Following the original OpenNotes study, transparent documentation expanded rapidly beyond its initial U.S. pilot sites, supported by accumulating empirical evidence and shifting policy frameworks. In Sweden, open notes were implemented nationally in 2012 through the Journalen platform, granting all citizens access to their electronic health records via a centralized portal (Cajander et al., 2024.). Norway and Estonia adopted comparable note-sharing frameworks through their national eHealth infrastructures (Hägglund et al., 2022), while the United Kingdom's National Health Service made access to general practitioner consultation notes mandatory in 2022 (Blease et al., 2023).

In the United States, the most significant policy development came with the 21st Century Cures Act, enforced in April 2021, which required all healthcare providers using certified EHR systems to provide patients free and immediate access to a broad range of clinical documentation, transforming transparent note-sharing from an institutional option into a legal obligation (*Fy2020-Performance-Plan.Pdf*, n.d.). Post-mandate surveys documented a rapid shift in clinician attitudes, with most practitioners increasingly supporting the practice and reporting limited effects on workflow, despite concerns about documentation burden and patient queries (DesRoches et al., 2021; Leonard et al., 2023; Ralston et al., 2021). Together, these developments mark a fundamental reconfiguration of the patient–provider relationship: the clinical note is no longer a purely professional artifact but a shared medium of communication, accountability, and care partnership.

1.3 Benefits of Open Notes Across Healthcare Settings

Across diverse clinical contexts, the empirical literature on open notes converges on a consistent set of patient-reported benefits that can be organized into four interrelated themes: comprehension and recall, engagement and self-management, patient safety, and communication and trust.

Comprehension and recall. Patients who read their notes consistently report improved recall of care instructions, greater understanding of their diagnoses and the rationale for treatment, and

enhanced confidence in interpreting clinical information (Delbanco et al., 2012; Esch et al., 2016; Walker et al., 2019). These cognitive gains support shared decision-making: patients who read more clinical notes report significantly higher levels of collaboration with their providers (Fossa et al., 2018), and large multi-site evaluations confirm substantial benefits in comprehension, control, and preparation for appointments across primary care, medical, and surgical specialties (Walker et al., 2019).

Engagement and self-management. Beyond individual encounters, regular access to notes has been associated with better medication adherence, improved follow-through on care recommendations, and an enhanced ability to manage chronic conditions outside the clinical setting (Mishra et al., 2019; Wolff et al., 2016). This effect appears across specialties and populations: patients with chronic obstructive pulmonary disease report that note access promotes self-management and strengthens the patient–provider relationship (Fisher et al., 2022), while patients with multiple chronic conditions and older adults describe notes as particularly important for managing their health and preparing for clinical visits (DesRoches et al., 2021).

Patient safety. Access to clinical notes positions patients as active contributors to safety, allowing them to identify potential inaccuracies such as incorrect medication dosages, misreported diagnoses, or omitted concerns. A mixed-methods study found that open notes helped patients identify diagnostic safety blind spots across multiple stages of the diagnostic process, framing access to notes as a scalable mechanism for engaging patients in safety monitoring (Bell et al., 2022). At the same time, although many patients and families notice errors when reading visit notes, a substantial proportion do not report them, citing uncertainty about how to do so or fear of negative consequences, which is an important implementation challenge (Lam, Bourgeois, DesRoches, et al., 2021).

Communication and trust. Transparent documentation fosters more open dialogue between patients and clinicians by giving patients direct insight into the reasoning and language in their records. Multiple studies report that patients who access their notes develop greater trust in their providers, particularly when notes are accurate, respectful, and consistent with the consultation (Bell et al., 2022; Esch et al., 2016)(Bell et al., 2016; Esch et al., 2015). Clinicians, in turn, often report adapting their documentation toward greater clarity and patient-centeredness once they

recognize that the note's audience and therefore its communicative function have changed(Erlingsdóttir et al., 2019; Vanka et al., 2025).

1.4 Challenges and Limitations Across Healthcare Settings

Despite this consistent pattern of benefits, open notes also introduce challenges that can be grouped into three levels: patient-level barriers, clinician-level concerns, and organizational or ethical issues.

Patient-level challenges are dominated by health literacy and digital accessibility. Not all patients have the literacy skills or technological resources to access, read, and interpret clinical documentation effectively (Mafi et al., 2016). This digital divide may disproportionately affect older adults, individuals with lower socioeconomic status, and patients with limited language proficiency, potentially concentrating benefits among those already most advantaged in the healthcare system. A longitudinal study found that note viewing declined substantially among racial minority groups when reminders were removed, suggesting that sustained engagement requires active support rather than passive availability (Mafi et al., 2016). Generalizability beyond Western contexts also remains uncertain: a study in Japan reported that older patients showed lower agreement that access to notes would improve their understanding (Elkhaili El Alami et al., 2020).

Clinician-level concerns center on the risk that patients may misinterpret medical terminology, clinical hypotheses, or speculative formulations not designed for lay audiences (Janssen et al., 2021; Nandiwada et al., 2018). In response, clinicians often adapt their documentation, using more careful language, avoiding stigmatizing terms, and sometimes omitting sensitive details with both benefits and risks. While more patient-centered language can improve comprehension and reduce offense, excessive self-censorship may compromise the utility of notes as professional communication tools(Crotty et al., 2018; Erlingsdóttir et al., 2019). A survey of general practitioners in England found that many anticipated increased workload, patient anxiety, and changes in documentation due to note sharing, with some intending to alter or withhold clinical content (Blease et al., 2023). Evidence from radiation oncology further shows that note complexity significantly affects users' cognitive load and performance. Yet overall comprehension remains incomplete even with simplified notes (Khasawneh et al., 2022), highlighting that readability alone does not guarantee understanding.

Organizational and ethical issues cut across patient and clinician concerns. Privacy is a recurrent theme: patients accessing their notes may encounter sensitive information about third parties, undisclosed diagnoses, or social circumstances documented without their full awareness. About one-third of patients report privacy concerns regarding access to notes, with higher rates among women, non-white patients, and those less confident in communicating with providers (Vodicka et al., 2013). In pediatric settings, sensitive adolescent information—including mental health, sexual health, and substance use- creates particular challenges for designing age-appropriate access controls (Parsons et al., 2020). These issues underscore that the safe implementation of open notes depends as much on documentation training, governance clarity, and portal design as on the principle of transparency itself.

1.5 Open Notes Across Specific Clinical Populations

The benefits and challenges outlined above do not manifest uniformly across healthcare settings. Different specialties involve distinct types of clinical information, relational dynamics, and vulnerabilities among the populations they serve. As a result, the same intervention, patient access to clinical notes, can produce qualitatively different experiences depending on the clinical context. Three settings illustrate this variation particularly well, as each surfaces a defining tension that the broader open notes literature must address.

Pediatrics: parental access and adolescent confidentiality. In pediatric settings, parents, rather than patients, are typically the primary note-readers. They consistently report benefits in comprehension, engagement, and sense of control, alongside challenges related to medical jargon, heightened anxiety in high-acuity environments, and privacy concerns for adolescent patients (Kelly et al., 2021, 2023; Smith & Kelly, 2022). Studies in pediatric and neonatal intensive care units show that families read notes frequently, rate them as accurate, and use them to revisit information and reinforce verbal communication, while still describing emotional burden and terminology as significant barriers (Chu et al., 2024; McCallie et al., 2024). The defining tension in pediatrics is therefore the balance between proxy access for parents and the need to protect confidentiality for adolescents managing sensitive aspects of their own care.

Oncology: emotionally sensitive and prognostic information. In oncology, patients encounter prognostic and diagnostic language that carries significant emotional weight. Patients with advanced cancer report that note access can improve comprehension and trust, particularly when

they feel overwhelmed during consultations. However, a subset describes increased anxiety when reading detailed clinical assessments alone (Kayastha et al., 2018). On the clinician side, oncologists have shown limited spontaneous adaptation of their documentation practices after the implementation of open notes (Alpert, Morris, Thomson, Matin, Geyer, et al., 2019), suggesting that specialty-specific training and guidance are needed to align note-writing with patient readability. Oncology thus exemplifies the challenge of sharing high-stakes, emotionally charged information in a way that supports rather than destabilizes the patient.

Mental health: therapeutic language, stigma, and risk documentation. Mental health is the setting in which the relational and interpretive dimensions of clinical documentation become most salient. Psychiatric and psychotherapy notes routinely contain therapeutic hypotheses, provisional diagnostic formulations, behavioral observations, stigma-laden descriptors, and risk appraisals that are indispensable for clinical continuity but highly context-dependent for lay readers (Blease, Kharko, et al., 2021). Mental health clinicians have expressed ambivalence about open notes, citing concerns about patient distress, disruption of the therapeutic relationship, and the tension between honest documentation and emotional safety (Dobscha et al., 2016). Patients in mental health care often report benefits in comprehension and trust when documentation is respectful and aligned with what was discussed in sessions, but a non-trivial minority report worry, feeling judged, or confusion when encountering uncontextualized clinical language w(Woods et al., 2013). These dynamics make mental health one of the most carefully studied contexts in the open notes literature and a setting whose specific implications have already been mapped in a dedicated scoping review by the present research group (Monaci et al., 2025).

Across these and other specialties, including ophthalmology, dermatology, and general internal medicine, a common pattern emerges- open notes generate meaningful benefits when implementation attends to documentation quality, patient preparation, and portal usability, and pose risks primarily when these conditions are absent (Henderson et al., 2021; Lee et al., 2017; Leveille et al., 2020).

1.6 Identifying the Research Gap

The preceding overview shows that open notes function as a system-level communication intervention whose effects are shaped by clinical setting, documentation practice, and organizational implementation. Yet despite the rapid global expansion of note-sharing initiatives

and a growing empirical literature, no comprehensive scoping review has simultaneously synthesized evidence across all healthcare specialties and stakeholder groups. Prior syntheses have tended to focus on specific subpopulations or have been limited to earlier publication periods that predated significant developments, including the 2021 United States policy mandate and the accelerated international adoption of patient portals(Schwarz et al., 2021).

Within this landscape, the evidence base for mental health has recently been mapped in a dedicated scoping review conducted by the present research group (Monaci et al., 2025), which examined stakeholder experiences and implementation considerations in psychiatry and psychotherapy. While that review provided an in-depth synthesis of a particularly sensitive setting, an equivalent cross-specialty synthesis remains missing. A mapping of the broader open notes literature is needed to identify reproducible patterns and specialty-specific considerations across general medical, surgical, and pediatric care, and to derive implications for clinical practice and documentation training that extend beyond mental health.

Such a synthesis is also needed because no existing review has systematically examined the full spectrum of measurement domains in the open notes literature: patient-centered outcomes (comprehension, engagement, safety, emotional responses), clinician-centered outcomes (documentation adaptation, workload, attitudes), notes-related factors (accuracy, readability, sensitivity), and organizational implementation conditions. Integrating evidence from these domains is essential for building a coherent understanding of how open notes function as a communication intervention across healthcare settings.

1.7 Aims and Structure of the Present Thesis

Building on the previously published mental health-specific review (Monaci et al., 2025), this thesis presents a scoping review of empirical evidence on the experiences, perceived impacts, and implementation of open notes across general healthcare settings and stakeholder groups. The aim is to map the breadth of available knowledge beyond mental health, identify reproducible patterns and specialty-specific considerations, and derive structured implications for clinical practice, documentation culture, and health policy.

Four specific objectives guided the review:

1. To examine how patients and families across diverse clinical settings experience open notes, including effects on comprehension, engagement, safety, emotional responses, and trust.
2. To explore how clinicians across healthcare specialties respond to patient access to their clinical notes, with attention to documentation adaptation, workload, and the patient-provider relationship.
3. To assess how note-related factors, including readability, accuracy, sensitivity of content, and portal usability, shape stakeholder experiences and outcomes.
4. To identify the organizational and implementation conditions that enable or hinder the safe and effective adoption of open notes across healthcare settings.

The thesis is structured as follows. Chapter 2 presents the research objectives and research questions in detail. Chapter 3 describes the scoping review methodology, including the search strategy, eligibility criteria, and data synthesis approach. Chapter 4 presents the results through a thematic synthesis of the included studies. Chapter 5 discusses the findings in light of the existing literature and their implications for clinical practice, documentation training, and policy. Chapter 6 presents the conclusions, limitations, and directions for future research.

Chapter 2: Research Objectives

2.1 Background and Rationale

Open Notes has been adopted with growing consistency across healthcare systems worldwide, generating a substantial but fragmented evidence base: individual studies tend to focus on a single population, setting, or outcome domain rather than integrating findings across the literature. This thesis draws on two complementary datasets, 57 studies from a broad search of the Open Notes literature across healthcare settings, spanning primary care, pediatrics, oncology, ophthalmology, dermatology, COPD, veteran care, and multi-specialty contexts, together with 22 studies from a previously published scoping review focused specifically on mental health care (Monaci et al., 2025), yielding a combined corpus of 79 studies from which four research objectives were derived. Where findings are specific to mental health, this is noted explicitly. The objectives move progressively from the individual patient (Objective 1) to the individual clinician (Objective 2), to the notes themselves as communicative artifacts (Objective 3), and finally to the organizational level (Objective 4), reflecting Open Notes as simultaneously

a patient experience, a clinical practice, a documentation challenge, and an implementation problem.

2.2 Objective 1: Patient and Family Experience Across the Treatment Pathway

Open Notes can be understood as a communication intervention that makes clinicians' reasoning visible to patients between encounters, with the potential to support health literacy, activation, and engagement across the arc of care (Delbanco et al., 2012). These effects unfold differently along the pathway: note access appears to aid comprehension around diagnosis and planning (Wolff et al., 2016), reinforce adherence during active treatment (Fisher et al., 2022), and support preparation during follow-up (Walker et al., 2019), while also functioning as a safety mechanism through error detection (Bell et al., 2022). The mental health dataset nuances this picture: most patients accessing psychotherapy notes describe improved self-understanding and trust (O'Neill et al., 2019), but a minority — particularly those with PTSD or borderline personality disorder — report worry when encountering uncontextualized language (Denneson et al., 2022), suggesting diagnostic profile and clinician support moderate outcomes. This objective asks what patients and families experience across settings with respect to comprehension, trust, safety, emotional well-being, and participation, through domains including comprehension, engagement, adherence, visit preparedness, safety, trust, emotional response, shared decision-making, and health self-efficacy — the most broadly represented objective across both the broader healthcare corpus and the mental health sub-corpus.

2.3 Objective 2: Clinician Experience, Documentation, and the Patient-Provider Relationship

When clinicians know their notes will be read by patients, the notes acquire a dual audience, creating both opportunities and pressures. Clinicians who engage thoughtfully with Open Notes report writing more clearly and respectfully (Erlingsdottir et al., 2019), and most in the United States came to support note sharing following mandatory implementation under the 21st Century Cures Act (DesRoches et al., 2020). The mental health dataset reveals a more ambivalent picture, with clinicians describing reduced candor and disrupted therapeutic relationships when sensitive formulations are read without context (Schwarz et al., 2024; Denneson et al., 2017). This

objective asks how clinicians experience Open Notes and what changes in documentation, workload, attitudes, and relationship accompany patient access, through domains including documentation adaptation, workload, attitudes, concerns about misinterpretation, therapeutic relationship dynamics, professional autonomy, and note-promoting behavior, with the mental health sub-corpus offering particularly rich qualitative accounts of how the clinical relationship is renegotiated under transparency.

2.4 Objective 3: Notes-Related Factors and Stakeholder Outcomes

Open Notes is not a uniform intervention: readability, accuracy, tone, and sensitivity vary considerably across notes, moderating outcomes for both patients and clinicians. Notes perceived as accurate and respectful are associated with greater trust (Leveille et al., 2020), while stigmatizing or jargon-heavy language generates confusion or distress (Bell et al., 2022), a dynamic especially pronounced in mental health documentation, where terms like "non-compliance" can read as accusatory outside a clinical context (O'Neill et al., 2019). Portal usability compounds these effects, with note-viewing sensitive to reminder systems and ease of navigation (Mafi et al., 2016). This objective examines how note characteristics and portal usability shape stakeholder experiences across domains, including accuracy, transparency, sensitivity, language and stigmatization, readability, portal usability, and audience awareness, drawing substantially on both the broader healthcare and mental health datasets.

2.5 Objective 4: Organizational and Implementation Conditions

Safe adoption of Open Notes depends on organizational conditions rather than the introduction of a portal alone: training, governance frameworks, patient orientation, and a clear policy on privacy and equity all shape implementation success. Structured training is consistently associated with more positive clinician attitudes and lower documentation burden (Leonard et al., 2023), while default opt-out sharing has been shown to increase sharing rates without increasing complaints (Bialostozky et al., 2020). The mental health dataset identifies narrowly defined exemption policies, patient guidance, and privacy-aware portal design as preconditions for safe implementation (Blease et al., 2021). Equity is a cross-cutting concern in both datasets, with documented disparities in note-reading across age, race, and digital literacy (Mafi et al., 2016).

This objective asks what organizational and policy-level factors facilitate or impede safe implementation, through domains including governance, clinician training, patient orientation, implementation design, privacy and legal frameworks, equity of access, and workflow integration.

Chapter 3: Methodology

3.1 Protocol and Reporting

The work presented in this thesis was carried out as a scoping review of empirical literature on Open Notes, mapping how patients, families, and clinicians experience patient access to clinician-authored documentation across the full range of healthcare settings. A written protocol was drafted by the research team before any screening activity began, and the review was pre-registered on the Open Science Framework. The decision to use a scoping rather than a fully systematic review design was deliberate: the literature on Open Notes is methodologically heterogeneous, spans qualitative and quantitative traditions, and is still expanding into new specialties, so the breadth-first logic of a scoping review fits the question better than the narrow comparative logic of a Cochrane-style synthesis(Arksey & O'Malley, 2005).

The review followed the Joanna Briggs Institute (JBI) methodology for scoping reviews, which provides guidance on framing the population–concept–context (PCC), structuring the search, and organizing evidence extraction when included studies differ in design (Aromataris et al., 2024). Reporting followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (Tricco et al., 2018), and the checklist was completed by the lead author and verified by the supervisor. The PRISMA-ScR flow of identification, screening, eligibility, and inclusion is shown in Figure 1.

The present thesis builds on but is distinct from an earlier paper published by the same research team (Monaci et al., 2025)(Monaci et al., 2025), which focused exclusively on Open Notes in mental health. Because that work mapped only a single clinical context, the supervisory team decided to broaden the thesis's scope to encompass all healthcare settings. The screening pipeline and data extraction were therefore rerun from the beginning using the same protocol and database queries, but with eligibility criteria expanded to include any specialty. Mental health was

retained as one of the included specialties, and the findings of the 2025 paper are used in the Results chapter as a reference point for comparing patterns observed in other clinical contexts.

The thesis is organized around two connected but analytically distinct components. The first draws on the published scoping review by (Monaci et al., 2025), which mapped Open Notes specifically in mental health settings; throughout this work, that body of evidence is referred to as the mental health sub-corpus and serves as a focused reference point rather than a primary data source. The second and primary component is the broader review of healthcare settings conducted for this thesis, which extends the analysis to all clinical specialties and serves as the main analytical framework for Chapters 4 and 5. Mental health is retained as one of the included specialties within this broader review, meaning the 22 mental health studies contribute to the combined corpus of 79 included studies; they are not counted twice.

The two components are kept analytically distinct throughout the Results chapter. Where findings are drawn from the mental health sub-corpus alone, this is stated explicitly; where they come from the broader healthcare settings review, that too is made clear; and where patterns are described across both, the combined corpus of 79 studies is the unit of reference. Two successive data extraction passes were carried out, one for the mental health paper and one for the broader thesis, and both were preserved in a single combined workbook. This was a deliberate methodological choice, not a source of duplication: retaining both passes enables domain-level tag-instance counts to be reported separately by source and compared directly, making the analytical provenance of each finding transparent. The broader healthcare settings review remains the primary framework of this thesis; the mental health sub-corpus functions throughout as a comparator and reference point, not as a parallel or competing analysis.

3.2 Review Questions and Objectives

The comprehensive question driving the review was how Open Notes shape the relationship between clinicians, patients, and caregivers when narrative clinical documentation moves from a professional artifact to a shared one. Three review questions guided the screening and extraction stages. The first concerned attitudes, perceptions, and lived experiences of patients, caregivers, and healthcare providers in the face of patient-readable notes (Delbanco et al., 2012). The second concerned the effects of note-reading on engagement, trust, shared decision-making, and other

patient-reported outcomes, as well as on the clinicians who write the notes (Bell, Mejilla, et al., 2017). The third concerned how patient portals that support Open Notes influence usability, accessibility, and stakeholders' perceptions of the benefits and limitations of transparent documentation (Fossa et al., 2018).

These three questions were operationalized through four specific objectives:

- To examine how patients and families across diverse clinical settings experience Open Notes, including effects on comprehension, engagement, safety, emotional responses, and trust.
- To explore how clinicians across healthcare specialties respond to patient access to their clinical notes, with particular attention to documentation adaptation, workload, and the patient–provider relationship.
- To assess how note-related factors, including readability, accuracy, sensitivity of content, and portal usability, shape stakeholder experiences and outcomes.
- To identify the organizational and implementation conditions that enable or hinder the safe and effective adoption of Open Notes across healthcare settings.

These objectives are not independent: the same primary study often addresses more than one of them, and the unified domains derived from the extraction data cut across all four. The objectives, therefore, function as a reading lens rather than as four mutually exclusive buckets. The explicit mapping of unified domains to objectives is given in Table 2.

3.3 Eligibility Criteria

Eligibility was defined using the JBI Population–Concept–Context (PCC) framework (Aromataris et al., 2024), and the same criteria were applied first at the title and abstract stage and then, more stringently, at the full-text stage.

3.3.1 Inclusion Criteria

- Population: patients, caregivers and care partners (including parents of pediatric patients), and healthcare providers, including physicians, nurses, residents, allied professionals, and organizational leaders.

- Concept: patient access to clinician-authored narrative clinical notes within an electronic health record or patient portal, that is, Open Notes in the strict sense, or analogous record-sharing systems where the notes themselves (not only test results, medication lists, or appointment summaries) are visible to the patient (Delbanco et al., 2012).
- Context: any healthcare setting, including primary care, hospital-based and inpatient services, pediatric and neonatal care, mental health, oncology, dermatology, ophthalmology, respiratory medicine, ambulatory specialty practices, and Veterans Affairs (VA) facilities, in any geographical region.
- Study designs: primary empirical research using qualitative, quantitative, or mixed methods. Surveys, interviews, focus groups, pre–post and quasi-experimental studies, longitudinal cohorts, implementation evaluations, and expert-consensus studies (Delphi) were all eligible.
- Articles published in English in peer-reviewed journals, with full text available.

3.3.2 Exclusion Criteria

- Secondary research: systematic and scoping reviews, meta-analyses, narrative reviews, editorials, commentaries, opinion pieces, and letters to the editor.
- Studies that referred to electronic health records or patient portals only in technical or architectural terms, without reporting stakeholder data on note-reading itself.
- Studies on patient portals that did not explicitly cover patient access to clinician-authored notes (e.g., portals limited to lab results, prescriptions, or messaging).
- Grey literature, including dissertations, conference abstracts without a full peer-reviewed paper, and reports without accessible methods.
- Articles not published in English, or for which the full text could not be retrieved after reasonable attempts.

The choice to exclude pure portal usability studies that never mention narrative notes is worth flagging. Several papers identified at the title and abstract stage discussed the patient portal as a generic platform but never made clear whether patients could read the clinician's prose. These were excluded at full-text review on the grounds that Open Notes, as a phenomenon, lives specifically

in the narrative text, the clinician's framing of the encounter, the wording chosen, the language about risk, and not in the structured data fields that accompany it.

3.4 Information Sources and Search Strategy

Five electronic databases were searched: PubMed (MEDLINE), Scopus, CINAHL, Web of Science, and the Cochrane Library. These databases were chosen to cover the biomedical literature (PubMed, Scopus), nursing and allied health journals (CINAHL), the broader social science and informatics literature relevant to digital health (Web of Science), and the secondary evidence base (Cochrane) for reference list checking. The final search was last updated in the run-up to data extraction, and additional records were identified by hand-searching the reference lists of included studies and of key earlier reviews (Monaci et al., 2025; Schwarz et al., 2021).

The search strategy combined controlled vocabulary (MeSH and CINAHL Subject Headings, where available) with free-text terms covering three conceptual blocks: the intervention ("open notes", "shared notes", "patient access to medical records", "OpenNotes"), the technology ("electronic health records", "patient portal", "personal health record", "EHR"), and the stakeholder focus ("patient experience", "perception", "attitude", "engagement", "clinician", "provider"). Terms within each block were combined with the OR operator, and the three blocks were combined with the AND operator. No date restriction was applied, which means the search covers the period from the first appearance of Open Notes in the empirical literature in the early 2010s, following the foundational Delbanco et al. (2012) study, through to the cut-off date of the final search.

Two reviewers independently ran the searches and exported all retrieved records into a shared reference manager. Search reproducibility was assessed by rerunning the strategy in PubMed at the end of the screening period; the same set of records was returned, indicating that the search was stable.

3.5 Study Selection

Selection followed the two-stage screening model recommended by JBI (Aromataris et al., 2024). Records exported from the five databases were uploaded into Rayyan (Ouzzani et al., 2016), an online systematic review management platform, where duplicate entries were automatically removed. The deduplicated record set was then manually checked to catch any near duplicates that

the automated routine had missed, most commonly the same article indexed with slightly different metadata in PubMed and Scopus. After this combined automated and manual de-duplication process, 4,054 unique records entered the title and abstract screening stage.

Title and abstract screening were conducted independently and in a blinded fashion by two reviewers. Each reviewer marked each record as include, exclude, or uncertain. Disagreements at this stage were resolved by discussion, and persistent disagreements were referred to a third reviewer (the supervisor). Records flagged as uncertain were automatically carried forward to the full-text stage rather than excluded, in line with the inclusive logic of a scoping review (Arksey & O'Malley, 2005).

Records retained after title and abstract screening (n = 119) were retrieved in full text. Where the full text could not be obtained through institutional subscriptions or open-access channels, the corresponding author was contacted; where this also failed, the record was excluded with the reason "paper not found" and counted in the PRISMA-ScR flow diagram. Full-text screening was conducted by two reviewers, again independently and against the same inclusion and exclusion criteria. Exclusions at the full-text stage were documented with reasons; the most frequent exclusion categories, not focused on Open Notes in the strict sense, did not report stakeholder perspectives, secondary data, non-English, and not peer-reviewed, are reported in the PRISMA-ScR diagram (Tricco et al., 2018).

After full-text review, 79 studies were judged to meet all inclusion criteria and were carried forward to data extraction.

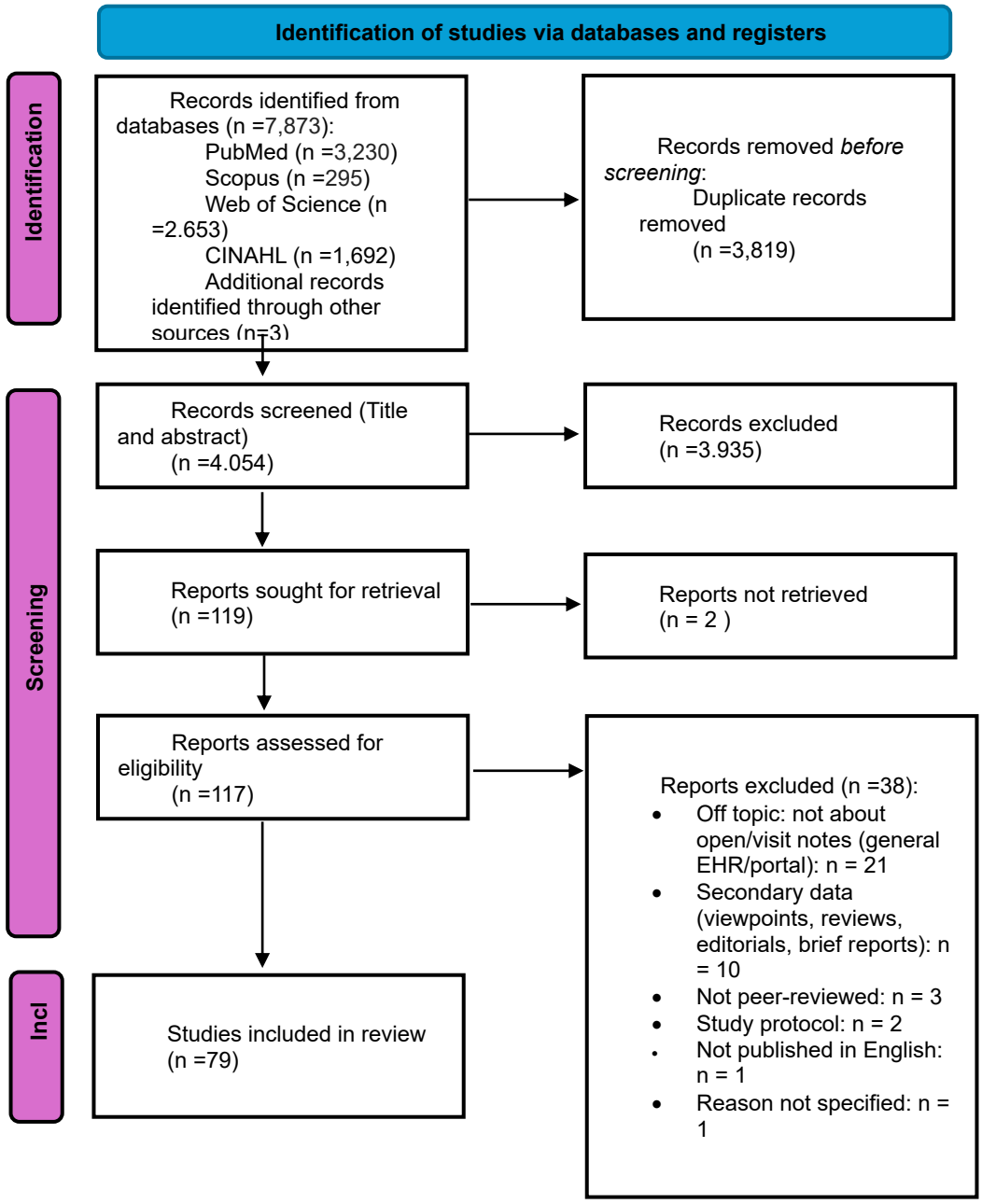

Figure 1. PRISMA-ScR flow diagram showing the identification, screening, and inclusion of studies.

3.6 Data Extraction

Data were extracted using a charting form developed in Microsoft Excel by the research team, capturing authors, year, country, and setting, stakeholder(s) studied, study design, sample size, and

percentage of female participants, where reported, primary outcomes and measures, and main results (Monaci et al., 2025). Where information was missing or unclear, for instance, gender distribution was frequently unreported, the relevant field was recorded as "Not Applicable" and no values were imputed. The form was piloted across five included studies by two reviewers, who double-extracted the initial subset to harmonize variable and tag interpretations; the form was then refined before being applied to the full sample. For the remaining records, extraction was carried out by a single reviewer and verified against the source paper by a second reviewer whenever ambiguities arose.

Beyond the structured fields described above, each study was also assigned one or more free-text "domain of measurement" tags by the lead author. These tags were descriptors capturing what the study had empirically measured, for example, "patients' comprehension", "clinicians' workload", "notes accuracy," or "patients' privacy," and were entered in a dedicated column of the charting workbook. This tagging step was intentionally open-ended rather than driven by a pre-specified coding scheme: rather than forcing each study into a fixed taxonomy at the point of extraction, the descriptors were allowed to reflect the actual language and constructs used in the primary papers. The consolidation of these raw tags into a unified analytical framework was carried out as a separate, subsequent step, described in full in section 3.6.2.

The thesis draws on two successive extraction passes. The second, broader pass was carried out specifically for this thesis after the scope was widened to all healthcare settings and is referred to throughout as Data Extraction 2. The first pass had been performed earlier for the mental-health paper (Monaci et al., 2025) and is preserved alongside Data Extraction 2 as a second column in the combined workbook. Where the two extraction passes covered the same study and disagreed, for instance, because additional fields were added in the second pass, the Data Extraction 2 entry was treated as authoritative.

The decision to retain both passes in a single combined workbook, rather than simply replacing the earlier extraction with the newer one, was deliberate. Because Article covered only mental health settings while Data Extraction 2 covers all healthcare specialties, the two passes are complementary rather than redundant: Article contributes tag instances that reflect the particular conceptual vocabulary of mental health Open Notes research constructs such as psychotherapy impact, therapeutic alliance, and clinicians' candor feature more prominently there than in the

broader sample (Monaci et al., 2025; Schwarz et al., 2021). Preserving both columns, therefore, allows per-source instance counts to be reported separately throughout the domain pipeline (Table1), making it transparent where the analytical weight of each domain comes from and enabling direct comparison between the mental-health subgroup and the wider literature.

3.6.1 Charted Items

For each included study, the following items were charted:

- Bibliographic details: first author, year of publication, country of the study population, and journal.
- The study's aim, as stated by the authors.
- Clinical setting and specialty (e.g., pediatric inpatient, primary care, oncology, mental health, ophthalmology).
- Stakeholder(s) studied: patients, care partners, parents, clinicians, residents, or organizational leaders.
- Study design and methods (qualitative, quantitative, mixed methods; pre–post, cross-sectional, longitudinal, implementation evaluation, Delphi).
- Sample size and, where reported, the proportion of female participants.
- Primary outcomes and their measures, as reported by the authors.
- The main results, summarized in the authors' own framing.
- A free-text 'domain of measurement' column, in which the lead author tagged each outcome with one or more descriptors capturing what the study had measured (e.g., 'patients' comprehension', 'clinicians' workload', 'notes accuracy', 'patients' privacy').

3.6.2 From Raw Tags to Unified Domains

The "domain of measurement" column was populated across the two extraction passes and then consolidated into a single combined workbook (Sheet4_combined in the appended file). Because two extraction passes were carried out at different times and against different scopes, the same construct could appear with slightly different wording in each, and a single workbook was needed before any analysis could be performed across the two datasets. The pipeline for moving

from raw tag entries to the final set of analytical domains is summarized in Table 1 and described step by step below.

Step 1: Assemble the two raw tag sets. The second extraction pass (Data Extraction 2, this thesis, all healthcare settings) yielded 350 raw tag instances; the first pass (Article, (Monaci et al., 2025), mental-health–only scope) yielded 194 raw tag instances. The two lists were combined into a single workbook as separate columns rather than concatenated up front, so that each tag instance retained its provenance and source counts could be reported separately throughout the rest of the procedure. The total number of raw tag instances available for aggregation was therefore 350 + 194 = 544.

Step 2: Exact-string consolidation across the two passes. Identical strings appearing in both columns were collapsed into a single row in the combined workbook, with two source-specific count columns and a total column. This step relied solely on byte-identical matching; it did not yet correct case, trailing whitespace, or spelling. The combined workbook produced 243 unique merged tag rows at this stage (Sheet4_combined), down from 544 raw instances.

Step 3: Typographical normalization. For this version of the analysis, the Data Extraction 2 source file had been pre-cleaned before import: trailing and leading whitespace was trimmed, capitalization was standardized, and obvious manual-entry slips were corrected (e.g., "patients elf care" → "patients selfcare"; "patients empowerments" → "patients empowerment"; "clinicians worklod" → "clinicians workload"). Because normalization was applied prior to import rather than after exact-string consolidation, the 243 unique rows from Step 2 already represent the post-normalization count. Tags appearing in both sources at this stage: 30.

Step 4: Conservative thematic aggregation into final domains. The 243 normalized tags were then aggregated into a smaller, fixed set of 17 unified domains that would form the analytical spine of the Results chapter. The aggregation was deliberately conservative: no domain was created based on a single tag, and no tag was merged into a larger group unless the construct it described was clearly a member of that group. Four explicit rules governed the merging.

- **Rule 1: Synonyms.** Tags expressing the same construct under different vocabulary were merged: for example, "patients understanding", "patients' comprehension", and "patients recall" were all collapsed into domain D1 (comprehension, recall & understanding of

notes), since the underlying construct measured in each was the patient's cognitive uptake of note content (Bell, Gerard, et al., 2017; Delbanco et al., 2012).

- **Rule 2: Stakeholder-level variants of the same construct.** Tags that named the same construct for different stakeholders were merged into a single stakeholder-agnostic domain: for example, "patients communication", "parents communication", "carepartner communication", and "carepartners communication" were merged into domain D5 (patient–clinician communication & therapeutic relationship). Within each domain, the underlying study still preserves its original stakeholder, so this merging does not collapse pediatric-specific or care-partner-specific findings; it only collapses redundant labels.
- **Rule 3: Construct-side vs. note-side framings of the same phenomenon.** Where a construct could appear in either of two framings, for instance, "patients' utility" (the patient's perceived usefulness) and "notes usefulness" (the note's perceived usefulness) both were merged into a single domain (here D10), since the construct being measured is the same and only the linguistic anchor differs. The same logic applies to "patients' privacy" / "notes sensitivity" (both into D11) and to "patients' safety" / "notes accuracy" (both into D12).
- **Rule 4: Distinct constructs remain separate.** Tags that, despite some lexical proximity, name distinct constructs were not merged. For example, "patients trust" and "patients trustworthy" were collapsed into D9 (trust, trustworthiness & candor) because both refer to the trust relation between patient and clinician, but "patients trust" was deliberately not merged into D10 (satisfaction/usefulness), even though trust and satisfaction often co-occur empirically. Likewise, D4 (self-care & adherence) and D2 (engagement, activation & uptake) were kept separate, because adherence behavior and reading uptake describe different downstream outcomes even though both load on patient agency(Delbanco et al., 2012).

Where a single normalized tag could plausibly have been assigned to more than one domain, it was placed in the domain whose central construct most closely matched the tag's most common usage in the included studies, and the assignment was recorded in the tag–domain mapping. The complete normalized tag list, including the counts of instances in Data Extraction 2 and Article,

the total count, and the unified domain assigned to each tag, was compiled and maintained throughout the mapping process.

Step 5: Verification of coverage. After the assignment rules had been applied to all 243 normalized tags, a coverage check was run on the combined workbook to confirm that (i) every normalized tag was assigned to exactly one domain, (ii) no tag was assigned to two domains, and (iii) the per-domain instance counts summed exactly to the source-specific raw totals (350 for Data Extraction 2, and 194 for Article; 544 combined). All three conditions were satisfied, with no residual unassigned tags.

Table 1 summarizes the full pipeline numerically:

Stage	Count	Operation applied
Raw tag instances from Data Extraction 2 (this thesis, all healthcare settings)	**350**	Verbatim tag strings entered in the 'domain of measurement' column for the broadened sample (revised file).
Raw tag instances from Article (Monaci, Javaher & Barello, 2025)	**194**	Verbatim tag strings from the earlier extraction pass, re-imported as a second column.
Combined raw tag instances (both passes)	**544**	Straight concatenation of the two source columns; no merging yet.
Unique tags after exact-string consolidation	**243**	Identical strings collapsed across both columns; row count of Sheet4_combined. Tags present in both sources: 30.
Unique tags after typographical normalization	**243**	Pre-cleaning of the DE2 source file corrected whitespace, capitalization, and spelling before import; no further reduction at this step.
Final unified domains used in the Results chapter	**17**	Conservative thematic aggregation of the 243 normalized tags into 17 measurement constructs (§3.6.2).

Table 1. Pipeline from raw tag instances to the 17 unified domains of measurement. Counts refer to the combined workbook described in section 3.6.2

3.6.3 Domains as Subsets of the Review Objectives

The 17 unified domains do not stand alone: each is allocated to one of the four review objectives defined in section 3.2, and the Results chapter is structured by walking through the domains under the objective to which they primarily contribute. Four domains (D5, D11, D12, and D14) contribute substantively to more than one objective and are therefore listed under more than

one; in those cases, the discussion in Chapter 4 makes the cross-cutting nature explicit at the start of the relevant section. The full mapping is given in Table 2.

Review objective	Unified domains contributing to this objective (shared domains flagged)
Objective 1 — Patient & family experience across the treatment pathway	D1 Comprehension; D2 Engagement; D3 Empowerment; D4 Self-care & adherence; D6 Decision-making & continuity; D7 Patient education & preparation; D8 Emotional response; D9 Trust & candor; D12 Patient safety, accuracy & note quality (patient-side); D5 Patient–clinician communication & therapeutic relationship (shared with Obj. 2)
Objective 2 — Clinician experience, documentation, and the patient-provider relationship	D15 Clinician documentation, workflow & workload; D16 Clinician attitudes, perceptions & experience; D5 Patient–clinician communication & therapeutic relationship (shared with Obj. 1)
Objective 3 — Notes-related factors and stakeholder outcomes	D10 Satisfaction, acceptability & perceived usefulness of notes; D11 Privacy, sensitivity & risks of sensitive disclosure (shared with Obj. 4); D12 Patient safety, accuracy & quality of notes (note-side, shared with Obj. 1); D13 Note language, readability & writing style; D14 Access, accessibility & equity of note use (shared with Obj. 4)
Objective 4 — Organizational & implementation conditions	D17 Implementation, training, governance & policy; D11 Privacy, sensitivity & risks of sensitive disclosure (shared with Obj. 3); D14 Access, accessibility & equity of note use (shared with Obj. 3)

Table 2. Mapping of the 17 unified measurement domains onto the four review objectives. Domains flagged as 'shared' are addressed under more than one objective in the Results chapter.

3.7 Data Synthesis

Given the heterogeneity of designs and outcomes across the included studies, no statistical pooling was attempted. Synthesis followed a narrative thematic approach, as recommended by JBI for scoping reviews (Aromataris et al., 2024), in which the goal is to map and describe rather than estimate an effect size.

Two complementary strategies were used. The first is domain-led: the 17 unified domains were grouped under the four review objectives (Table 2), and the included studies were re-read within each domain to identify recurring patterns, points of agreement, and points of tension. The second is specialty-led: within each domain, findings were also examined by clinical setting, allowing the reader to see, for example, where concerns about sensitive content (privacy domain, D11) clustered in pediatric and mental-health settings (Schwarz et al., 2021), or where workload effects (clinician-documentation domain, D15) were reported as modest in primary care but more

substantial in oncology. Where relevant, results are explicitly compared with the findings of the team's earlier mental-health review (Monaci et al., 2025) so that mental health functions in this thesis both as one of the included specialties and as a reference point for the cross-specialty discussion.

Quotations from primary studies are reported only where the original wording is needed to convey nuance that a paraphrase would lose; in all other cases, findings are summarized in the lead author's own words and traced back to the source paper through standard citation.

3.8 Ethical Considerations

Because this review draws exclusively on already-published, peer-reviewed material, it did not require ethical approval from an institutional review board. The work nonetheless engages with ethically sensitive material, patient autonomy, informed consent, the privacy implications of transparent documentation, and the equity consequences of digital access to clinical notes—and these dimensions are treated explicitly in the Discussion chapter.

3.9 Use of Generative AI

Generative AI tools were used in a limited and clearly bounded way during the preparation of this thesis. Their use was restricted to language editing of draft paragraphs (grammar, spelling, punctuation, and minor stylistic edits) and to constructing summary tables from already-extracted data. All substantive content, including screening decisions, the extraction entries, the unification of the raw tag set into the 17 domains, the interpretation of patterns within and across specialties, and the final write-up of the Results and Discussion chapters, is the author's own work and was reviewed and approved by the supervisor. This approach is consistent with the AI-use policy adopted by the research team in prior publications (Monaci et al., 2025).

Chapter 4: Results

4.1 Search Results

The study selection process is depicted in the PRISMA-ScR flow diagram (Figure 1). Across the five databases and additional sources, a total of 7,873 records were identified. Following the removal of 3,819 duplicates, 4,054 records proceeded to title and abstract screening. 119 reports were sought for full-text retrieval, of which one could not be obtained. Of the 117 full texts

assessed for eligibility, 38 were excluded, most commonly because they did not address Open Notes as operationally defined (n = 21) or drew on secondary data (n = 10). A final total of 79 studies met all inclusion criteria. Of these, 22 were conducted in mental health settings and overlap with the published mental health review (Monaci et al., 2025); the remaining 57 derive from the broader healthcare settings extraction conducted for this thesis.

4.2 Characteristics of Included Studies

The 79 studies included in this review span more than a decade of empirical research on Open Notes, from the earliest formal trials in 2012 through to a 2025 qualitative study. The included studies are summarized in Tables 4.1 and 4.2.

4.2.1 Country of Study and Year of Publication

The publication record is notably weighted towards the period from 2018 onwards: 58 of the 79 studies (n = 58, 73%) were published between 2018 and 2025, with a visible cluster in 2021 (n = 11, 14%; see Appendix A). This pattern likely reflects the growing policy momentum behind note sharing in the United States, particularly the 21st Century Cures Act's information-blocking provisions, as well as parallel initiatives in Sweden, the Netherlands, and Germany.

Geographically, the literature is highly concentrated in the United States, which accounts for most of the combined corpus (n = 64, 81%; see Appendix A). The remaining studies (n = 15, 19%) come from Sweden (Petersson & Erlingsdóttir, 2018a), the Netherlands (Janssen et al., 2021), Germany (Meier-Diedrich, Blease, et al., 2025; Meier-Diedrich, Esch, et al., 2025; Schwarz et al., 2021; Schwarz, Neumann, et al., 2024), Norway (Nielsen et al., 2024), Canada (Kassam et al., 2022), Switzerland (Kharko et al., 2024), the United Kingdom (Blease et al., 2023), Japan (Elkhaili El Alami et al., 2020), and two international multi-country studies (Blease, Kharko, et al., 2021; Blease, Torous, et al., 2021). The North American dominance reflects the history of the OpenNotes movement, which originated in a US multi-site trial (Delbanco et al., 2012) and subsequently generated a dense body of follow-up research from the same networks. While this gives the evidence base internal coherence, it limits generalizability to healthcare systems with different portal infrastructure, cultural norms around medical transparency, or legal frameworks for patient access.

4.2.2 Study Methods and Designs

Study designs were varied (see Appendix A for the full list). Surveys and cross-sectional questionnaires were the most common method (n = 31, 39%), followed by qualitative designs including interviews and focus groups (n = 19, 24%), mixed methods (n = 13, 16%), and quasi-experimental or pre–post intervention designs (n = 9, 11%). A small number of studies used Delphi consensus methods (n = 2, 3%; Blease, Torous, et al., 2021; Nielsen et al., 2024) or were implementation evaluations and retrospective chart reviews of note-sharing rates (n = 5, 6%).

4.2.3 Study Populations and Stakeholder Groups

Many studies enrolled multiple stakeholder groups simultaneously (see Appendix A). Across the 79 included studies, patients or patient proxies, including parents and veterans, were represented in just under two-thirds of the corpus (n = 48, 61%), clinicians, physicians, nurses, or mixed provider groups, in more than a third (n = 27, 34%), and care partners or parents as a co-primary or exclusive focus in a smaller subset (n = 10, 13%). These categories are not mutually exclusive, as several studies recruited two or more stakeholder groups concurrently.

4.2.4 Healthcare Settings

The included studies spanned a wide range of clinical contexts (see Appendix A). The majority were conducted in primary care or multi-specialty ambulatory settings (n = 30, 38% of the combined corpus), followed by mental health settings (n = 22, 28%; discussed in detail in Section 4.2.5), pediatric inpatient and outpatient settings (n = 18, 23%), and Veterans Affairs facilities (n = 7, 9%), which represent an important early-adopter context given the US Department of Veterans Affairs' longstanding investment in patient portal infrastructure (Nazi et al., 2015). Oncology settings accounted for a smaller share (n = 4, 5%; Alpert, Morris, Thomson, Matin, Geyer, et al., 2019; Alpert, Morris, Thomson, Matin, Sabo, et al., 2019; Kayastha et al., 2018; Rahimian et al., 2021), as did neonatal and pediatric intensive care (n = 2, 3%; Chu et al., 2024; McCallie et al., 2024), ophthalmology (n = 1, 1%; Lee et al., 2017), and dermatology (n = 1, 1%; Henderson et al., 2021). Notably, several studies were conducted in multiple or unspecified settings, particularly large, multi-site US surveys that simultaneously drew participants from primary care, specialty care, and Veterans Affairs systems. This distributional

pattern reflects both the historical trajectory of Open Notes research, which began in primary care before expanding to specialty and inpatient contexts, and the continued concentration of implementation activity in the United States healthcare system.

4.2.5 Mental Health Sub-Corpus and Broader Healthcare Settings

Of the 79 included studies, 22 constitute the mental health sub-corpus (n = 22, 28% of the combined corpus; Blease, Kharko, et al., 2021; Blease, Torous, et al., 2021; Chimowitz et al., 2020; Cromer et al., 2017; Denneson et al., 2017; Denneson et al., 2018; Dobscha et al., 2016; Kassam et al., 2022; Kharko et al., 2024; Meier-Diedrich, Blease, et al., 2025; Meier-Diedrich, Esch, et al., 2025; Monaci et al., 2025; Nielsen et al., 2024; O'Neill et al., 2019; Peck et al., 2017; Petersson & Erlingsdóttir, 2018a; Petersson & Erlingsdóttir, 2018b; Pisciotta et al., 2019; Schwarz et al., 2021; Schwarz, Hoetger, et al., 2024; Schwarz, Neumann, et al., 2024; Woods et al., 2013), overlapping with the published review by Monaci et al. (2025). The remaining studies derive from the broader healthcare settings extraction conducted for this thesis (n = 57, 72% of the combined corpus; see Appendix B). Throughout the Results chapter, findings from the mental health sub-corpus are used as a reference point and comparator, while the broader healthcare settings review provides the overarching analytical framework.

4.2.6 Overview of Measurement Domains

Across all 79 included studies, the combined domain analysis yielded 544 raw tag instances: 350 from the broader healthcare settings extraction (Data Extraction 2) and 194 from the mental health sub-corpus (Article). These were subsequently normalized and aggregated into 17 unified measurement domains (D1–D17). The most frequently occurring domains by tag-instance count across the combined corpus were clinician documentation concerns, patient comprehension and recall, patient empowerment, and patient engagement with healthcare. The full domain mapping, with tag-instance counts reported separately by source, is presented in Table 3 and described in detail in Section 4.3.

4.3 Thematic Synthesis Across Outcomes

Thematic analysis of the 79 included studies reveals a clear pattern of research concentration, with the highest density of evidence clustering around clinician-facing documentation concerns and patient informational outcomes, and progressively sparser coverage toward structural and organizational dimensions of open notes implementation.

Clinician documentation, workflow, and workload (D15) were the most extensively evidenced domains across the combined literature, with 62 raw tag instances drawn from both Data Extractions. Studies in this domain documented a range of clinician-reported responses to patient note access, including modifications to documentation language and content, heightened awareness of the audience for clinical writing, and concerns about the time and cognitive burden of producing patient-readable records. This domain's prominence in both the broader healthcare literature and the mental health subset signals that the question of how open notes reshape clinicians' documentation practices is one of the most consistently examined issues in the field, cutting across specialties, settings, and study designs.

Comprehension, recall, and understanding of notes (D1; n=55 tag instances) ranked second, reflecting extensive evidence that patients across diverse clinical settings experienced meaningful improvements in their ability to understand diagnoses and care plans, retain information from clinical encounters, and feel adequately informed about their own health. This was followed by emotional response: worry, confusion, distress, and offense (D8; n = 46 tag instances across the combined corpus) and patient–clinician communication and therapeutic relationship (D5; n = 45 tag instances), two domains that together capture the relational and affective dimensions through which patients most immediately encounter their clinical notes. While note access was broadly associated with more open dialogue and a stronger sense of connection to clinicians, a substantial body of evidence documented adverse emotional responses, particularly when notes contained perceived inaccuracies, stigmatizing terminology, or content experienced as impersonal or dismissive. These findings were especially prominent in the mental health literature.

Self-care, self-management, and adherence (D4; *n* = 44 tag instances) ranked fifth, with consistent evidence that note access supported patients in managing chronic conditions, following through on treatment plans, and engaging more purposefully with their care between clinical encounters. Privacy, sensitivity, and risks of sensitive disclosure (D11; *n* = 42 tag instances across the combined corpus) were closely behind, with studies across both sources identifying patient and clinician concerns about the appropriate sharing of sensitive content, including mental health diagnoses, substance use histories, and social risk information, as a recurring tension in open notes practice. Satisfaction, acceptability, and perceived usefulness of notes (D10; *n* = 41 tag instances across the combined corpus) and engagement, activation, and uptake of notes (D2; *n* = 41 tag instances) were equally represented, together indicating that the literature has attended substantially to whether patients adopt note reading as a regular practice, and to the experiential quality of that engagement.

At intermediate levels of representation, patient safety, accuracy, and quality of notes (D12; *n* = 28 tag instances) captured evidence of patients and families identifying documentation errors, omissions, and clinical discrepancies, positioning open notes as a potential patient safety mechanism when supported by accessible reporting pathways. Empowerment, confidence, and self-efficacy (D3; *n* = 27 tag instances) and trust, trustworthiness, and candor (D9; *n* = 26 tag instances) addressed the relational preconditions through which note access translates or fails to translate into meaningful participation in care. Note language, readability, and writing style (D13; *n* = 22 tag instances) reflected the particular attention paid in the mental health literature to the linguistic and interpersonal dimensions of clinical documentation, with studies in this domain examining how terminology, tone, and writing conventions shape the way patients experience and interpret their clinical notes.

The least-represented domains addressed structural and equity-related conditions for open-notes implementation. Clinician attitudes, perceptions, and experience (D16; *n* = 18 tag instances), access, accessibility, and equity of note use (D14; *n* = 16 tag instances), and patient education and preparation for notes (D7; *n* = 15 tag instances) each pointed to important but underexplored preconditions for equitable and effective note sharing. Evidence in D14 indicated that patients from less-educated, non-English-speaking, and medically underserved communities reported disproportionately high perceived benefit from access to notes, a finding that

foregrounds equity as a dimension warranting greater systematic attention. Implementation, training, governance, and policy (D17; n = 10 tag instances) and decision-making, shared planning, and continuity of care (D6; n = 6 tag instances) were the least represented domains overall, appearing in a limited but conceptually significant subset of studies. The former consistently identified the absence of structured organizational preparation and staff training as a barrier to safe implementation; the latter linked higher note-reading frequency to greater perceived involvement in clinical decisions, positioning open notes as a potential, though weakly evidenced, mechanism for advancing shared decision-making. The complete distribution of raw tag instances across all 17 domains is presented in Table 3.

Table 3. Domain-Level Prevalence of Measurement Themes Across the Included Literature

ID	Domain	Tags (n)	DE2 (n=350)	Art. 1 (n=194)	Total	Objective
D15	Clinician documentation, workflow & workload	14	38	24	**62**	Obj. 2
D1	Comprehension, recall & understanding of notes	17	40	15	**55**	Obj. 1
D8	Emotional response: worry, confusion, distress & offence	17	31	15	**46**	Obj. 1
D5	Patient–clinician communication & therapeutic relationship	23	25	20	**45**	Obj. 1 / Obj. 2
D4	Self-care, self-management & adherence	12	36	8	**44**	Obj. 1
D11	Privacy, sensitivity & risks of sensitive disclosure	27	31	11	**42**	Obj. 3 / Obj. 4
D10	Satisfaction, acceptability & perceived usefulness of notes	24	27	14	**41**	Obj. 3
D2	Engagement, activation & uptake of notes	17	32	9	**41**	Obj. 1
D12	Patient safety, accuracy & quality of notes	8	22	6	**28**	Obj. 1 / Obj. 3

ID	Domain	Tags (n)	DE2 (n=350)	Art. 1 (n=194)	Total	Objective
D3	Empowerment, confidence & self-efficacy	10	21	6	**27**	Obj. 1
D9	Trust, trustworthiness & candor	7	12	14	**26**	Obj. 1
D13	Note language, readability & writing style	17	6	16	**22**	Obj. 3
D16	Clinician attitudes, perceptions & experience	15	3	15	**18**	Obj. 2
D14	Access, accessibility & equity of note use	12	10	6	**16**	Obj. 3 / Obj. 4
D7	Patient education & preparation for notes	11	10	5	**15**	Obj. 1
D17	Implementation, training, governance & policy	7	2	8	**10**	Obj. 4
D6	Decision-making, shared planning & continuity of care	5	4	2	**6**	Obj. 1
	Total	**243**	**350**	**194**	**544**	—

Table 3. *Distribution of raw tag instances across the 17 unified domains, sorted by total prevalence (descending). Tags (n) = number of unique normalized tags collapsed into each domain. DE2 = Data Extraction 2 (this thesis, all healthcare settings; 350 raw tag instances). Art. = Article (Monaci, Javaher & Barello, 2025, mental-health–only paper; 194 raw tag instances). Domains marked with two objectives contribute to both, with the primary objective listed first.*

The studies reviewed under this objective did not present implementation as a uniform process but as one shaped by a cluster of interacting conditions that varied in salience across settings. At the patient level, diagnosis and acuity repeatedly surfaced as variables with direct implications for how note access should be configured, not as grounds for blanket restriction, but as factors warranting calibrated responses. Note readability and emotional tone, portal usability, and the availability of adequate clinical time for writing and post-reading debrief were similarly identified as structural preconditions whose absence was associated with avoidable harm rather than neutral outcomes. Legal and privacy clarity emerged less as a policy formality and more as a practical requirement: in several contexts, ambiguity about what could be withheld and by whom was reported as a source of clinician hesitation that, downstream, affected documentation quality. For higher-risk presentations, including acute psychiatric episodes, active trauma, and certain third-party safety scenarios, the evidence favored proportionate exemption or brief delay mechanisms over unrestricted access, a position supported by both implementation evaluations and expert consensus work. Clinician training in audience-aware documentation and structured patient preparation prior to initial note access were the most consistently recommended enablers across settings, and their absence was the most consistently cited explanation for confusion and distress in early implementation phases. These patterns replicate the implementation-condition findings reported in the mental health context (Monaci et al., 2025) and extend them to primary care, oncology, veteran care, and pediatric settings included in the broader dataset. Studies addressing adolescent and geriatric populations placed particular emphasis on governance clarity and dedicated clinician support, given that access decisions in these groups carry additional complexity, proxy management, developmental sensitivity, and, in the adolescent case, the difficult boundary between transparency to the young patient and confidentiality for their caregivers.

Several studies across both datasets gave explicit attention to the institutional level of Open Notes adoption, a dimension that is sometimes treated as peripheral in a literature dominated by patient and clinician experience data, but which emerged here as consequential. Healthcare managers and organizational leaders appeared not simply as administrators of a policy already decided elsewhere, but as active agents whose decisions shaped the texture of implementation on

the ground: the extent of workflow adaptation, the specificity of exemption criteria, and whether patient preparation resources were developed and maintained over time or treated as one-off additions. The concept of organizational readiness, defined across the reviewed studies as a combination of staff training, governance coherence, and portal design that takes privacy seriously from the outset, was the most frequently cited systemic precondition for adoption that holds beyond initial rollout. This held across a range of healthcare organizations, though the evidence was most detailed in large multi-specialty systems, where the absence of coordinated institutional infrastructure tended to produce inconsistent clinician practice and higher reported rates of patient confusion. What this body of evidence suggests, taken as a whole, is that organizational conditions are not background features of Open Notes implementation but among its primary determinants, the difference between a practice that is nominally in place and one that reliably delivers the communicative benefits the research otherwise documents.

4.4 Patient and Family Experiences Across the Treatment Pathway

4.4.1 Comprehension, recall, and understanding

Improved comprehension is the single most consistently documented patient benefit across the entire dataset. In the US, Walker et al. (2019) found, across nearly 30,000 respondents at three large health systems, that the vast majority of note readers cited a better understanding of their health conditions and care plans as the primary reason for accessing notes. In a pre-post design across the same three sites, Delbanco et al. (2012) found that patients reported feeling more informed and in control following access to their notes. In Japan, El Alami et al. (2020) found broadly positive patient attitudes toward accessing electronic health records for comprehension purposes, though agreement that notes would improve understanding was lower among older adults, a finding that underscores health literacy as a cross-cultural moderator. Note that language remains the primary barrier: across settings, patients consistently cite jargon and unexplained abbreviations as obstacles to comprehension (Mishra et al., 2019; McCallie et al., 2024).

4.4.2 Engagement, activation, and uptake

The core tension here is that engagement benefits are real but conditional on actual reading. In the US, Mafi et al. (2016) followed 14,360 patients and found note viewing fell substantially once reminders stopped, demonstrating that uptake is not self-sustaining. At a US safety-net hospital, Badwal et al. (2024) found that engagement peaked at launch and declined, with only a minority of portal users regularly accessing notes over time. Among those who do engage, however, Walker et al. (2015) and Delbanco et al. (2012) documented greater involvement in care and a greater sense of control. Lam et al. (2021) found, across 7,246 adolescents and young adults in US academic hospitals, that note reading improved trust, patient–provider alignment, and health-related behaviors, like findings in adult populations. Jackson et al. (2022) found that care partners surveyed across 29,656 respondents were often more positive about note sharing than patients themselves, extending the engagement benefit beyond the individual.

4.4.3 Empowerment, confidence, and self-efficacy

Qualitative studies across settings consistently describe note access as enabling a less passive stance in care. In a US Veterans Affairs (VA) qualitative study, Woods et al. (2013) found that veterans described access to records as enabling a greater sense of agency and prompting appropriate clinical follow-up. In psychotherapy, O'Neill et al. (2019) at Beth Israel Deaconess Medical Center (BIDMC) found that patients cited greater control and a sense of validation as primary benefits. In a US chronic disease setting, Fisher et al. (2022) found that COPD patients engaged more confidently in care conversations after reading notes. Empowerment effects were moderated by note content: where language was perceived as judgmental or reductive, some patients described a sense of disempowerment rather than agency (Cromer et al., 2017, VA, USA).

4.4.4 Self-care, self-management, and adherence

This is among the most quantitatively evidenced domains. Walker et al. (2015) and Delbanco et al. (2012), both in US multi-site primary care settings, documented patient-reported improvements in medication adherence and self-care following access to notes. DesRoches et al. (2021), across three US health systems, found that patients with multiple chronic conditions were

particularly active note readers and reported the strongest self-management benefits, including better care plan recall and medication understanding. Fisher et al. (2022) found that COPD patients used notes to prepare for appointments and follow through with recommendations between visits. In pediatric settings, McCallie et al. (2024), in a US community NICU, and Wolff et al. (2016), at Geisinger Health System, found care partners used notes to monitor adherence to care plans and check alignment between the documented and understood plan. Effects appear strongest among patients with higher health literacy and more regular engagement with notes.

4.4.5 Patient–clinician communication and therapeutic relationship

From the patient side, note access consistently improves the quality and precision of clinical communication. In the US VA, Woods et al. (2013) found that veterans described notes as supplementing in-person communication and supporting more productive clinical conversations. Gerard et al. (2017) found that patients in primary care used notes to formulate better questions and to check communication accuracy. Fisher et al. (2022) found that patients with COPD experienced more reciprocal, transparent communication with clinicians. In psychotherapy, O'Neill et al. (2019) found that notetaking generally reinforced therapeutic rapport, while Chimowitz et al. (2020) at BIDMC noted that patients rarely raised note content spontaneously in sessions, suggesting that the communicative affordance of notes is available but unevenly exercised.

4.4.6 Decision-making, shared planning, and continuity of care

Evidence here is limited but directionally consistent. Fossa et al. (2018), in a cross-sectional survey of 6,316 patients at a Boston academic medical center, found a dose-response relationship: patients who read more notes reported higher shared decision-making. Lam et al. (2021) found that note reading is associated with better patient–provider alignment and perceived responsiveness to patient goals. In pediatric settings, Zellmer et al. (2021) and Kelly et al. (2023) found that notes supported parental preparation for and participation in clinical rounds.

4.4.7 Patient education and preparation

Walker et al. (2019) found visit preparation to be among the most highly endorsed benefits across nearly 30,000 US respondents. Vanka et al. (2025), in a US qualitative study drawing on discussions between patients and clinicians, identified clear next steps and accessible language as the mechanisms through which notes best realize their educational function, producing guidelines subsequently integrated into medical education. Pisciotta et al. (2019), at a US VA facility, found that both patients and clinicians endorsed notes as a therapeutic educational resource when actively incorporated into clinical conversations.

4.4.8 Emotional responses: worry, confusion, distress, and offense

This domain uniquely encompasses both positive and negative experiences. The dominant finding in large US surveys is that most note readers report reassurance and validation rather than distress: Walker et al. (2019) and DesRoches et al. (2021) found only a minority reported increased worry or confusion. Grossman et al. (2018), in a US acute care inpatient portal study, found note access associated with decreased anxiety and increased appreciation for clinicians. However, negative emotional responses are consistently more common among patients reading content about serious diagnoses, psychiatric formulations, or clinical uncertainty. Kayastha et al. (2018) found that a subgroup of US cancer patients at the Duke Cancer Institute experienced heightened anxiety when reading unmediated oncological descriptions. Denneson et al. (2018), in a US VA survey of 178 mental health note readers, found mostly positive emotional balance, with negative reactions concentrated where language was perceived as judgmental. Critically, emotional impact is substantially modifiable by how notes are written, a finding that directly relates to D13 (Objective 3).

4.4.9 Trust, trustworthiness, and candor

Note access is associated with enhanced trust across settings. Bell et al. (2016), in a US primary care pre-post study, found that patient-reported trust increased following access to notes. Henderson et al. (2021) found that dermatology patients at BIDMC reported greater confidence in their clinician after reading the clinician's notes. In oncology, Kayastha et al. (2018) found that most cancer patients experienced note access as trust-reinforcing, valuing the transparency about

their disease trajectory. In psychotherapy, O'Neill et al. (2019) and Cromer et al. (2017) both found that perceived consistency between what clinicians said and what they wrote was the central mechanism of trust formation. A significant counterpoint comes from Sweden, where Petersson and Erlingsdóttir (2018) found that psychiatric clinicians anticipated and reported reduced candor in documentation in response to patient readership, a clinician-side tension addressed under Objective 2.

4.5 Stakeholder-Differentiated Findings

4.5.1 Clinician Documentation, Workflow, and Workload

The dominant finding across the US primary care literature, where Open Notes has the longest implementation history, is that actual workload effects were substantially smaller than clinicians anticipated. Delbanco et al. (2012), across three US health systems involving 105 primary care physicians, found only modest changes to visit length, documentation time, and patient-initiated queries after note sharing began. Walker et al. (2015) confirmed this pattern, noting that where workload effects occurred, they were typically limited to occasional one-off clarifications. DesRoches et al. (2020), in a survey of 1,628 clinicians across BIDMC, Geisinger, and University of Washington Medicine, found most reported little workflow impact, though approximately one-third perceived increased documentation time. Ralston et al. (2021), in a pre-post survey at Kaiser Permanente Washington, found that post-implementation workload concerns were fewer than pre-implementation fears, with many previously skeptical clinicians shifting to endorsement. Leonard et al. (2023), surveying 609 clinicians at the University of Kansas Health System following the 21st Century Cures Act mandate, found the majority considered note sharing a good idea and did not describe adverse documentation effects.

The picture is more complex in specific settings. In US pediatric inpatient care, Zellmer et al. (2021) found that intern physicians expressed significantly greater documentation burden concerns than attending physicians, citing the challenge of writing for a dual audience, clinical team, and family simultaneously. Kelly et al. (2021) and Smith et al. (2022) both identify documentation adaptation and note preparation time as meaningful implementation challenges in this context. In the UK, Blease et al. (2023), in a national survey of 400 GPs in England, found clinicians anticipated increased workload, reduced efficiency, and burnout risk concerns

considerably more prominently than in the established US primary care literature, likely reflecting both the earlier stage of implementation and structural differences in primary care organization.

Documentation adaptation active changes in note language, clinical detail, or framing in response to patient readership is a pervasive related finding. DesRoches et al. (2020) found that clinicians across specialties reported writing more clearly for lay readers and being more careful in framing diagnostic uncertainty. In oncology, Alpert et al. (2019) found that oncologists at a US National Cancer Institute-designated center were largely resistant to changing their note-writing style, viewing notes primarily as tools for colleague communication rather than for patient education, and detected no significant pre-post linguistic changes. In contrast, Meier-Diedrich et al. (2025), in a pre-post linguistic analysis of psychiatric outpatient notes in Germany, found measurable improvements in note quality following implementation: notes became more personal, resource-oriented, and positive in emotional tone, and less controlling or stigmatizing, one of the most direct empirical demonstrations that Open Notes can drive genuine documentation improvement. In mental health, however, adaptation also carries risks: Petersson and Erlingsdóttir (2018) in Sweden and Schwarz et al. (2024) in Germany found that subgroups of psychiatric clinicians reported reduced candor, omitting sensitive clinical observations or softening risk assessments out of concern about patient interpretation.

4.5.2 Clinician Attitudes, Perceptions, and Experience

Clinician attitudes vary considerably by specialty, seniority, country, and implementation stage, but a consistent pattern across the US literature is that attitudes improve with experience. Ralston et al. (2021) documented this directly: the proportion endorsing note sharing as a good idea increased significantly after implementation across primary care, medical specialty, and surgical specialties. Leonard et al. (2023) found that clinicians who received structured institutional training held significantly more positive attitudes. DesRoches et al. (2020) found broad acceptance across three US health systems. Crotty et al. (2015), in a qualitative study of residents and faculty at BIDMC and Geisinger, found that while both groups saw potential benefits, residents emphasized litigation risk and documentation fatigue, whereas faculty expressed concerns about professional norms and note transparency. Nandiwada et al. (2018), at

a US academic internal medicine clinic, found residents reported greater discomfort than attending physicians, specifically around documenting sensitive topics and legal exposure.

In mental health and psychiatric settings, attitudes are consistently more ambivalent than in primary care. Dobscha et al. (2016), in a survey of 208 VA mental health clinicians and nurses, found a roughly even split between supporters and those who were neutral or opposed, with concerns centered on patient distress and disruption of the therapeutic relationship. Kassam et al. (2022), in a qualitative study of Canadian psychiatric clinicians, found support for transparency in principle but strong calls for training, patient preparation, and clear exemption policies. Schwarz et al. (2024) found German psychiatrists held predominantly cautious views, particularly around acute inpatient care, while a separate survey of German psychotherapists found predominantly negative expectations about therapeutic impact. In Switzerland, Kharko et al. (2024) found that psychotherapy trainees held mixed views, with 94% agreeing that Open Notes training should be a formal part of clinical education.

Outside the US and German-speaking world, acceptance is also lower. El Alami et al. (2020) found in Japan that clinicians expressed greater concern about the consequences for clinical communication than their US counterparts. In the Netherlands, Janssen et al. (2021) found that most hospital physicians preferred not to share outpatient notes, contrasting sharply with the strongly positive attitudes of patients in the same study, a mismatch with direct implications for implementation. Nielsen et al. (2024), through a Delphi consensus in Norway, found that expert agreement on safe note-sharing recommendations for adolescents in child and adolescent mental health services was achievable but required careful governance and professional training.

4.5.3 Patient–Clinician Communication and Therapeutic Relationship

From the clinician side, communication effects are mixed but broadly moderate in magnitude. DesRoches et al. (2020) found that some clinicians reported better-prepared, more targeted patient conversations following note sharing, while others expressed concern that patients might form incomplete impressions of clinical reasoning. Bell et al. (2016) found that PCPs anticipated more patient disagreement and note correction requests than materialized.

Walker et al. (2015) found neither visit length nor the overall character of encounters changed substantially post-implementation across the pre-post evidence base.

In mental health, the communication dimension is more sensitive. Chimowitz et al. (2020), in a qualitative study of clinical social workers at a US academic medical center, found largely positive overall experiences with minimal disruption to therapeutic relationships, but noted patients rarely raised note content proactively in sessions. Pisciotta et al. (2019), through qualitative interviews at a US VA facility, found that the most effective communication model involved clinicians actively inviting patients to discuss their notes rather than leaving engagement entirely to the patient, a proactive, rather than passive, communicative stance.

4.6 Notes-Related Factors as Mediators of Stakeholder Experience

4.6.1 Satisfaction, Acceptability, and Perceived Usefulness

Satisfaction with Open Notes is consistently high among patients who read their notes across all settings, with the important caveat that non-readers are structurally absent from most samples, preventing generalization to all portal-registered patients. Among readers, Leveille et al. (2012) documented high satisfaction and a strong preference for continued access in the original US multi-site OpenNotes trial. Walker et al. (2019) found that the large majority of nearly 30,000 US respondents endorsed note reading as very or somewhat helpful. Leveille et al. (2020), across 21,664 patients at three US health systems, found most described notes as easy to understand, accurate, and associated with a greater willingness to recommend their clinician. In pediatric settings, Zellmer et al. (2021), McCallie et al. (2024), Kelly et al. (2023), and Sarabu et al. (2021) each report high family satisfaction, with notes described as accurate, helpful, and trust-reinforcing. In oncology, Alpert et al. (2018) found broad patient acceptance, modulated more strongly by note language and emotional content than in primary care.

Crucially, where clinicians anticipated patient confusion or dissatisfaction, a common pre-implementation concern, post-implementation evidence consistently found these fears not borne out. In the Netherlands, Janssen et al. (2021) found that patient satisfaction considerably exceeded physicians' predictions. Ralston et al. (2021) documented an identical pattern at Kaiser Permanente Washington, where post-implementation patient satisfaction was more positive than

clinicians had anticipated. This gap between predicted and actual dissatisfaction is a recurring finding with direct implications for how implementation resistance should be addressed.

4.6.2 Patient Safety, Accuracy, and Quality of Notes

It works like a bridge between Objectives 1 and 3, representing both a patient-experience outcome and a note-quality feature. Bell et al. (2022), in a mixed-methods study of 22,889 patients across three US healthcare centers, found that a substantial proportion of note readers identified errors or inaccuracies, ranging from factual medication and allergy errors to discrepancies between what patients recalled hearing and what was written, with a subgroup taking active steps to correct the record. Lam et al. (2021) replicated these findings across adult and pediatric populations, finding similar error-detection rates in both groups, though young people were less likely to report errors due to uncertainty about how to do so. Bell et al. (2016), piloting a patient feedback tool at BIDMC, found that clinician review confirmed a significant proportion of patient-flagged concerns as legitimate safety issues, with some leading to actual changes in the medical record or care plan.

Bell et al. (2022) further conceptualized patients as partners in identifying diagnostic safety blind spots, gaps in the diagnostic process visible from the patient's vantage point but not apparent to clinicians, across four categories: diagnostic misalignment, documentation omissions, events occurring outside the visit, and cascading diagnostic breakdowns. This positions Open Notes not merely as a transparency measure but as a scalable patient-engagement mechanism with direct clinical safety implications. Leveille et al. (2020) found that the subgroup of patients who perceived inaccuracies in their notes reported lower trust and reduced likelihood of recommending their clinician, linking note quality directly to relational outcomes.

4.6.3 Note Language, Readability, and Writing Style

Note language is an emerging but increasingly well-evidenced domain that connects clinician documentation behavior directly to patient outcomes. Khasawneh et al. (2022), in a 2×2 experimental study in a US radiation oncology setting, found that simplified notes produced better comprehension performance and higher satisfaction than complex clinical notes, with no evidence of information loss. Vanka et al. (2025), in a US qualitative study involving patients

and clinicians, developed 10 concrete patient-centered documentation guidelines, covering person-first language, avoidance of jargon and abbreviations, objective descriptions of physical examinations, and empowering next steps, which were subsequently integrated into US medical education curricula. Leveille et al. (2020) found that patients across three health systems consistently recommended reduced jargon, clearer next steps, and error-correction mechanisms as priorities for note improvement.

In mental health, language carries clinical weight. Meier-Diedrich et al. (2025), in a pre-post linguistic analysis of psychiatric outpatient notes in Germany, found measurable improvements following the implementation of Open Notes: notes became significantly more comprehensible, personal, resource-oriented, and positive in emotional tone, and less controlling, demeaning, or stigmatizing. This represents direct empirical evidence that implementation can drive genuine improvements in language quality rather than simply reduced candor. In oncology, Alpert et al. (2018, 2019) found US oncologists wrote primarily for colleague communication rather than patient comprehension, with limited plain language and no significant post-implementation linguistic changes, suggesting that without structured institutional support, documentation adaptation in complex specialties may not occur spontaneously.

4.6.4 Privacy, Sensitivity, and Risks of Sensitive Disclosure

With 42 instances across 27 unique tags, D11 is the most extensively evidenced Objective 3 domain, reflecting the breadth of privacy-related concerns across settings. In US pediatric outpatient care, Parsons et al. (2020), in a retrospective audit of over 1,100 notes at a freestanding children's hospital, found a significant proportion contained content classified as sensitive in the adolescent privacy context, including sexual health, substance use, mental health, and family circumstances, with the available confidential note type widely used by clinicians navigating this boundary. Smith et al. (2022) found that pediatric clinicians described the dual-audience writing challenge as particularly acute when notes contained sensitive family observations, child protection concerns, or undisclosed diagnoses.

In mental health settings, privacy and sensitivity concerns are the most consistently cited implementation barrier in the evidence base. Petersson and Erlingsdóttir (2018), in Sweden, found psychiatric clinicians anticipated patient distress and conflict when risk assessments or

psychopathology formulations were shared without contextual mediation, concerns that persisted post-implementation. Schwarz et al. (2024) identified patient encounters in Germany with distressing information without clinical support as a primary implementation risk. Kassam et al. (2022) found in Canada that psychiatric clinicians strongly endorsed the need for clear exemption pathways for notes that pose clinical risk. Nielsen et al. (2024), using a Delphi consensus in Norway, produced expert recommendations on when notes should be withheld from adolescents in child and adolescent mental health services. In the Netherlands, Janssen et al. (2021) found hospital physicians particularly concerned about inpatient notes, which contain more sensitive clinical formulations than outpatient visit records. Across the evidence, the consistent implication is that privacy and sensitivity concerns are genuine, are greatest in mental health, pediatric, and inpatient settings, and require systematic implementation responses, including confidential note types, clinician training, and clear disclosure protocols, rather than uniform sharing policies.

4.6.5 Access, Accessibility, and Equity

Under Objective 3, the relevant question is whether note characteristics, such as language complexity, format, and readability, differentially affect comprehension and benefit across demographic groups. The evidence is consistent: patients with lower health literacy, older age, or limited digital familiarity are less able to extract benefit from complex clinical notes even when portal access is equal. Khasawneh et al. (2022) found that even with simplified notes, overall comprehension remained incomplete, suggesting language improvement alone cannot resolve comprehension equity. Patients in the US consistently recommend plain language, reduced jargon, and accessible formatting as priorities (Leveille et al., 2020; Vanka et al., 2025). The structural and demographic dimensions of the equity problem, that is, who has access to notes in the first place, are addressed under Objective 4.

4.7 Implementation, Equity, and the Structural Conditions for Safe Open Notes Adoption

4.7.1 Access, Accessibility, and Equity

A consistent and concerning pattern across the included evidence is that the populations with the greatest potential to benefit from Open Notes are frequently the least likely to access notes in practice. Mafi et al. (2016), in a longitudinal cohort of 14,360 US patients, found that

Black and multiracial patients were significantly less likely than white patients to view notes within 30 days of availability, even among portal-registered users. Gerard et al. (2018), in a survey of 6,913 patients at a US urban academic medical center, found that less educated and non-white patients who did read notes were especially likely to describe them as very important for understanding care and making decisions yet these same groups were structurally less likely to be portal users in the first place, creating a layered inequity in which portal access gaps and health literacy gaps combine to concentrate benefits among more advantaged populations.

Badwal et al. (2024), at a US safety-net hospital serving a predominantly low-income and racially diverse population, documented substantially lower note engagement rates than those reported in studies from more advantaged settings, even after accounting for portal registration. Murugan et al. (2022), in a large US urban pediatric health system, found that disparities in note-sharing and note-reading rates persisted across racial and socioeconomic groups even after the full Open Notes launch, suggesting that structural access barriers extend beyond simple digital connectivity. In Germany, Meier-Diedrich et al. (2025) found that older psychiatric patients and their care partners valued Open Notes but required substantial digital literacy support to engage independently with the portal, pointing to age and digital literacy as cross-cultural equity moderators.

The equity findings collectively imply that an Open Notes policy alone does not produce equitable access to its benefits. Gerard et al. (2018) make this particularly consequential: the populations most likely to benefit are the least likely to be reached. Active strategies, targeted patient education, multilingual access to notes, plain-language documentation, portal design improvements, and outreach to underserved groups are necessary to translate the policy potential of Open Notes into equitable clinical outcomes.

4.7.2 Implementation, Training, Governance, and Policy

The evidence across implementation-focused studies converges on a small set of preconditions for effective and safe Open Notes adoption.

4.7.3 Default sharing design

This emerges as among the most powerful implementation levers. Bialostozky et al. (2020), in a quasi-experimental study at a US academic pediatric institution, found that transitioning from opt-in to default opt-out note sharing dramatically increased the proportion of eligible notes shared, from a small minority to the large majority, without a commensurate increase in patient messages or adverse events. Murugan et al. (2022) replicated this pattern across a large US pediatric health system, finding that full launch under default sharing produced substantial increases in both note-sharing and note-reading rates, and that reviews of confidential notes identified workflow refinements needed to protect sensitive content.

4.7.4 Clinician training

This is consistently identified as a precondition. Leonard et al. (2023) found in the US that clinicians who received structured institutional training reported significantly more positive attitudes toward note sharing and greater confidence in writing patient-facing documentation. Vanka et al. (2025) demonstrated that patient-centered documentation guidelines derived from collaborative patient–clinician research could be directly integrated into medical education curricula. In mental health, Blease et al. (2021), through a modified Delphi process involving 70 international experts across six countries, identified clinician training, patient preparation, and clear exemption pathways as the three most critical preconditions for safe Open Notes adoption, with consensus that proactive education for both clinicians and patients must precede rather than follow implementation.

4.7.5 Governance and exemption policies

These are particularly important in sensitive settings. Nielsen et al. (2024), through a Delphi consensus in Norway, developed 17 recommendations for sharing notes with adolescents in child and adolescent mental health services, covering how to introduce access, when and how to withhold notes, and how to support professionals through clear governance structures. Kassam et al. (2022) found that psychiatric clinicians in Canada strongly endorsed the need for institutional policies that define exemption criteria and manage sensitive content. Schwarz et al. (2024) identified four conditions for safe implementation in psychiatry in Germany: explicit exemption

pathways, structured patient preparation, clinician training in patient-facing documentation, and clear institutional governance of the scope of sharing. In pediatric settings, Parsons et al. (2020) demonstrated that a confidential note type, when available, is actively used by clinicians to navigate the transparency–privacy boundary, but that guidance on consistent application is needed.

4.7.6 Patient preparation

This is the fourth recurring precondition. Pisciotta et al. (2019), at a US VA facility, found that actively inviting patients to read and discuss notes, rather than leaving engagement entirely to the patient, was associated with more productive therapeutic use of note content. Kelly et al. (2021, 2023) and Smith et al. (2022) each emphasize that pediatric implementation strategies must include dedicated tools for parent education, clear communication about what can be accessed and why, and mechanisms for managing sensitive family-facing content.

Chapter 5: Discussion

5.1 Overview and Interpretive Framework

The central objective of this thesis was to systematically map the breadth of empirical evidence regarding how patients, families, and clinicians experience open notes across diverse, general healthcare settings. Building upon this research group's earlier, focused synthesis of transparent documentation within mental health care (Monaci et al., 2025), the present analysis aimed to identify reproducible cross-specialty patterns, context-specific tensions, and the structural prerequisites necessary for safe adoption. As the findings outlined in Chapter 4 reveal, transforming the clinical note from a guarded professional record into a shared communicative space fundamentally reconfigures the relational dynamics of health care, a shift with consequences that, as this review demonstrates, are neither uniformly beneficial nor uniformly harmful, but deeply contingent on setting, implementation, and documentation quality.

The purpose of this chapter is not to reiterate the empirical charting results, but rather to interpret these 17 synthesized measurement domains within the broader theoretical evolution of patient-centered care and medical transparency (Delbanco et al., 2012). The observed outcomes,

whether they manifest as enhanced patient comprehension or heightened clinician anxiety, must be understood not as inevitable consequences of the technology itself, but as conditional effects heavily shaped by specific clinical environments, implementation strategies, and documentation practices.

To critically examine these dynamics, this discussion is structured around the four core research objectives that guided the review. Section 5.2 interprets the patient and family experience, contextualizing the documented benefits of comprehension and engagement (Leveille et al., 2020; Walker et al., 2019) against the boundaries and safety implications of unmediated access to clinical information. Section 5.3 addresses the clinician response, framing the widespread transition from anticipatory pre-implementation apprehension (Delbanco et al., 2012; Ralston et al., 2021) to adaptive, audience-aware documentation as a complex professional shift. Section 5.4 conceptualizes note quality, readability, and content sensitivity as crucial mediating variables that govern the ultimate utility of transparency. Subsequently, Section 5.5 examines the broader organizational conditions necessary for sustainable practice, with a critical focus on persistent equity gaps that threaten to disproportionately concentrate the benefits of open notes among already advantaged populations (Gerard et al., 2018; Mafi et al., 2016). Finally, Section 5.6 synthesizes these insights by employing the mental health sub-corpus as an analytical comparator, highlighting what this cross-specialty analysis reveals about the limitations of generalized, one-size-fits-all transparency mandates.

5.2 Patient Experience

The most consistently observed phenomenon across all clinical settings is the ability of transparent documentation to shift patients from passive recipients of medical instruction to active agents in their own care (DesRoches et al., 2021; Fisher et al., 2022; Walker et al., 2019). Rather than treating comprehension and engagement as isolated clinical outcomes, this pattern suggests a fundamental structural shift in patient agency; continuous access to the clinician's narrative may help bridge the informational gap that typically accumulates between clinical encounters. Taken together, the robust improvements in medication adherence, recall, and chronic disease self-management suggest that open notes may not simply inform patients but appear to support the core tenets of collaborative, patient-centered care by equipping them with

the cognitive scaffolding necessary to participate meaningfully in their treatment plans (DesRoches et al., 2021; Fisher et al., 2022; Walker et al., 2019).

Beyond fostering self-management, transparent documentation introduces a critical yet often underexploited safety mechanism: integrating the patient as a continuous diagnostic partner. Identifying errors in the clinical record is not merely a byproduct of reading notes; it represents a scalable, system-level defense against diagnostic misalignment and documentation omissions. As the evidence highlights, patients and families are uniquely positioned to detect "diagnostic safety blind spots" that fall outside the clinician's immediate purview, potentially positioning the note as a quality-control mechanism (Bell et al., 2022; Lam, Bourgeois, DesRoches, et al., 2021). However, this theoretical safety benefit is severely constrained by an implementation boundary: the recurrent finding that a substantial proportion of patients notice serious inaccuracies but fail to report them due to fear of negative consequences or uncertainty about the reporting process. This discrepancy underscores that error detection is effective only when healthcare systems establish explicit, psychologically safe, and accessible feedback channels (Bell, Gerard, et al., 2016; Lam, Bourgeois, Dong, et al., 2021).

What distinguishes transparent documentation from purely benign digital interventions is its inherent emotional complexity; the empowering benefits of access are inextricably linked to the risk of patient distress. While most note readers report feeling reassured and validated, the emergence of worry, confusion, or offense is not random. Instead, these adverse emotional responses are highly conditional, clustering disproportionately around encounters that involve diagnostic uncertainty, unmediated prognostic details, or language perceived as reductive and judgmental (Denneson et al., 2018; Grossman et al., 2018; Kayastha et al., 2018). This conditional dynamic indicates that emotional harm is rarely caused by the principle of transparency itself, but rather by the stylistic choices and clinical jargon embedded within the text. Consequently, mitigating these boundaries relies heavily on the communicative quality of the documentation, an interplay that directly links patient emotional safety to the specific note-level characteristics discussed subsequently in Section 5.4.

5.3 Clinician Response: From Anticipated Harm to Adaptive Practice

A defining feature of the clinician experience across the literature is a consistent temporal dissonance: the anticipatory fears regarding open notes routinely exceed the actual disruptions

experienced post-implementation. This gap suggests that initial clinician resistance is often driven more by a perceived threat to professional autonomy and workflow stability than by empirical operational failures. Before implementation, practitioners frequently articulate profound concerns that transparent documentation will inevitably lead to unmanageable workloads, elongated visit lengths, and a deluge of patient queries (Delbanco et al., 2012; Ralston et al., 2021). However, the post-implementation reality consistently contradicts these fears; as clinicians habituate to the new communicative landscape, their attitudes tend to shift toward broader endorsement, suggesting that direct experiential learning appears to demystify the intervention and neutralize anticipated harms (DesRoches et al., 2020; Leonard et al., 2023).

The transition to transparent documentation fundamentally disrupts traditional medical writing, prompting clinicians to engage in "documentation adaptation"—a dual-faceted phenomenon that represents both a profound opportunity for patient-centered care and a substantial clinical risk. Writing for a dual audience of colleagues and patients forces practitioners to actively renegotiate the linguistic norms of their records. On the positive side, this heightened audience awareness can tangibly elevate the quality of the note, driving clinicians to replace stigmatizing jargon with clear, resource-oriented, and empowering language that actively supports patient education (Meier-Diedrich, Blease, et al., 2025; Vanka et al., 2025). Conversely, this exact same pressure frequently induces defensive documentation behaviors. Out of concern that patients might misinterpret diagnostic uncertainty or react poorly to sensitive formulations, many clinicians actively omit critical clinical details or soften risk appraisals, resulting in a problematic reduction of clinical candor (Petersson & Erlingsdóttir, 2018a; Schwarz, Hoetger, et al., 2024). This tension highlights a persistent structural trade-off: enhancing a note's educational utility for the lay reader can inadvertently compromise its primary function as a rigorous, inter-professional communication tool.

Crucially, the magnitude of this clinician response is not uniform, but rather highly contingent on clinical specialty and regional documentation cultures. The notably elevated apprehension observed in mental health care and non-US healthcare systems underscores how sensitive clinical contexts and differing baseline norms amplify the perceived risks of transparency. Practitioners in European and Canadian contexts, alongside those working within the interpretive and relationship-dependent dynamics of psychiatric and psychotherapeutic practice, articulate far deeper concerns regarding therapeutic rupture and the ethical limits of

unmediated information sharing than their primary care counterparts in the United States (Blease et al., 2023; Janssen et al., 2021; Kassam et al., 2022; Schwarz, Hoetger, et al., 2024; Schwarz, Neumann, et al., 2024). This variance reveals that clinician resistance is not an inherent trait, but a contextual response. Consequently, successful adoption cannot rely on generic mandates; rather, as will be explored through the organizational conditions in Section 5.5 and the targeted cross-specialty analysis in Section 5.6, securing clinical buy-in requires tailored governance, robust training frameworks, and clear exemption pathways that respect the unique vulnerabilities of specific healthcare settings.

5.4 Note Quality as a Mediating Variable

This position notes quality not merely as a static endpoint of clinical documentation, but as a critical mediating variable that dictates whether transparency serves as a catalyst for engagement or a vector for confusion. The clinical narrative's structural characteristics—specifically its readability, formatting, and reliance on plain language—profoundly shape the reader's cognitive load and subsequent comprehension. For instance, while reducing medical jargon is a modification consistently demanded by patients, experimental evidence reveals that even when notes are intentionally simplified, overall comprehension frequently remains incomplete (Khasawneh et al., 2022); patients themselves consistently identify plain language and clearer next steps as priorities, yet to be fully realized in practice (Leveille et al., 2020). This constraint highlights the absolute necessity of deliberate, audience-aware writing strategies, such as integrating person-first language and maintaining objective descriptors, to translate nominal access to the record into actual health literacy (Vanka et al., 2025).

Beyond readability, the functional utility of open notes is heavily mediated by the boundaries of privacy and content sensitivity. What the evidence collectively demonstrates is that the imperative for transparency cannot be applied uniformly; the therapeutic value of sharing clinical narratives is highly contingent upon the specific vulnerabilities of the patient population. In highly sensitive environments—most notably pediatric, mental health, and inpatient settings—the unfiltered release of provisional diagnostic formulations, third-party social observations, or adolescent sexual health histories introduces acute risks of distress and relational rupture. Navigating these complex boundaries requires moving beyond blanket sharing mandates toward highly nuanced documentation practices, including the utilization of confidential note types and

the establishment of clear, diagnosis-specific exemption pathways to protect patients from clinically destabilizing information (Kassam et al., 2022; Nielsen et al., 2024; Parsons et al., 2020; Schwarz, Hoetger, et al., 2024).

Ultimately, the linguistic choices embedded within clinical notes do more than just facilitate or impede cognitive comprehension; they actively define and mold the therapeutic relationship itself. When patients encounter clinical language that feels reductive, judgmental, or overly stigmatizing, the resulting emotional response often directly erodes clinical trust and disempowers patients (Cromer et al., 2017; Denneson et al., 2018; Kayastha et al., 2018). Conversely, when documentation is perceived as accurate, respectful, and resource-oriented, it may validate the patient's lived experience and appear to reinforce the collaborative alliance (Leveille et al., 2020; Meier-Diedrich, Blease, et al., 2025). Because note quality acts as the primary conduit through which patients experience this transparency, mitigating the risks of stigmatizing language cannot be left to individual clinicians' discretion. Instead, as Section 5.5 will explore, securing high-quality, non-judgmental documentation across diverse specialties requires a robust organizational infrastructure, explicit governance policies, and systemic implementation strategies that formally support clinicians in this communicative shift.

5.5 Implementation Conditions and the Equity Problem

The safe and sustainable adoption of open notes does not occur organically; rather, the evidence suggests that a mere technological mandate fails unless it is underpinned by an integrated matrix of specific organizational preconditions. The literature consistently identifies four interdependent pillars required for successful implementation: a robust default sharing architecture (such as an opt-out rather than opt-in model) to drive structural engagement, comprehensive clinician training in audience-aware documentation, proactive patient preparation, and the establishment of explicit governance and exemption policies (Bialostozky et al., 2020; Blease et al., 2021; Leonard et al., 2023). Without these systemic supports, the intervention is prone to erratic clinician uptake and localized workflow disruptions. Conversely, when healthcare organizations integrate structured documentation guidelines and clear thresholds for withholding sensitive content, they actively mitigate anticipated harms and create a standardized environment where transparency can thrive safely (Nielsen et al., 2024; Vanka et al., 2025).

However, even when robust organizational frameworks are implemented, a fundamental systemic vulnerability persists: granting equal access to electronic health records does not inherently produce equitable clinical benefits. The evidence reveals a troubling paradox regarding digital health disparities: the patient populations uniquely positioned to derive the greatest communicative benefit from open notes are structurally the least likely to utilize them. Studies consistently demonstrate that while non-white, less-educated, and socioeconomically disadvantaged patients who do read their notes place exceptionally high value on them for self-care and decision-making, these exact same groups exhibit significantly lower baseline portal registration and note-viewing rates (Badwal et al., 2024; Gerard et al., 2018; Mafi et al., 2016). This layered disparity is further compounded by intersecting factors such as age and digital literacy, with older patients highly valuing transparency but frequently requiring substantial proxy assistance to navigate the digital interface independently (Meier-Diedrich, Esch, et al., 2025). Consequently, simply launching an open-notes initiative without addressing these underlying structural barriers to access threatens to inadvertently widen the digital divide rather than close it (Murugan et al., 2022).

Resolving this entrenched equity gap requires healthcare systems to abandon the paradigm of passive availability in favor of robust, active outreach. To ensure that transparent documentation serves as a genuinely inclusive intervention, organizations must consciously deploy targeted educational initiatives, optimize portal design for diverse levels of digital literacy, mandate the use of plain language, and provide multilingual access. Treating open notes merely as a digital feature activated within a patient portal is fundamentally insufficient; it must be managed as an ongoing, structurally supported clinical intervention (Bialostozky et al., 2020; Leonard et al., 2023). As the following section will demonstrate, the mental health sub-corpus provides the sharpest analytical test of these dynamics, functioning throughout this thesis as a comparative reference point against which the broader cross-specialty patterns can be most rigorously interrogated.

5.6 Mental Health as a Comparator: What the Cross-Specialty Analysis Reveals

Throughout this analysis, the mental health sub-corpus has functioned not as an anomalous outlier, but rather as a powerful magnifying glass that amplifies the central tensions present across the combined corpus. As initially documented in this research group's dedicated synthesis

(Monaci et al., 2025), the deeply interpretive nature of psychiatric documentation intensifies the risks of patient distress, the clinician's defensive reduction of candor, and the sheer complexity of safe implementation. When evaluating the broader literature, it becomes evident that the profound clinician ambivalence and demands for strict exemption policies observed in mental health are acute manifestations of universal transparency challenges (Dobscha et al., 2016; Kassam et al., 2022). The persistent concerns regarding therapeutic rupture and the ethical limits of unmediated sharing demonstrate how the highest-stakes clinical environments stress-test the basic premises of the open notes policy (Petersson & Erlingsdóttir, 2018a; Schwarz, Hoetger, et al., 2024).

Crucially, placing this sub-corpus alongside primary care, pediatrics, and oncology yields a methodological insight that a single-specialty review could not fully capture: the implementation hurdles in mental health are ultimately differences in degree, rather than differences in kind. The broader healthcare settings review reveals that the same foundational struggles exist elsewhere: the delicate management of adolescent privacy in pediatrics parallels the content-sensitivity challenges in child psychiatry, while the reluctance to document harsh prognostic realities in oncology mirrors the candor tensions in adult psychotherapy. However, within the mental health sub-corpus, all these variables, sensitivity, relational dependence, and diagnostic uncertainty, intersect simultaneously, requiring the most rigorous guardrails and the highest levels of therapeutic communication (Blease et al., 2021; Chimowitz et al., 2020). This comparative lens confirms that the structured interventions necessary to protect the psychiatric alliance are broadly applicable across specialties managing high-acuity, emotionally complex care (Nielsen et al., 2024; O'Neill et al., 2019).

Ultimately, synthesizing the corpus yields a single, unifying conclusion: open notes must be conceptualized as a systemic communication intervention rather than a mere technical policy or portal feature. The evidence consistently suggests that when the four foundational conditions- audience-aware note quality, structured organizational implementation, targeted equity strategies, and explicit governance- are robustly aligned, the benefits for patient agency and safety appear meaningful and supported by the available evidence. Conversely, when transparency is mandated without these supportive scaffolds, the risks of patient distress, clinician burnout, and widening health disparities become equally tangible. Moving forward, the imperative is no longer to debate the philosophical merits of sharing clinical records, but to optimize the practice

structurally, an objective that drives the final recommendations, limitations, and future directions detailed in Chapter 6.

Chapter 6 Conclusions

The synthesis of patient and family experiences suggests that transparent documentation may support a meaningful shift in how individuals relate to their own care, moving away from passive receipt of decisions toward a more active partnership. Access to visit notes appears to yield consistent benefits in comprehension, treatment engagement, and medication adherence (Walker et al., 2019), and there is evidence of patients' potential role as a systemic check against diagnostic error (Bell et al., 2022). That said, this shift is neither automatic nor uniform. The emotional experience of reading clinical notes remains highly conditional: while most patients report feeling reassured (Walker et al., 2019; Delbanco et al., 2012; Leveille et al., 2012), the emergence of distress or confusion tends to surface in encounters involving diagnostic uncertainty or unmediated prognostic language (Grossman et al., 2018; Kayastha et al., 2018). What shapes the patient experience, then, is less the mere availability of records and more the communicative clarity, or opacity of the note.

Regarding the clinician response, the evidence points to a recurrent temporal pattern: anticipatory fears about workload and workflow disruption tend to exceed those reported after implementation (Delbanco et al., 2012; Leonard et al., 2023). As clinicians adjust to transparent documentation, many appear to engage in a form of documentation adaptation, a practice that can simultaneously encourage more patient-centered language and, in some cases, induce a cautious reduction in clinical candor (Meier-Diedrich, Blease, et al., 2025; Petersson & Erlingsdóttir, 2018a). This adaptive response also appears to be shaped by context. Practitioners in mental health settings and non-US healthcare systems tend to report higher levels of apprehension, which suggests that clinician resistance may reflect specialized relational and institutional dynamics rather than a generalized professional disposition (Kassam et al., 2022; Schwarz, Hoetger, et al., 2024).

The analysis of note-related factors points to documentation quality as a likely mediating variable in shaping the outcomes of open notes. Structural readability and plain language appear

to reduce cognitive load, though simplified syntax alone may not be sufficient to support full comprehension without proactive patient preparation (Khasawneh et al., 2022; Vanka et al., 2025). The utility of the note also seems to be bounded by privacy and sensitivity concerns — particularly in pediatric, inpatient, and psychiatric contexts, where unfiltered access may risk relational rupture. Navigating these high-stakes environments appears to require nuanced writing strategies, the judicious use of confidential note types, and clear protocols for managing sensitive diagnostic formulations (Kassam et al., 2022; Nielsen et al., 2024; Parsons et al., 2020).

Finally, the organizational picture that emerges from this review is one in which safe and sustainable adoption appears to depend on structured implementation conditions. The literature points to four recurring preconditions: default-sharing architectures, comprehensive clinician training, proactive patient preparation, and explicit governance policies (Bialostozky et al., 2020; Blease et al., 2021; Leonard et al., 2023). Equity deserves particular attention here: the populations who may stand to gain most from access to their records are often those facing the highest structural barriers to digital participation (Gerard et al., 2018; Mafi et al., 2016). Taken together, these findings suggest that open notes may be most productively understood not as a passive technological policy, but as a dynamic communication intervention — one that appears to require sustained organizational support if nominal transparency is to translate into genuinely equitable clinical engagement.

6.1 Limitations

The generalizability of these findings is constrained, in the first instance, by a pronounced geographic concentration within the literature. Of the 79 studies included in this review, 64 were conducted in the United States (n = 64, 81% of the combined corpus). While this reflects the historical origins of the OpenNotes movement and the influence of recent federal mandates, it limits how far the synthesized findings can travel across different healthcare systems and cultural contexts. The regulatory, financial, and institutional dynamics of the US system are not straightforwardly transferable to non-Western settings or systems with different baseline attitudes toward medical hierarchy and data privacy. Empirical evidence from low- and middle-income countries is entirely absent from this corpus, leaving open questions about how transparent documentation functions outside well-resourced, thoroughly digitized healthcare infrastructures.

Beyond geography, the scoping review methodology introduces structural constraints that shape what can and cannot be concluded. By design, scoping reviews map the breadth of available evidence rather than evaluate its quality; no formal quality appraisal or risk-of-bias assessment was therefore conducted for the included studies, in keeping with JBI reporting guidelines (Aromataris et al., 2024). The substantial heterogeneity across study designs, measured domains, and clinical settings also precluded any quantitative synthesis.

A further methodological consideration concerns the thesis's two-component structure. The mental health sub-corpus and the broader healthcare settings review were conducted as separate but connected components, each with its own search flow, data extraction table, and set of included studies. While this structure was deliberately adopted to build on the published mental health review by Monaci et al. (2025) and extend the analysis to other clinical settings, it introduces an inherent asymmetry. The mental health literature has been more extensively mapped through two successive passes, so mental health findings may carry proportionally greater analytical weight in the combined domain analysis than their share of the corpus alone would suggest. Readers should interpret cross-setting comparisons with this in mind.

Finally, a self-selection constraint runs through much of the primary literature: most surveys and qualitative inquiries in this corpus recruited patients who had already registered for patient portals and were actively reading their notes, which means the experiences of non-readers and digitally disconnected populations remain largely unrepresented in the evidence base.

The existing literature also contains inherent gaps that limit the depth of what can be said. The overwhelming majority of synthesized data rests on stakeholder self-report, perceived comprehension, anticipated workload, and subjective emotional response, with comparatively little attention to objective, measurable clinical outcomes such as verified reductions in adverse events or longitudinal changes in service utilization. The perspectives of adult patients and physicians dominate the corpus, while adolescents, extended care partners, and allied health professionals remain markedly underrepresented. There is also a temporal dimension worth noting. A significant proportion of the included studies captured pre-implementation anxieties or early-stage adoption dynamics that predated large-scale policy shifts such as the 21st Century Cures Act (Delbanco et al., 2012; DesRoches et al., 2019; Gerard et al., 2018). These findings may therefore reflect the friction of initial transition more than the realities of mature, fully normalized note-sharing practice.

6.2 Future Research Directions

To move beyond the predominantly descriptive and self-reported foundations of the current evidence base, future research would benefit from greater investment in experimental and quasi-experimental designs. As healthcare systems transition from early implementation to sustained practice, randomized controlled trials or stepped-wedge designs could offer more rigorous evaluation of targeted documentation training and patient-centered writing interventions. There is also a need to bridge the gap between subjective perception and objective clinical endpoints: subsequent studies might systematically link self-reported benefits to measurable outcomes, quantified error-correction rates, shifts in service utilization, and formal patient safety records, thereby building a stronger empirical case for transparency as a contributor to clinical quality.

Future research should also actively address the demographic and contextual gaps embedded in the current literature. Exploring open notes in international and non-Western healthcare systems would help clarify how cultural norms around medical authority and privacy moderate the experience of transparency. Within established systems, targeted work is needed to bring in the voices of underrepresented groups: adolescents navigating confidentiality thresholds, older adults and low-literacy patients facing digital barriers, and allied health professionals whose documentation shapes much of the narrative of multidisciplinary care. There is also scope for deeper inquiry into specialty-specific environments, acute inpatient care, oncology, pediatrics, where the stakes of unmediated communication are particularly high and where generic implementation protocols may be insufficient.

Looking ahead, two emerging domains warrant particular attention. First, co-design methodologies that actively partner with diverse patient panels to develop accessible language guidelines and intuitive portal architectures could help ensure that future implementations genuinely reflect user needs rather than institutional assumptions. Second, the growing integration of artificial intelligence in clinical documentation raises questions that the field has only begun to address as AI increasingly drafts or summarizes medical records, it will be important to understand how this technological mediation affects patient trust, clinical comprehension, and professional accountability. The future of transparent documentation may lie less in simply providing access to the clinical record and more in continuously refining it — into a shared, co-created instrument that supports equitable participation and deepens the therapeutic relationship for every patient who encounters it.

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Appendixes:

Appendix A. Characteristics and main findings of the 22 included studies from the mental health sub-corpus (Monaci et al., 2025).

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/Measures	Main Results
(Blease, Torous, et al., 2021)	2021	Elicit international expert recommendations to prepare patients and clinicians for MH OpenNotes.	International (6 countries)	Experts (clinicians, leaders, advocates)	Qualitative expert inquiry	70	50.0%	Recommendations for preparing patients and clinicians for MH OpenNotes (training, communication, exceptions, safety).	Consensus guidance emphasized proactive patient education, clinician training on language, clear exemption pathways for safety risks, and organizational policies for consistent implementation.
Blease et al., 2021 (Blease, Kharko, et al., 2021)	2021	Build expert consensus on benefits, harms, and mitigations of Open Notes in mental health.	International	Experts	Three-round modified Delphi	70	50.0%	Consensus on benefits and harms of MH OpenNotes; prioritization of risks/mitigations.	Top benefits: engagement, accuracy checks, recall, safety through error detection. Top harms: increased worry/confusion, potential impact on therapeutic candor; mitigation through guidance and training.
Chimowitz et al., 2020 (Chimowitz et al., 2020)	2020	Examine clinical social workers' attitudes and experiences with sharing psychotherapy notes via OpenNotes.	USA (BIDMC; large urban academic medical center + community health center, Boston)	Clinical social workers (therapists, MSWs)	Qualitative interviews and focus group	9	N/A	Experiences, concerns, and perceived benefits of open psychotherapy notes.	Participating therapists reported mostly positive attitudes, minimal workload disruption, and potential benefits for communication and patient empowerment, though noted patients rarely discussed notes. Non-participating

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/Measures	Main Results
									therapists expressed concerns about privacy, workload, clinical language misinterpretation, and potential harm to therapeutic relationships. Overall, sharing notes was feasible and often beneficial, but more training and research are needed.
Cromer et al., 2017 (Cromer et al., 2017)	2017	Examine how reading mental health notes influences veterans' trust in their clinicians.	USA (VA)	Patients	Qualitative interviews	28	57.0%	How reading mental health notes influences trust in clinicians.	Trust frequently increased due to perceived honesty/consistency; decreases occurred when patients perceived errors, judgmental language, or discrepancies.
Delbanco et al., 2012 (Delbanco et al., 2012)	2012	Evaluate effects of inviting patients to read primary care visit notes on patients and clinicians (pre/post).	USA (3 health systems)	Primary care physicians & adult patients	Quasi-experimental (pre/post surveys)	Patients ≥1 note: 13,564; post-survey ≈5,391	N/A	Patient-reported effects on understanding, self-care, medication adherence; clinician-reported workload, visit length, and documentation changes.	Patients widely reported benefits (better understanding, feeling in control); clinicians reported minimal change in workload or visit length but some changed wording; support for continued access was high.
Denneson et al., 2017	2017	Explore how patient access to MH notes affects clinicians'	USA (VA)	Clinicians & Nurses	Qualitative interviews	28	57.0%	Perceived impact of patients' online access to mental health	Clinicians described a shift in power toward patients and increased

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/Measures	Main Results
(Dennesen et al., 2017)		perceptions of power, documentation, and the therapeutic relationship.						notes on power dynamics, documentation practices, and therapeutic alliance.	attention to wording; some limited candor in notes to prevent harm, but many recognized transparency and engagement benefits.
Denneson et al., 2018 (Denneson et al., 2018)	2018	Quantify patients' positive and negative reactions to reading their mental health notes online.	USA (VA)	Patients (Veterans)	Cross-sectional survey of note readers	178	21.0%	Patient-reported positive (e.g., feeling informed, trusting) and negative (e.g., worry, offense) reactions to reading MH notes; impacts on care use and self-management.	Most respondents reported positive effects on understanding and involvement; a minority reported worry or feeling judged; overall net positive balance with actionable feedback for clinicians.
Dobscha et al., 2016 (Dobscha et al., 2016)	2016	Assess mental health clinicians' attitudes, perceived benefits/risks, and self-reported documentation changes with OpenNotes in VA.	USA (single VA Medical Center)	Clinicians & Nurses	Cross-sectional survey	208	56.3%	Attitudes toward OpenNotes in mental health; perceived benefits/harms; self-reported changes to documentation; effects on workflow & therapeutic relationship.	About half endorsed OpenNotes as a good idea; many reported writing notes less candidly or changing wording; perceived risks included patient worry and safety concerns, but most anticipated benefits for engagement and accuracy checks.
Kassam et al., 2022 (Kassam et al., 2022)	2022	Explore Canadian psychiatric clinicians' experiences, uses, benefits, and challenges	Canada (Ontario psychiatric settings)	Clinicians	Qualitative interviews	23	82.6%	Perceived uses, benefits, and challenges of OpenNotes in psychiatric care; implementatio	Clinicians supported transparency and collaboration but cited need for training, patient preparation, and clear policies for

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/Measures	Main Results
		with OpenNotes.						n supports needed.	sensitive content and safety concerns.
Kharko et al., 2024 (Kharko et al., 2024)	2024	Explore psychotherapy trainees' familiarity with and opinions about patients' access to psychotherapy notes (open notes).	Switzerland (University of Basel psychotherapy training programs)	Psychotherapy students/trainees (various programs)	Mixed-methods survey (web-based questionnaire with quantitative and qualitative components)	72	86.1%	Psychotherapy trainees' familiarity with open notes and their opinions on the impact for patients, therapists, and psychotherapy practice.	Views were mixed: many trainees anticipated negative impacts (increased workload, constrained note-writing, risk to therapeutic alliance, patient confusion/offense) but also saw benefits (greater transparency, trust, empowerment, better informed consent, communication). Four main themes: negative impact on therapy, positive impact on therapy, impact on patients, and documentation changes. Almost all (94.1%) agreed education on open notes should be part of training.
Leveille et al., 2020 (Leveille et al., 2020)	2020	Assess patient evaluations (understandability, accuracy, helpfulness, safety) for a single recently read visit note.	USA multi-site (general)	Patients (general; note readers)	Cross-sectional survey focused on a single recalled note	22,947	N/A	For one recent note: understandability, correctness, helpfulness, and safety (error identification); comparisons across note types.	Vast majority rated notes easy to understand and accurate; many reported finding errors/omissions and contacting clinicians; mental health notes represented a small fraction but showed similar

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/Measures	Main Results
									usability concerns.
Meier-Diedrich et al., 2025 (Meier-Diedrich, Blease, et al., 2025)	2025	Examine objective and perceived changes in clinical documentation after implementing Open Notes in mental health care.	Germany/ Psychiatric outpatient clinics (Brandenburg Medical School, Rüdersdorf)	Clinicians (psychiatrists, psychologists, social worker)	Mixed-methods pre-post study (linguistic analysis + qualitative interviews)	107 (97 patients; 10 clinicians)	55.7% (patients); 50.0% (clinicians)	Linguistic analysis of 16 language features; qualitative interviews on documentation practices and perceptions.	After Open Notes, notes showed significantly increased comprehensible, resource-oriented, personal, and positive emotional language and reduced controlling, demeaning, and stigmatizing language. Clinicians wrote more patient-friendly and reflective notes, with greater attention to clarity and sensitivity; workload increased but no loss of clinical content was reported.
Meier-Diedrich et al., 2025 (Meier-Diedrich, Esch, et al., 2025)	2025	Explore the experiences, barriers, and opportunities of older mental health patients and their care partners using proxy access to Open Notes.	Germany/ Psychiatric outpatient clinics (Rüdersdorf and Strausberg)	Older patients (≥60 years) and care partners (family members, spouses, children)	Qualitative interviews (constructivist grounded theory)	20 (10 patients; 10 care partners)	70%	Experiences, digital literacy, trust, relationship dynamics, autonomy, and perceived impact of proxy Open Notes.	Access to Open Notes with proxy accounts improved understanding, engagement, and communication between patients, care partners, and clinicians; benefits included better preparation for appointments and enhanced support, but also raised concerns about privacy, control, and

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/Measures	Main Results
									emotional burden; trust and digital literacy were key enablers.
Nielsen et al., 2024 (Nielsen et al., 2024)	2024	Develop expert-based recommendations for digital sharing of clinical notes with adolescents in mental health care and assess staff agreement.	Norway/ Child and Adolescent Mental Health Services (CAMHS)	Experts (authors of scientific papers) and CAMHS staff	Delphi consensus + cross-sectional survey	Delphi: 27 (Round 1)/21 (Round 2); Staff survey: 41	81% (Delphi); 90% (Staff)	Consensus level on 43 proposed recommendations; staff agreement with 17 finalized recommendations.	Consensus reached on 17 recommendations covering how to introduce access, write notes, support professionals, and withhold notes when necessary. High agreement among staff (>60%) on all recommendations, especially training, respectful language, and clear criteria for withholding. Uncertainty remained on optimal age and parental access timing.
O'Neill et al., 2019 (O'Neill et al., 2019)	2019	Investigate psychotherapy patients' experiences reading their therapists' notes and perceived impacts on care.	USA (BIDMC outpatient psychotherapy)	Patients	Mixed methods (survey + 11 interviews)	85 surveys; 11 interviews	76.0%	Perceived helpfulness, control, trust, self-care; adverse reactions; interest in continued access to psychotherapy notes.	Large majority valued access for reflection, recall, and trust-building; few adverse experiences were reported; most wanted continued access.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/Measures	Main Results
Peck et al., 2017 (Peck et al., 2017)	2017	Pilot patient access to electronic psychiatric records and assess feasibility, satisfaction, and note characteristics.	USA (Beth Israel Deaconess, outpatient psychiatry)	Patients & Clinicians	Pilot with post-visit surveys & note ratings	64 (52 patients; 12 clinicians; 160 notes rated)	N/A	Feasibility; patient satisfaction/understanding; clinician perceptions; note readability/appropriateness.	Most patients reported satisfaction and better recall; clinicians generally accepted feasibility but flagged potential for confusion and extra clarification; few instances of perceived harm in rated notes.
Petersson & Erlingsdóttir, 2018 (Petersson & Erlingsdóttir, 2018a)	2018	Assess psychiatric professionals' expectations and concerns before implementation of Open Notes in Swedish psychiatric care.	Sweden (regional psychiatric services)	Psychiatric care professionals	Pre-implementation web survey	871	73.8%	Expected impacts of open notes on patients, documentation, workflow, and therapeutic relationship (before rollout).	Many anticipated more patient worry and disagreements and reported intent to be less candid in documentation; anticipated limited benefits for patient involvement relative to somatic care.
Petersson & Erlingsdóttir, 2018 (Petersson & Erlingsdóttir, 2018b)	2018	Evaluate psychiatric professionals' experiences and perceived impacts after Open Notes implementation in Sweden.	Sweden (regional psychiatric services)	Psychiatric care professionals	Post-implementation web survey	699	72.1%	Experienced impacts on documentation practices, workflow, patient contact, and patient understanding after roll-out.	Concerns about reduced candor persisted; little change in visit length; some professionals perceived increased patient involvement, but apprehensions about misunderstandings and conflicts remained.
Pisciotta et al., 2019 (Pisciotta et al., 2019)	2019	Provide mental health clinicians with recommendations identified by patients	USA (Veterans Health Administration – Pacific	Patients (veterans) & Clinicians	Qualitative interviews	56 (28 patients; 28 clinicians)	57.0%	Identification of recommendations regarding note-writing, communicatio	Three domains: (1) write respectful, clear notes highlighting progress; (2)

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/Measures	Main Results
		and clinicians for practicing effectively in the context of OpenNotes.	Northwest, 13 urban and rural facilities)					n, and use of notes.	communicate with patients about notes (transparency, openness to discussion); (3) use notes as a therapeutic resource and collaborative tool.
Schwarz et al., 2024 (Schwarz, Hoetger, et al., 2024)	2024	Identify conditions and perceived consequences for implementing Open Notes in psychiatry from psychiatrists' perspectives.	Germany (adult psychiatry; inpatient, day clinic, outpatient)	Psychiatrists	Qualitative semi-structured interviews; thematic analysis (COREQ)	18	44.4%	Perceived conditions for successful implementation (user groups/settings, time, resources/usability, legal/privacy) and expected changes (documentation, treatment processes, clinician–patient interaction).	Four conditions needed (diagnoses/severity triage; more time for writing/debrief; simple integrated portal & resources; clear legal/data-protection rules). Expected changes: more patient-centred language and occasional 'closed' notes; potential benefits (transparency, trust, continuity, adherence) but risks (misunderstandings, distress, conflicts) especially in acute phases—suggest case-by-case access limits.
Schwarz et al., 2024 (Schwarz, Neumann, et al., 2024)	2024	Describe German psychotherapists' views and expectations regarding OpenNotes in psychotherapy practice.	Germany (nationwide online survey)	Psychotherapists (medical & psychological)	Cross-sectional online survey	129	62.0%	Attitudes and expectations about OpenNotes; anticipated effects on psychotherapy, documentation	Predominantly negative expectations regarding therapeutic impact and workload; respondents requested clearer

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/Measures	Main Results
								burden, and relationship.	exemptions and patient preparation.
Walker et al., 2019 (Walker et al., 2019)	2019	Characterize patient experiences and perceived impacts after several years of exposure to OpenNotes across health systems.	USA multi-site (BIDMC, UW Medicine, Geisinger)	Patients (general)	Large cross-sectional survey	28,782	62.8%	Reading frequency; perceived helpfulness; effects on understanding, recall, engagement, and safety-checking; communication with clinicians.	Most readers reported better understanding/recall and feeling in control; many found notes very helpful for managing care and confirming accuracy; small minority reported confusion or worry.

Appendix A. MH = Mental Health; NA = Not Applicable; VA = Veterans Affairs; CAMHS = Child and Adolescent Mental Health Services; COREQ = Consolidated Criteria for Reporting Qualitative Research; BIDMC = Beth Israel Deaconess Medical Center; UW = University of Washington Medicine. *Source: Monaci, M.; Javaher, S.; Barello, S. Open Notes in Mental Health: A Scoping Review of Stakeholder Experiences and Implications for Clinical Practice. Healthcare 2025, 13, 2777.*

Appendix B. Characteristics and main findings of the 57 included studies from the broader healthcare settings review (Data Extraction 2).

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
(Smith et al., 2019)(Smith & Kelly, 2022)	2019	To identify parent perspectives of the idea of sharing doctors' notes with parents during their child hospitalization.	USA – Midwest children's hospital	Parents with experience caring for a hospitalized child	Qualitative study	8	87.5%	BENEFITS: Reference for improving family education/ understanding; enhance communication/continuity; promote advocacy/empowerment. CHALLENGES: Note content (medical jargon, sensitive diagnoses); impaired communication; negative parent emotion.	Parents perceived potential benefits related to improved education, communication, and engagement, while recognizing unique challenges such as privacy concerns for adolescents and heightened anxiety in high-acuity settings. Parents described how note access could support communication during rounds, enhance continuity, and help identify errors.
(Kelly et al., 2021)	2021	To identify the benefits and challenges of sharing hospital physicians' notes with parents during hospitalization from stakeholders' perspectives, and identify	USA – Midwest tertiary children's hospital	Parents, bedside nurses, pediatric interns/residents, attending hospitalists, hospital administrators	Qualitative study	34	79%	BENEFITS: Reinforcing information; improving parental knowledge; increasing empowerment; enhancing communication; facilitating partnership	Stakeholders anticipated multiple benefits and drawbacks. Findings will inform the design and implementation of an intervention to share notes using an inpatient portal and evaluation of its effect on child, parent, and healthcare team outcomes.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
		strategies to aid implementation.						; increasing provider accountability. CHALLENGES: Increasing workload; heightening parental distress/anxiety; causing confusion; impairing relationship.	
(Nazi et al., 2015)	2015	To explore the experience of early patient adopters who accessed clinical notes online via the My HealtheVet portal; understand how/why veterans read notes, and whether reading causes distress or confusion.	USA – VA, nationwide (My HealtheVet portal)	Veterans	Cross-sectional survey	29,191	10.22 %	Patient experience/ usability; reported benefits (preparedness, understanding, recall, self-care, medication adherence, control) and concerns (worry, confusion); follow-up communication; satisfaction.	Results highlight the need to better inform patients about their ability to access clinical notes. Clinicians should consider note-sharing as a tool to reinforce treatment. While many patients seek clarification after reading notes, some contact providers due to concerns or perceived errors.
(Leveille et al., 2012)	2012	To design and run a one-year multi-site OpenNotes trial; assess patients' and PCPs' attitudes and experiences	USA – online setting (multi-site)	Primary care patients, primary care physicians, health systems	Mixed-methods	90,826	57.3%	Preference to continue OpenNotes; patient beliefs/attitudes; PCP concerns and perceived impact; patient–	One of the first large-scale multisite evaluations of patient access to primary care visit notes. Despite initial concerns, many physicians agreed to participate,

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
		; measure effects on patient behavior, portal use, and patient–doctor communication.						doctor communication; portal/OpenNotes use.	demonstrating feasibility. Established a foundation for assessing the impact of note sharing on clinicians and patients.
(Zellmer et al., 2021)	2021	To evaluate parent and physician perceptions of sharing notes with parents during hospitalization.	USA – Midwest tertiary children's hospital	Parents of children; physicians (attending and interns)	Mixed-methods	25	76%	Parents: satisfied with access, better recall, useful information, better prepared, notes more helpful than confusing. Physicians: increased transparency, improved documentation; downsides include limited documentation of sensitive topics, increased workload.	Parents reported that reading bedside notes helped them remember the care plan, prepare for rounds, and feel more in control. Physicians—especially interns—were more skeptical, but most did not report increased workload. Some physicians felt they needed to change documentation, which could affect team communication.
(Henderson et al., 2021)	2021	To evaluate a survey of dermatologic patients on their attitudes toward the OpenNotes system.	USA – Beth Israel Deaconess Medical Center	Dermatologic patients	Survey	333	60%	Privacy worry; note viewing behavior; better skin care; confidence level in dermatologist based on notes.	Most respondents viewed OpenNotes positively, saying it increased their confidence in their dermatologist and helped them feel more in control of their health.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
									Privacy was a common concern, though no gender differences were found.
(Smith & Kelly, 2022)	2022	To investigate the anticipated impact of increasing flow of EHR information—specifically physicians' daily inpatient progress notes—via a patient portal to parents during acute hospital stay.	USA – Midwest academic children's hospital	Hospital administrators, hospitalist physicians, interns/residents, nurses, parents	Qualitative study	34	79%	BENEFITS: Communication, recapitulation and reinforcement, education, stress reduction, quality control, improving family-provider relationships. CHALLENGES: Burden on provider, medical jargon, sensitive content, decreasing trust.	Giving patients and caregivers portal access improves information sharing and helps them participate more actively in care. Parents acted as both guardians of their child's health and observers of clinical processes, seeing themselves as partners on the care team.
(Fisher et al., 2022)	2022	To understand the impact of sharing clinic notes on communication and self-management among patients with COPD and develop recommendations for writing	USA	Patients with COPD	Qualitative interview study	30	NR	Exchanging information; enabling self-management; fostering the relationship; managing uncertainty.	Sharing clinic notes is a promising tool that, among patients with COPD, can promote self-management and information exchange, strengthen the patient-provider relationship, and help patients manage disease-related uncertainty.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
		patient-centered notes.							
(Leonard et al., 2023)	2023	To assess clinicians' initial experiences with and attitudes toward sharing visit notes after the Cures Act mandate, and determine preferences regarding instant record release.	USA – University of Kansas Health System	Physicians, physician assistants, nurse practitioners, resident physicians, critical care/emergency nurses	Cross-sectional survey	609	NR	Good idea to make notes available; OpenNotes as patient engagement tool; speaking to patients before record access; documentation timing; clinical value of notes for other clinicians; encouraging patients to read notes.	Overall, clinicians felt sharing visit notes is a good idea and emphasized that clinicians should talk with patients before patients access records. Those who supported note sharing saw it as a helpful engagement tool, while those neutral or opposed were less likely to encourage patients to read notes.
(Lam, Bourgeois, DesRoches, et al., 2021)	2021	To understand the effect of note-reading practices, patient-provider relational effects, safety/quality outcomes, and safety behaviors in adolescents and young adults.	USA – academic adult and pediatric hospitals	Patients (adolescents and young adults)	Survey	7,246	62.8%	Perceptions about importance of notes; patient-provider relationship effects (trust, teamwork, alignment, activation); safety knowledge and behaviors (understanding tests, recall, medication adherence, follow-up	Adolescents and young adults benefit from open notes similarly to adults. Reading notes helped both groups feel more engaged, improved trust, and supported safety behaviors. However, young people were less likely to report serious errors they noticed, mainly because they didn't know how.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
								attendance).	
(Nandiwada et al., 2018)	2018	To compare differences between resident and attending physicians' perceptions before implementation of patient access to provider notes.	USA – primary academic general internal medicine clinic	Resident and attending physicians	Survey	51	NR	Anticipated empowerment; expected patient worry; concerned about follow-up questions; changing documentation about sensitive topics.	Both groups felt OpenNotes could empower patients, but both were also worried about documenting sensitive topics. Residents reported greater discomfort, especially about litigation risk and writing about issues like obesity or possibly offending patients.
(Vanka et al., 2025)	2025	To develop informed guidelines for documentation in medical records in the era of open and transparent communication.	USA	Physicians, patients, medical students, resident physicians	Qualitative interview study	27	48.14 %	Guidelines: use person-first language; refer to patients as they want to be identified; avoid abbreviations; say what you write; verify past history; avoid bias/judgment; keep physical exam objective; empower with encouraging words; attend to sensitive topics; write from	This study developed 10 concrete guidelines for writing clinical notes in a more patient-centered way. These guidelines were derived from a qualitative analysis of interactive discussions between patients and clinicians and incorporated into medical education for evaluating students' note-writing.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
								your perspective.	
(Crotty et al., 2018)	2018	To assess anticipatory attitudes about open notes and explore factors influencing residents' propensity toward note transparency.	USA – BIDMC, Geisinger, Harborview, University of Colorado	Resident physicians	Cross-sectional survey	176	55%	Anticipated effects on resident practice and workload; anticipated effects on patients; anticipated effects on education.	Residents reported mixed expectations: many thought OpenNotes could improve transparency, patient education/engagement, safety, and trust. They worried about increased workload, overwhelming patients, and being less candid in documentation. Most reported limited preceptor feedback on their notes.
(Delbanco et al., 2012)	2012	To evaluate the effect on doctors and patients of facilitating patient access to visit notes over secure internet portals.	USA – BIDMC, Geisinger, Harborview	Patients and primary care physicians	Quasi-experimental intervention (pre–post)	13,564 patients; 105 PCPs	NR	Visit length; follow-up questions outside visits; documentation time; candor/detail in note writing; documentation content for sensitive topics; care efficiency; communicating/educating patients.	Most patients actively read their visit notes and felt more informed and in control, with some reporting better medication-taking. A minority expressed privacy concerns or negative reactions. Clinicians reported only modest workload changes, though some adjusted documentation. Patients strongly wanted open notes to continue.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
(Lam, Bourgeois, Dong, et al., 2021)	2021	To describe patient and family attitudes, experiences, and barriers related to speaking up about perceived serious note errors.	USA – 2 northeast US academic medical centers	Patients and pediatric families	Survey	6,913 adult; 3,672 pediatric patients/ families	NR	Reporting mistakes improves patient safety; barriers to speaking up; patient and family recommendations about reporting mistakes.	Many patients and families who read notes reported noticing mistakes, but many did not tell the healthcare team. The biggest reasons: not knowing they could report errors, not knowing how, and fear of negative consequences. Systems should create easy, timely ways for patients to report errors.
(Wright et al., 2020)	2020	To develop and evaluate the validity of a scale to assess patients' perceived benefits and risks of reading ambulatory visit notes online.	USA – ambulatory care in three large US health systems	Patients	Questionnaire (scale development study)	1,189	NR	Benefits scale: better understand condition, better care of themselves, remember care plan, more control, better visit preparation, better medication adherence. Risk scale: worry more, privacy concern, notes more confusing than helpful, felt offended.	The benefits scale worked well and is reliable. The risk scale did not perform well, so a strong 'risk' measure could not be confirmed. The benefits scale can be used to evaluate patients' experiences with note reading across groups.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
(Grossman et al., 2017)	2017	To evaluate usage of a clinical notes feature in an acute care patient portal and describe inpatient perspectives regarding receiving their clinical notes.	USA – NewYork-Presbyterian Hospital / Columbia University Medical Center	Hospitalized patients	Mixed-methods	10	1%	Usefulness of clinical notes; comprehension and insight; emotional reactions; health behavior change; patient safety.	Patients who read their notes described better insight into medical conditions, better access to information, decreased anxiety, increased appreciation for clinicians, improvements to health behaviors, and engagement with medical decision-making.
(Bell et al., 2022)	2022	To investigate whether sharing clinical notes with patients can support identification of 'diagnostic safety blindspots'.	USA – three US health care centers	Patients	Mixed-methods	22,889	63.1%	Types of diagnostic safety blindspots: diagnostic misalignment, omissions, events occurring outside the visit, cascading into diagnostic breakdowns.	Giving patients access to clinical notes helps them spot diagnostic safety blind spots and 'good catches' across many parts of the diagnostic process. Open notes can serve as a scalable way to engage patients and families in safety. Health systems need routine feedback channels and supportive policies.
(Woods et al., 2013)	2013	To examine patients' views and experiences with reading their health records, including clinical notes, online.	USA – Portland, Oregon VA Medical Center	Veteran patients	Qualitative interview study	30	11%	Theme 1: Enhanced communication with providers. Theme 2: Improved patient knowledge and self-care. Theme 3: Greater patient	Patients felt seeing records positively affected communication, enhanced health knowledge, and allowed greater participation in care. While some felt that seeing undisclosed information, derogatory

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
								participation in care. Theme 4: Challenges from viewing records and electronic documentation.	language, or inconsistencies caused challenges, they overwhelmingly felt that having more health information provided benefits.
(Walker et al., 2015)	2015	To describe the OpenNotes movement in the US and how sharing notes with patients is spreading; underline the case for research to assess long-term effects.	USA – BIDMC, Geisinger, Harborview	Primary care patients and primary care physicians	Pre–post intervention (quasi-experimental)	17,680 patients; 105 physicians	NR	Patient-reported benefits (better understanding, self-care, medication-taking, feeling in control); concerns/harms (confusion/worry/offense); sharing behavior; clinician impact/workload; documentation changes.	Evidence suggests benefits of open notes for patients outweigh the risks, and clinicians are increasingly recognizing these advantages. Doctors worry about added workload, follow-up questions, and requests for edits, though studies have generally shown only minimal impact on doctors' work.
(Huang et al., 2019)	2019	To evaluate the results of access to medical notes among adolescents/ young adults (AYA) with chronic disease at a pediatric gastroenterology clinic.	USA – Rady Children's Hospital, San Diego & UCSD	Adolescent and young adult patients with chronic GI/liver disease	Cross-sectional survey	55	45%	Short Test of Functional Health Literacy; satisfaction with documentation (accuracy, health problems, office event summary); comprehen	AYA reported high satisfaction with note accuracy and generally understood the content, showing strong agreement with physician interpretations. Only a small number wanted to edit notes. Concerns about health literacy, comprehension,

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
								sion (% agreement with physician readers).	and harm from sharing notes with adolescents appear largely unfounded.
(Gerard et al., 2018)	2018	To examine the importance of visit notes to non-white and less educated patients.	USA – one urban US academic medical center	Patients	Survey	6,913	62.82 %	Understanding health conditions; feeling informed about care; understanding provider's thought process; remembering the plan of care; making care decisions.	Less educated and non-white patients who used the portal were especially likely to say reading notes is very important for staying informed, remembering the care plan, and making decisions. People in poorer health also reported notes helped them better understand their care.
(Badwal et al., 2024)	2024	To analyze trends in outpatient open note access over time; characterize usage by age, sex, and clinical interaction type; assess method of access.	USA – Erie County Medical Center	Outpatients and inpatients	Retrospective cohort observational study	4,615	63.4%	Quantify outpatient open note access; characterize users.	Only a minority of portal users accessed outpatient open notes, with users more often female and clustered around two main age ranges. Note viewing increased sharply when open notes launched then declined over time, with pandemic-related visit notes likely driving much of the early surge.
(Wolff et al., 2016)	2016	To examine the acceptability and effects of delivering	USA – Geisinger Health System	Adult patients and care partners	Cross-sectional survey	184 patients; 272 care partners	NR	Potential risks (confusion, worry, privacy); care	Patients reported greater confidence and preparedness at follow-up for managing health

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
		doctors' visit notes electronically to patients and care partners with authorized access to patients' electronic medical records.						partner access risks and benefits; potential benefits (medication adherence, self-care, visit preparation, sense of control, recall, understanding).	information and understanding the care plan. Care partners showed little change in perceived ability to manage patient's care but reported better satisfaction with communication with providers.
(Crotty et al., 2016)	2015	To identify resident and faculty preceptor attitudes about sharing notes with patients, and assess specific educational needs and approaches to facilitate implementation.	USA – BIDMC and Geisinger Health System	Residents and faculty physicians	Qualitative study	36 (24 residents; 12 faculty)	NR	Implications of full transparency; note audiences and ideology; trust between patients and doctors; time pressures; potential benefits and recommendations.	Participants felt transparency through open notes could push medicine to address deeper system problems, improve note quality, and strengthen patient engagement. They highlighted an 'inversion of trust' where clinicians must learn to trust patients with sensitive information. Open notes could reshape medical education.
(Gerard et al., 2017)	2017	To learn more about patients' experiences with reading and providing feedback on their visit notes.	USA – hospital-based primary care	Patients and care partners	Qualitative study	260	NR	What patients liked: confirm and remember next steps, quicker access to results, positive	Patients and care partners said reading notes helps them remember next steps, feel less overwhelmed, understand their condition, and become more proactive. They

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
								emotions, sharing information. Use of notes and feedback tool: accuracy/correcting mistakes, partnership/engagement, bidirectional communication, enhanced education.	valued checking note accuracy, sharing notes with family, and having an easy way to give feedback.
(Jackson et al., 2014)	2014	To evaluate the characteristics of patients who reported sharing their visit notes during the study, including views on associated benefits and risks.	USA – BIDMC, Geisinger, Harborview, University of Washington	Patients	Quasi-experimental (pre-post)	4,516	60.27 %	Patient-doctor interaction and patient confidence in communication; behavioral perceptions of patients who shared notes (self-care, medications, privacy concern).	Some patients shared visit notes with others and many wanted an option for family/friends to have their own access. People who shared notes tended to report better self-care and medication-taking. Privacy concerns existed, but sharers were not more worried than non-sharers.
(Mishra et al., 2019)	2019	To analyze patients' perceptions about the patient portal experience with access to primary care and specialists' notes and evaluate	USA – Virginia Commonwealth University Health System	Patients	Survey	872	NR	Convenience; communication; understanding; information-related measures.	Most portal users had read outpatient notes and found them helpful for understanding the care plan, following results, and taking better care of themselves. Most reported good understanding. Main negatives:

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
		free-text comments.							missing/incorrect information, portal frustrations, confusion with abbreviations.
(Parsons et al., 2020)	2020	To evaluate and characterize the use of a confidential clinic note type as part of the implementation of open notes at a freestanding children's hospital.	USA – pediatric outpatient clinic	Attending physicians, house staff, APPs, psychologists; ambulatory pediatric clinic notes	Single-center retrospective chart review	1,100	NR	Type of confidential content: paternity, medical child neglect, foster/custody, disagreements, legal, social situation, guardian violence/substance abuse/mental health, patient sexual health/substance abuse/mental health.	A confidential note option was widely used in pediatric outpatient clinics, especially for sensitive topics. It was used more often for adolescent and female patients. Some notes marked confidential did not clearly contain sensitive content, suggesting need for clearer guidance.
(Erlingsdóttir et al., 2019)	2019	To deepen the academic writing on the type of transparency connected to Open Notes.	Sweden	Healthcare professionals (assistant nurses, doctors, secretaries, nurses, OT, PT, psychologists, social workers, unit managers)	Pre-post survey	Pre: 388; Post: 1,166	NR	Effectiveness; trust; accountability; autonomy and control; confidentiality/privacy/anonymity; fairness; legitimacy.	Healthcare professionals' comments showed that OpenNotes creates complex trade-offs affecting their work, patient relationships, and EHR use. Many adapted documentation preventively—being less candid—to avoid perceived harms. Some noted benefits for certain patients

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
									but questioned whether many psychiatric patients can realistically use the service.
(Mafi et al., 2016).	2016	To examine whether patients invited to review clinicians' notes continue to access them and to assess the impact of reminders on whether patients continued to view notes.	USA – secure electronic portals	Patients	Longitudinal observational cohort	14,360	57.8%	Primary outcome: notes viewed within 30 days of availability.	Patients continued to view visit notes when they received ongoing invitations and reminders. When reminders stopped, note viewing dropped substantially. A subanalysis found that Black and other/multiracial patients were less likely than White patients to view notes, suggesting need for targeted strategies.
(Khasawneh et al., 2022)	2024	To understand families' interaction with and perception of inpatient hospital notes shared via patient portal in a community NICU.	USA – patient portal in Neonatal Intensive Care Unit	NICU families; neonatologists, nurses, ancillary staff	Mixed-methods	59	NR	Frequency of note reading; understanding that notes come from different care team members; motivations for reading; perceived accuracy; understandability; change in caregiver perception/ trust; follow-up communication;	Families frequently read OpenNotes, understood them, and found them accurate and helpful. Notes reinforced the care plan, improved recall, and were associated with equal or improved perceptions of physicians. Some families noted confusion due to medical jargon and expressed interest in clearer note author differentiation.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
								perceived benefits and harms; recommendations.	
(Khasawneh et al., 2022)	2022	To assess the effect of note complexity and number of accesses on user performance, perceived usability, cognitive workload, and satisfaction.	USA – radiation oncology setting	Healthy volunteers (surrogates for caregivers)	2×2 mixed subjects experimental design	53	77%	Participants' performance with note complexity; perceived usability; perceived cognitive workload; satisfaction with access.	Performance was highest when participants read simplified notes with continuous access, but overall understanding remained incomplete. Perceived usability, cognitive workload, and satisfaction scores were generally low across conditions, with continuous access associated only with slightly higher satisfaction.
(Esch et al., 2016)	2015	(A) To gain insights into experiences of patients invited to view visit notes; (B) to examine relationships among fully transparent EMRs and quality of care, the patient-doctor relationship, patient engagement, self-care,	USA – Greater Boston	Patients cared for by primary care physicians	Mixed-methods qualitative study	576	71.87 %	Overall experience, individual use, and constraints; trust; clarity, error detection, and correction; sharing, co-authoring notes, and withholding information; self-care, control, and	Frequent OpenNotes users reported improved understanding of health information, enhanced trust and communication, and greater engagement in self-care. Many did not share notes with others. Some preferred features such as delayed access, note commenting, and customizable privacy options.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
		and clinical outcomes.						engagement.	
(Ralston et al., 2021)	2021	To describe changes in clinicians' attitudes about sharing notes with patients.	USA – Kaiser Permanente Washington	Primary care, medical specialties, surgical specialty clinicians	Survey (pre- and post-implementation)	119 primary care; 47 medical specialties; 26 surgical specialties	53%	Change in 'good idea' endorsement; clinician workload/ workflow; documentation behavior; perceived effects on care; perceived benefits (patient engagement, self-care, understanding, recall, preparedness, empowerment, medication adherence); perceived harms (confusion, anxiety/worry).	After implementation, most physicians reported note sharing was beneficial, with many changing prior unfavorable views and reporting fewer workload concerns. Some continued to express concerns about patient confusion, reduced candor, and documentation changes. Perceived improvements in patient safety and satisfaction declined post-implementation.
(Vodicka et al., 2013)	2013	To identify patients' attitudes toward privacy when given electronic access to their medical records, including visit notes.	USA	Primary care patients	Pre-post survey	3,874	59.44 %	Health & health care experiences (confidence in communicating with physicians, trust, self-rated health); OpenNotes acceptability; note access behavior;	About one-third reported privacy concerns at baseline, higher among women, non-white patients, and those with lower communication confidence. Privacy concerns were not associated with note access or desire for continued access. Nearly all

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
								discussing notes with others; preference for ongoing access.	participants supported ongoing access regardless of concern.
(Lee et al., 2017)	2017	To understand ophthalmology patients' perceptions about potential benefits and harms of accessing their own clinic notes via a patient portal.	USA – three US eye clinics	Ophthalmology patients	Cross-sectional survey	451	54%	Worry more; privacy concern; take medication; take better care; prepared for visit; feel in control; remember plan; understand better.	Ophthalmology patients expressed strong interest in online access to clinic notes and generally perceived it as beneficial for improving understanding and self-care. Concerns about privacy and confusion were reported, but overall enthusiasm was similar to prior OpenNotes studies in primary care.
(Bialostozky et al., 2020)	2020	To describe a pediatric integrated delivery network's journey to default share notes in ambulatory specialty practices with parent proxies and teens.	USA – single academic healthcare institution	Physicians/providers, patients, proxies (caregivers/legal representatives)	Quasi-experimental study	446,615 clinical notes analyzed	NR	Provider note-sharing rate—whether ambulatory pediatric subspecialty notes were actually shared, comparing opt-in vs. opt-out/default-share periods.	During opt-in period, very few eligible notes were shared; during opt-out/default sharing, the large majority were shared. Transitioning to default note release substantially increased sharing rates without increasing patient messages or formal chart amendment requests.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
(Jackson et al., 2022)	2022	To better understand the characteristics and perceptions of care partners who read patients' electronic visit notes.	USA	Care partners and patients	Survey	29,656 (874 care partners; 28,782 patients)	58% care partners; 41% patients	Perceived benefits (self-care, recall, visit preparation, maximizing visits, medication management, active care role); open question about potentials, risks, and suggestions.	Most care partners reported that making visit notes available was a good idea and described notes as easy to find and helpful for communication, decision-making, and medication management. Care partners were generally more positive than patients about the benefits of reading notes.
(Kayastha et al., 2018)	2018	To understand how patients with advanced cancer experience reading their own medical records.	USA – Duke Cancer Institute	Adult patients with metastatic or incurable cancer	Interview study	20	45%	Comprehension; uncertainty, anxiety, and control; trustworthy.	Patients with advanced cancer reported that reading notes improved comprehension, supported more active participation, and enhanced trust in clinicians, particularly when they felt overwhelmed during visits. A subset experienced increased anxiety. Medical jargon and repetitive content were identified as key areas for improvement.
(Murugan et al., 2022)	2022	To develop a just-in-time education system to help providers	USA – urban pediatric health system, Southeastern US	Family/patients; patients; parents/legal guardians	Implementation evaluation / Quality improve	1,315,488 provider clinical notes	NR	OpenNotes utilization: how many eligible signed provider notes were	Before full implementation, very few notes were shared and read. After full launch, most notes were shared

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
		adapt to the OpenNotes requirements in the 21st Century Cures Act, with unique challenges for pediatric health systems.			ment study			shared to the patient portal and how many were read by patients/families.	and many more were read. Reviews of confidential notes identified issues such as accidental sensitive information inclusion, overly detailed content, and incorrect documentation choices, leading to workflow changes.
(Elkhaili El Alami et al., 2020)	2020	To explore general patients' expectations toward potential benefits and risks of patient open-EHR solution in Japan.	Japan – Teikyo University Hospital	Patients	Cross-sectional survey	183	69%	Potential benefits (acceptability, understanding, recall, self-management, medication adherence, patient empowerment, visit preparation); potential risks (anxiety/emotional impact, privacy/confidentiality, comprehension burden/confusion).	Most respondents in Japan expressed positive views about accessing their EHRs online and believed it would improve understanding of health conditions. Agreement varied by age, with older participants less likely to endorse the benefit. Privacy concerns were common across groups.
(Leveille et al., 2020)	2020	To examine patients' views on the clarity, accuracy, and thoroughness of notes,	USA – BIDMC, Geisinger, University of Washington	Patients	Survey	21,664	96.43 %	Note transparency/authorship clarity; note understanding; perceived	Patients reported high levels of understanding across clinician types and specialties; most described notes as accurate and

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
		suggestions for improvement, and associations between perceptions and willingness to recommend clinicians.	Medicine					accuracy; perceived completeness; patient suggestions for improving notes (structure, jargon, accuracy, process, portal, negative tone, patient input, completeness, communication during visit).	helpful. A small subgroup reported limited comprehension or perceived inaccuracies. Patients suggested improvements such as clearer next steps, reduced jargon, error correction mechanisms, and technical enhancements.
(Blease et al., 2023)	2023	To explore the experiences and opinions of GPs in England about patients' access to their full web-based health record, including clinicians' free-text summaries.	UK – anonymous nationwide web-based survey of GPs in England	General practitioners	Mixed-methods survey	400	40.2%	Increased strain on GPs (extra work, reduced efficiency, GP burnout); potential to harm patients (increased anxiety, risks to safety); changes to documentation (reduced candor, record functionality); legal concerns (litigation risks, lack of guidance).	GPs in England expressed concerns that patient access to full electronic health records would increase workload, reduce efficiency, and contribute to burnout. They anticipated patient anxiety and safeguarding risks, and reported changing documentation practices, including reducing candor. Legal concerns were also raised.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
(Sarabu et al., 2021)	2021	To better understand how pediatric patients and families perceived OpenNotes.	USA – pediatric and obstetric healthcare system	Patients aged 0–11; guardians	Survey	159	NR	Caregiver-perceived note accuracy; ease of understanding; change in caregiver feelings toward clinician (trust/confidence/relationship); follow-up communication triggered by note reading.	Most patients and families understood notes, considered them accurate, and reported improved trust in their clinician after reading them. Most did not contact clinicians with questions. Concerns about misunderstanding, damaged relationships, or increased workload were not supported by survey responses.
(Bell, Mejilla, et al., 2017)	2016	To explore whether providing patients access to clinical notes would strengthen or weaken the patient–doctor relationship, including concerns about perceived errors.	USA	Primary care physicians and patients	Pre-post survey	99 PCPs; 4,592 patients	60% patients	PCP perceptions on providing access (errors, disagreement, satisfaction, trust, litigation risk); patient measurement (motivation, accuracy, ease of understanding, trust, follow-up contact, engagement, safety).	(Pre-post survey; results not separately summarized in extracted data – see primary source for full findings.)
(Janssen et al., 2021)	2021	To gather opinions about sharing	Netherlands – academic and	Patients; physicians	Mixed-methods (survey and	350 physicians; 99 patients	55.4% physicians; 72%	Anticipated benefits and concerns:	Most physicians preferred not to share visit notes, expressing

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		outpatient clinic visit notes from patients and hospital physicians in the Netherlands, where there is currently no policy or incentive plan.	non-academic hospital		interview)		patients	interest/support, expected benefits (understanding/recall/control), expected risks (confusion, worry, privacy, workload, communication issues).	concerns about patient confusion, anxiety, sensitive content, increased workload, and legal/privacy risks. In contrast, most patients considered access important and anticipated benefits such as better recall and sense of control. A mismatch between physician and patient expectations was highlighted.
(Alpert, Morris, Thomson, Matin, Sabo, et al., 2019)	2019	Qualitative interviews and pre- and post-linguistic analysis to determine whether oncologists changed the content and style of their notes after OpenNotes implementation.	USA – National Cancer Institute-designated cancer center, central Virginia	Oncologists	Mixed-methods	13	54%	Oncologists' awareness that patients can read notes; notes are mainly written for colleagues; notes can improve communication.	Oncologists were generally reluctant to change how they write notes after OpenNotes implementation, prioritizing accurate documentation for multidisciplinary care. No significant changes in writing style were found before and after implementation. Language in notes can influence patient and provider perceptions.
(DesRoches et al., 2020)	2020	To assess clinicians' views and experiences with sharing	USA – BIDMC, Geisinger, University of	Clinicians	Survey	1,628	65%	Clinician-perceived usefulness for patient engagement;	Most clinicians with experience sharing notes supported the practice with little effect on

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		clinical notes (open notes) with patients.	Washington Medicine					willingness to recommend; encouragement behavior; patient-initiated note discussions; patient follow-up contact; perceived documentation time change; perceived interprofessional usefulness.	workflow, although about one-third perceived increased documentation time. Clinicians with fewer weekly patient hours and more years in practice were generally more positive. Broad clinician acceptance was found alongside ongoing documentation concerns.
(Chu et al., 2024)	2024	To understand how parents experience and navigate open access to clinical notes in their child's EHR and their interactions with clinicians during a PICU admission.	USA – quaternary academic freestanding pediatric hospital	Parents and legal guardians	Semi-structured interview	NR	NR	Applied benefits; psychosocial and emotional value; negative consequences; practical limitations; parental approach; appraisal.	In the ICU setting, open notes gave parents a way to revisit information and feel more informed and involved in their child's care. Challenges included medical jargon, concerns about impersonal language, and uncertainty about authority in interpreting notes. Findings suggest need to rethink note-writing objectives and the evolving role of parents in the EHR.
(DesRoches et	2021	To examine the experiences	USA – BIDMC, UW	Older patients	Cross-sectional survey	7,688	54.50 %	Experience with note reading	Older adults and patients with multiple chronic

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
al., 2021)		with and perceptions of open notes among patients with multiple chronic conditions.	Medical Center, Geisinger Health System					(frequency, duration of use, discussion with clinician, encouragement, sharing behavior, confusion, emotional impact); perception of note reading (importance for self-care, empowerment, visit effectiveness, participation, recall, visit preparation); reading notes and medication taking.	conditions reported reading open notes was very important for managing health, feeling in control, and making the most of clinical visits. Patients with multiple chronic conditions were more likely to read and share notes. Few reported increased confusion or worry.
(Dobscha et al., 2016)	2016	To describe VA mental health clinicians' attitudes toward and experiences with OpenNotes.	USA – one VA Medical Center	Mental health clinicians and nurses	Survey	208	56.3%	Views on OpenNotes and anticipated impacts; documentation practices and experiences; OpenNotes in general.	Mental health clinicians were generally positive about OpenNotes but expressed greater ambivalence in mental health settings, citing concerns about patient distress, therapeutic relationship disruptions, and documentation challenges. About half supported making mental health notes available.

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
(Walker et al., 2019)	2019	To examine the ongoing experiences and perceptions of patients who read ambulatory visit notes written by a broad range of doctors, nurses, and other clinicians.	USA – BIDMC, Geisinger, University of Washington Medicine	Patients	Survey	29,656	62.82 %	Benefits: feeling in control, preparing for visit, remembering plan of care, taking care of health, making most of visits, having active role. Risks: privacy concern, confusing, worried.	In this large assessment, most patients reported substantial benefits including greater control, improved recall, and better preparation for visits. Few reported confusion or increased worry. Medically underserved groups reported particularly strong benefits. Overall approval was high, though few recalled discussing notes with their clinicians.
(Kelly et al., 2023)	2023	To identify parent perceptions of the benefits and challenges of real-time note access during their child's hospitalization and strategies to optimize note sharing at the bedside.	USA – tertiary children's hospitalist service	Parents of hospitalized children	Qualitative interview study	28	75%	Benefits of reading OpenNotes; challenges of reading OpenNotes; strategies to improve note sharing.	After experiencing note access during hospitalization, parents believed benefits outweighed risks and wanted continued access in future admissions. Parents reported increased knowledge, engagement, and trust in the healthcare team. Challenges such as confusion were limited and often theoretical.
(Fossa et al., 2018)	2018	To investigate whether patients who read	USA – large adult care institutio	Patients	Cross-sectional survey	6,316	NR	Measure SDM: understanding of health	Patients who read more clinical notes reported higher levels of shared decision-

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
		more notes would report greater shared decision making (SDM).	n, Boston					issues, clinician receptiveness to patient priorities about health issues, receptiveness to priorities about the treatment plan.	making (SDM), supporting the hypothesis that greater note use is associated with stronger engagement. A possible threshold effect was observed, where reading multiple notes is associated with greater perceived SDM benefits.
(Alpert, Morris, Thomson, Matin, Geyer, et al., 2019)	2018	To understand oncologists' perceptions of OpenNotes while establishing a baseline of linguistic characteristics and patterns used in notes.	USA – National Cancer Institute	Oncologists (hematology/oncology, radiation oncology, surgical oncology)	Mixed-methods	30	54%	Audience uncertainty; censorship due to social terms; relationship building.	Before OpenNotes implementation, oncologists primarily wrote notes for other providers rather than patients, reflected in technical language and low patient-centered framing. No significant changes in writing style were found. Language in notes can influence perceptions, and patient access may support engagement and note accuracy improvement.
(Bell, Gerard, et al., 2017)	2017	This study aimed to test an OpenNotes patient reporting tool focused on safety concerns.	USA - Beth Israel Deaconess Medical Center (online patient OpenNot	patients and care partners	Quality Improvement (QI) Pilot Study	NR	NR	1. Patient safety 2. quality improvement 3. documentation accuracy/re	A portion of patients who read their notes used the feedback tool to comment, and most said they understood what they read. Some reports flagged possible mistakes

Study	Year	Main Aim	Country/ Setting	Stakeholder(s)	Design	Sample (N)	Female (%)	Primary Outcomes/ Measures	Main Results
			es Feedback Tool)					cord quality 4. Implementation/workflow impact.	or missing information, and clinician review confirmed that many of these were legitimate safety concerns, with several leading to changes in the medical record or care. Overall, patients and care partners valued the tool and wanted it to continue, and clinicians did not report negative effects on workflow or patient relationships.

Appendix B. Characteristics of included studies (n = 57). Studies are ordered approximately chronologically within each first-author group. N = sample size; VA = Veterans Affairs; NICU = neonatal intensive care unit; MC = medical center; PC = primary care.