



‘What we have lost is patients who can’t handle the information’ – information misuse and open record access

Camilla Lyckblad

DOI: <https://doi.org/10.47989/ir30CoLIS52273>

Abstract

Introduction. This paper aims to broaden the understanding of information misuse by drawing on findings from an ongoing study investigating how open record access in paediatric psychiatry influences documentation practices. It explores the boundaries of what constitutes information misuse, raising the question: can individuals misuse their own information?

Method. Semi-structured interviews with fifteen paediatric psychiatry clinicians experienced in open record access documentation were used as a basis for conceptual discussion on the notion of information misuse.

Analysis. Conceptual discussion based on thematic analysis of interview transcripts.

Results. Informants described situations regarding both clinicians’ and patients’ information behaviours that are highlighted as possible instances of authorised information misuse extending beyond malicious intent or personal gain, broadening the concept’s boundaries beyond descriptions in current research.

Conclusion. Findings indicate that the concept of information misuse is far more nuanced than current research often assumes. An action deemed misuse in one context might be considered best practice in another, emphasising that the distinction between information use and misuse is heavily influenced by context and the consequences of the action.

Introduction

Medical records, initially a working tool held close to heart by medical staff, have evolved into an increasingly shared document providing online access for patients. This shift reflects the global zeitgeist of patient-centred care and a legal and ethical change towards recognising patient ownership of their health data, with medical records being increasingly viewed as belonging more to patients than clinicians. Motivations behind what in the article will be referred to as open record access to medical records include enhancing healthcare efficiency, increasing patient empowerment and encouraging patients to take more responsibility for their health (Moll et al., 2018; Tapuria et al., 2021). Online systems granting patients access to their medical records have been implemented globally, allowing individuals to stay informed about their health and strengthening communication with healthcare professionals (Mamra et al., 2017). Many patients report an improved understanding of their health through open record access, which can also facilitate self-management and positive health outcomes (Kujala et al., 2022; Neves et al., 2020; Zanaboni et al., 2022). However, some patients and clinicians have raised concerns about the potential negative outcomes of open record access, which may verge on information misuse. These include the involuntary disclosure of sensitive information (de Lusignan et al., 2014), anxiety or distress caused by reading sensitive content in personal health records (Wang et al., 2023) and the omission of critical preliminary or sensitive information from records to prevent confusion or anxiety among patients (Blease et al., 2023; Denneson et al., 2017; Pisciotto et al., 2019).

Similarly to information use that has remained under-studied and -theorised in information science research, information misuse has attracted only rather sporadic attention so far in the literature (Nguyen and Simkin, 2017; Pasquetto et al., 2024; Sinha and Randall, 2022). While it is easy to provide examples of fairly clear cases of what counts as information misuse and its underpinning factors, open records access provides a useful context to investigate and theorise cases of experienced misuse that are anything but straightforward.

This article aims to expand the understanding of information misuse and problematise the concept, drawing on findings from an ongoing study examining the effects of open record access on information practices within paediatric psychiatry. Findings in the study propose that the concept of information misuse is more nuanced than current research suggests, extending beyond actions such as personal gain or malicious intent. By critically engaging with the literature and examining how possible information misuse might impact the integrity of medical records, patient-provider relationships and overall care quality, this paper aims to broaden the discussion of what constitutes information misuse and why.

Related literature

Exceptions and challenges in psychiatric record access

The risk of adverse effects of open records access has been suggested to be especially high in the context of psychiatric care (Wang et al., 2023). Access to psychiatric records online remains limited and contentious. In Sweden, where a national eHealth portal has been operating since 2015 providing online records access in all 21 regions of the country, as of 2018, only two regions had allowed online access to psychiatric records, reflecting a broader hesitation to share these sensitive records digitally. Paediatric psychiatry, in particular, is an area of heightened vulnerability and complexity. At the present, open record access practices in paediatric psychiatry vary widely across Swedish healthcare regions: while some regions restrict access entirely, others provide limited access with age-based restrictions for children and their guardians (Bärkås, 2024).

Clinicians can, during documentation, use designated keywords, such as *early hypothesis* or *threats and violence*, to shield particularly sensitive information from appearing online through the Swedish patient portal *Journalen* (Petersson and Erlingsdóttir, 2018). These restrictions and keyword-based blocking practices are intended to protect the functions of the document as a

working tool, as well as the patient's privacy, and to prevent potential information misuse in sensitive cases. That said, a manual blocking system, as described, relies on the documenting clinician to anticipate which specific information may be considered sensitive for a particular patient at any given time – an assessment that can vary significantly from one patient to another.

Information misuse

In the field of information behaviour, information misuse encompasses various aspects and parallel concepts. In a simple sense, information misuse can be understood as an antithesis of the still relatively under-studied (even if interest has been increasing in health contexts and beyond, cf. e.g., Chen's 2015 notion of information use (Savolainen, 2009)). Kari (2010) identifies seven approaches to conceptualise information use as information practices, information search, information processing, knowledge construction, information production, applying information and effects of information. The opposite or negation of each of these can be understood as a form of information misuse. To illustrate, examples of information misuse might include manipulative behaviours such as selectively presenting or withholding information to mislead others (Pasquetto et al., 2024; Karlova and Fisher, 2013). Additional examples involve privacy violations, such as the misuse of customer data (Nguyen and Simkin, 2017), and the exploitation of information for malicious purposes, including harassment or blackmail driven by personal gain (Sinha and Randall, 2022).

When discussing data misuse, essentially a variety of information misuse, Pasquetto et. al (2024) emphasise the challenges in defining what it entails, noting that it encompasses a range of behaviours, from unintentional methodological errors to deliberate, misleading use of data to influence public opinion. Misuse definitions are further complicated by epistemological differences, as what constitutes misuse in one community may be seen as best practice in another. The review highlights the need for a shared understanding of misuse that prioritises the wellbeing of individuals, communities and the environment. Pasquetto et. al (2024) further discuss how the fear of misuse is a significant barrier to data sharing in the open science community. Concerns include the potential for misinterpretation, errors in secondary analysis and the fear of replication experiments revealing flaws in original research.

Information misuse is also indirectly implicated in the notions relating to disinformation. Karlova and Fisher (2013) introduce misinformation and disinformation as extensions of information behaviour, exploring how inaccurate or deceptive information diffuses through social networks. They emphasise the importance of information literacy in recognising and evaluating credibility cues. Huvila (2018) argues that information literacy and practices exist on a spectrum, with varying degrees and nuances of purposefulness depending on the specific context. He interrogates potential conceptualisations of what it entails not to be information literate in terms of illiteracy and unliteracy. Similarly, there is individual variation in how certain practices are perceived as suboptimal and in how they affect different individuals and groups engaged in particular information literacy practices. What one person may interpret as ambiguous or indicative of information illiteracy another might view as a flexible and resourceful strategy. Earlier research has also argued that notions like information seeking and acquisition suffer similarly from too rigid dichotomising. The concept of *information-taking* (Huvila, 2022) focuses on the processes through which information is made one's own, rather than its subsequent application through understanding, learning or making sense. It encompasses a wide range of activities, both active and passive, that relate to how individuals or systems acquire and internalise information for various purposes. As Ingold (2017) notes, this spectrum extends from deliberate action to passive reception, offering a broader framework than terms like information acquisition (Savolainen, 2016). By including modes such as seeking, non-seeking, browsing and passive engagement, information-taking avoids rigid boundaries between these activities, presenting them as interconnected

aspects of a larger information experience. This perspective highlights the spectrum of how information is absorbed, prepared for use and transformed into personal or functional value.

Besides residing in a continuum between clear cases of misuse and others equally clearly being not misuse, misuse is also relative to stakeholders and their perspectives. Nguyen and Simkin (2017) delve into how firms' misuse of customer data generates perceptions of unfairness tied to privacy violations from the customer's perspective, even if the firm itself considers such information use completely legitimate. The findings reveal that beyond pricing, factors such as service quality and communication practices significantly affect customers' perceptions of fairness. This approach not only highlights the ethical implications of information misuse but also demonstrates its potential to undermine customer trust and loyalty. Also, the research into data misuse has highlighted the diverging perspectives on equitable use and misuse concerning what is considered a fair redistribution of benefits, especially when information is collected from vulnerable or marginalised communities (Pasquetto et al., 2024).

As an example of earlier theorising of information misuse, a study by Vikas Sinha and Bill Randall (2022) examined factors leading trusted insiders to misuse their authorised access to information. The study emphasises that insider threats cannot be fully mitigated through technical solutions alone, highlighting the importance of understanding the motivations and behaviours behind such actions. To illustrate, the authors present a hypothetical example involving a human resources manager with access to sensitive employee information, such as compensation details, social security numbers, health records and performance reviews. An individual in this role, motivated by malicious intent, could exploit this data to manipulate records, target vulnerable employees or engage in blackmail for personal gain. The framework proposed by Sinha and Randall aims to deepen understanding of how authorised insiders engage in opportunistic information behaviour and the conditions under which such misuse occurs.

Information misuse in healthcare systems

The literature on information misuse in healthcare systems has largely overlooked instances where misuse might originate from patients themselves, making this paper a valuable addition to the broader discussion on information misuse and what it constitutes. The existing literature highlights significant ethical, legal and practical challenges arising from unauthorised access, alteration or theft of sensitive patient data. Caputo et al. (2008) provide insights into detecting information misuse by studying how insider behaviour varies between malicious and benign users, employing empirical methods to identify indicators of potential misuse. This approach is relevant for healthcare settings, where the risk of internal misuse can compromise patient confidentiality and trust. In healthcare, unauthorised access and alterations are particularly concerning, with examples ranging from privacy breaches to data manipulations that affect patient outcomes (Pool et al., 2024; Smith, 1998). This research underscores the risks within healthcare, where professionals who improperly handle medical data may face serious legal repercussions, including dismissal and prosecution under data protection laws (Smith, 1998). In healthcare, breaches involving unauthorised access and data manipulation present critical concerns, impacting both patient privacy and care quality. Smith (1998) details various incidents illustrating the severe consequences of such violations. For example, a nurse was incarcerated under the Computer Misuse Act of 1990 for altering a prescription in 1994, while another faced permanent dismissal for unauthorised access to a colleague's medical records. Other cases include a general practitioner charged with perverting justice and manslaughter for falsifying records to conceal an incorrect prescription and a nurse dismissed after erasing malpractice-related records.

The misuse of medical information poses significant ethical challenges, involving issues such as confidentiality, secrecy and the integrity of patient-provider relationships. Jayasundra (2004) emphasises that healthcare professionals are ethically bound to protect patient data, despite rapid technological changes that introduce new vulnerabilities. Pool et al. (2024) address these issues

from a sociotechnical perspective, noting that both technical and human factors contribute to medical records misuse. Their model identifies two dimensions – data misfit (including availability, meaning, and place misfit) and improper data processing – offering a framework to understand how misuse impacts healthcare delivery and patient safety. This approach aligns with findings from Smith (1998), who documents various legal consequences for health professionals and organisations failing to protect patient data, highlighting the real-world implications of data misuse in healthcare.

Methods

This study draws from the analysis of semi-structured interviews with fifteen clinicians from various professions in paediatric psychiatry, all experienced in documenting within an open record access system that provides insight to both patients and their guardians. The investigation focused on documentation practices in this particularly sensitive setting, where clinicians, paediatric patients and guardians may consciously safeguard information and where levels of trust between doctors, patients and guardians can vary significantly.

Participant recruitment and consent

Participants were recruited through upper management in paediatric psychiatry departments across Sweden, as well as through public advertisements placed in hospital areas around Stockholm and Uppsala. All participants provided informed consent, signing a document allowing their interviews to be recorded and used solely for research purposes. The consent form emphasised the anonymity of the data; all identifying details were removed during transcription to maintain confidentiality. Participation in the study was entirely voluntary, with no financial or material compensation provided.

Interview procedure

All interviews were conducted by the author, who had no prior relationship with the interviewees. Given the demanding schedules of clinical staff, interviews were conducted digitally via Zoom, allowing participants to choose times that best fit their availability and enabling broader participation. All sessions were recorded with participants' consent, and the recordings were transcribed and anonymised to protect privacy. After transcription, the voice recordings were deleted. The interviews, which lasted approximately one hour each, were conducted in Swedish with participants fluent in the language; transcripts were later translated for publication. The interviews were conducted in a semi-structured format, allowing flexibility while focusing on key topics relevant to the study. Interviews began with an off-the-record introduction, during which participants were briefed on the study's aims and assured that they could pause or withdraw from the interview at any time. This introduction also allowed participants to ask questions before the recording commenced. Each interview lasted approximately one hour, allowing interviewees ample time to add final remarks at the end.

Data collection and analysis

In line with thematic analysis methods (Braun, 2022), the transcriptions were coded to identify prominent themes and concepts. Coding centred on clinicians' information practices, clinical dilemmas and ethical considerations regarding medical record ownership and usage. The coding process allowed for an in-depth exploration of the nuances within clinicians' documentation practices in the context of open record access. Questions focused on various aspects of documentation behaviour, including the process of recording information in medical records, whether practices have changed since records became digitally accessible and any guidelines provided to clinicians on documenting in open records. The questions also delved into clinicians' concerns about omitting information, such as preliminary results, suspicions based on experience or future assessments, and whether staff now prioritise factual data over other observations. Additionally, clinicians were asked if they document outside of the official record, if transparency

influences patient or guardian behaviour and whether they adapt records to be more understandable to non-professionals. Further questions addressed whether clinicians had experienced any adverse consequences from open record access and if any cases have raised ethical concerns or hesitation about documentation.

Findings

Information misuse in healthcare reveals a paradox involving insiders, malicious intent and perceived benefits. The study's findings show that patients themselves sometimes engage in behaviours that could be considered misuse of their own information. While individuals typically have the right to access their health information – since confidentiality does not apply to them – exceptions exist. For instance, access may be restricted when disclosure could significantly undermine the purpose of their care or treatment, in a Swedish context regulated under the Swedish Public Access to Information and Secrecy Act (25 ch. 6 §).

Clinician informants in the study report that specific patients, befriending and identifying with their disease, leverage the information provided through open record access as a means of controlling their care and actions from the staff, hindering their proper care and treatment, as shown in the following informant quote:

What we have, what we have lost, is patients who can't handle the information, and who use it to ... How should I express it ... Some patients, especially those with personality issues, may want to be sick. I mean, they, they have an identity tied to it, and they, in a way, befriend their illness, if I may put it that way. And that's part of the problem, so it's not that they are, are, kinda, they are sick [sighs with a small laugh]. And then, they can, use things we write to ... Let me give you an example just so you understand; If, for example, I write that I assess this patient as not suicidal because 'this and this and this and this ...' For instance, 'has plans for the future' or 'has clearly used their crisis plan,' or whatever I can write. So when they come to me next time, they say 'I have no plans for the future'. So, they have seen my argumentation and how I position myself in the medical records to support a low suicide risk, for example. And then they use it to, and it's not that they actually change in their ... They are not more or less suicidal, but they create a rhetoric and a way of talking that sort of makes it difficult for us to use our medical language to support what we think eventually. What we use today will be used against us at the next visit. We never used to encounter that before. (Informant (5), Upper Management Clinician, Paediatric Psychiatry)

In this scenario, there would seem, at first, to not be sensitive information that needed to be blocked in the record; what the clinician reported was 'has plans for the future,' something that would not be labelled as sensitive information but as a positive care outcome. The patient later uses this same documentation to control their care in ways that are negative to their treatment, a possible form of information misuse seen from a clinician's perspective. This shows a somewhat paradoxical situation showing the complexities of open record access in psychiatry. The informant voiced concerns in the above quote that they are losing patients who struggle to handle the information in their medical records. Several informants have expressed similar concerns in the study, with patients turning open record access into what could be argued to be a tool of control through documentation, complicating clinician-patient interactions and adopting a rhetoric that challenges clinicians' ability to employ medical language effectively. This is shifting the clinical documentation process from a supportive tool into something with the potential to be misused, with patients leveraging documented information to influence care decisions. Clinicians report that some patients, informed by access to clinicians' notes, use specific language that prompts mandatory actions like admission, even when clinicians believe these actions may worsen the patient's condition. This creates a tension where clinicians feel compelled to act against their professional judgement due to legal and procedural obligations. The findings revealing that

clinicians fear their current documentation choices may be used against them in future interactions challenge the primary goals of open record access for patients. While online access to medical records is intended to improve healthcare, empower patients and foster transparency and information freedom (Moll et al., 2018; Tapuria et al., 2021), the study reveals that open record access may entail unanticipated complexities for certain patient groups who possibly misuse the information in their medical records, hindering their own care.

Control through documentation

One clinician informant in the study describes a case involving a young girl with severe anorexia. Due to her condition, she has strict movement restrictions and is not permitted to exercise in any way. However, the clinician suspects that the entire family may be struggling with eating disorders, indicating a broader family issue. Aware that the parents read the medical records, the clinician documented observation of the family biking to the eating disorder unit despite the daughter's restriction against any physical activity. The clinician highlighted their lack of adherence to the prescribed care plan, aiming to provoke a reaction. This approach proved effective: by the next appointment, the parents had read the entry, asked questions about it and began following the treatment guidelines more closely, turning the medical record into a tool creating an opportunity for reflection.

Another clinician noted that if a patient became upset over something documented in the record, they would use the situation as a therapeutic opportunity, encouraging the patient to explore why certain words were distressing and using it to deepen their therapeutic dialogue. This, however, was argued to depend on the prior establishment of clinician-patient trust.

Additionally, several informants describe threatening situations that may be regarded as information misuse, most likely driven by malicious intent, with information accessed through online patient portals enabling open record access. Informants describe patients showing up uninvited at clinicians' homes or repeatedly calling their private phones in a threatening manner after working hours. This is facilitated by Sweden's unique openness regarding public information, where names and addresses are official records and easily accessible online through websites that profit from ad revenue. As a result, anyone without a protected identity is at risk of home harassment if they offend the wrong person. This risk is heightened in fields like adult psychiatric care, where medical records, even with specific information blocked through keywords, are still openly signed with the clinician's full name. The issue has drawn the attention of the Swedish Association of Young Doctors (SYLF), which has advocated for the pseudonymisation of medical records to enhance clinician safety (Wernström, 2023).

These cases highlight how patient access to medical records can serve as a tool of control – empowering clinicians to influence patient or family behaviour while also allowing patients to reflect and use the same documentation in differing ways. The findings shed light on the complexity surrounding the concept of information misuse. What one individual may consider misuse might, for another, represent best practice. This ethical ambiguity of proper use of information is evident in both clinicians' use of information to provoke specific actions and patients' use of information to exert control over their care – actions that, according to clinicians, may not always be beneficial for the patients or their psychiatric conditions.

Discussion

Complex information uses

Previous studies underscore the diverse nature of information misuse, illustrating its application across various sectors – from the security risks associated with insider threats to the deterioration of consumer trust resulting from data mismanagement. Drawing from the existing literature, we can define information misuse as the inappropriate leverage of accessible information by individuals within a system, typically insiders such as healthcare providers or private companies.

However, this paper highlights a different facet of information misuse in the context of healthcare, where patients – with legitimate access to their health information – may use their medical documentation in ways that counteract their recovery. Unlike Sinha and Randall's model (2022), there are no motives like financial benefit or fears of repercussions; instead, patients may hinder their care through behaviours tied to their psychiatric conditions. This behaviour is not necessarily driven by conscious malicious intent. Instead, it reflects the complexities of the patient's condition, where access to certain information influences self-harming behaviours and limits the efficacy of care interventions.

A question arises from these healthcare examples of possible information misuse: when does information go from simply being information use to information misuse? For example, does controlling someone else's actions through information constitute misuse, or is it sometimes a legitimate or even necessary action? In healthcare, a pregnant patient seeking control over their care through questioning their medical records may most likely not be considered information misuse. Still, the same behaviour might be viewed differently in a self-harming patient whose actions conflict with therapeutic goals. These distinctions underline the importance of considering context, purpose and consequences in evaluating information behaviours.

How does one misuse information?

In this paper, it is essential to question whether the term information misuse is even appropriate to use, as the concept is far from straightforward. Huvila (2018), in his discussion on alternatives to the traditional literacy/illiteracy dichotomy, argues that information practices exist on a spectrum. These practices vary in degrees of purposefulness, depending on specific contexts. Similarly, what one person interprets as ambiguous or indicative of misuse another might view as a flexible and resourceful strategy. This highlights the complexity of assessing information use and misuse, as individual norms, ideals and practices often clash.

Pasquetto et al. (2024) also address the challenges in defining misuse, noting that it encompasses a wide range of behaviours – from unintentional methodological errors to deliberate misuse aimed at influencing public opinion. Definitions of misuse are further complicated by epistemological differences, as what one community might perceive as misuse could be seen as best practice by another. These differing perspectives emphasise that use and misuse cannot always be understood as binary opposites. Instead, they must be examined within their specific contexts and evaluated based on their outcomes and consequences. Drawing on examples from the study, patients who leverage their access to medical information to prompt mandatory actions that obstruct their proper care could be seen as engaging in information misuse. This is particularly evident when such actions hinder clinicians from using precise medical language and compel them to act against their professional judgement.

Is misuse of information simply abnormal use?

The boundary between use and misuse often hinges on questions of power, norms and intent. While deviations from ordinary practices are frequently viewed negatively, not all forms of control or unconventional practices are inherently harmful. For instance, patient empowerment involves exercising control and ownership over one's healthcare information, which is generally seen as positive. On the other hand, what happens when systems or individuals define normal use too narrowly? Rather than focusing solely on norms, the concept of misuse could instead address how systems function. Misuse does not necessarily have to involve illegal acts. It can arise from unmet needs or systemic misalignment.

From an ethical perspective, questions about the clinician's role regarding information misuse come into play. Is it, drawing on the example in the study, ethical for the clinician to intentionally provoke a patient with information in their medical record to initiate a response, or is this, in fact, information misuse? The informant in the study claiming that the patients *can't handle* their

information also leaves questions concerning what proper handling of one's information even means. Handling information is, at its core, a subjective process. Similarly, patients may use information to exert control over their care in ways that clinicians view as unhelpful or even harmful, but where the patients believe it to be the other way around. This dynamic raises broader questions about how information use – whether by patients or clinicians – can be framed as misuse depending on the intent, outcomes and context.

Vulnerable information

In psychiatric care, information carries a unique weight compared to other medical fields. Open record access, while empowering patients, may paradoxically harm both patients and clinicians by undermining trust and impeding the use of medical records as effective working tools, making them a target for possible information misuse. One could argue that the accessibility of digital medical records exacerbates the issue of possible information misuse, the prior administrative effort for patients to access them acting as a barrier to frequent access. Today, the digitalisation of records has made them readily accessible, often just a click away on smartphones – devices nearly ubiquitous in modern society among both children and adults. While this ease of access supports patient autonomy, it also amplifies the risks of harmful information misuse, particularly for those with psychiatric vulnerabilities.

Conclusion

Drawing on examples from the healthcare domain, this paper problematises the concept of information misuse – traditionally defined as unauthorised or improper use for personal gain – to include what could be seen as a form of authorised misuse. This includes instances where patients, exercising their legitimate access to medical records, use this information in ways that challenge clinical norms or therapeutic goals. In psychiatric care, such behaviours highlight a tension between patient empowerment and clinical judgement. For instance, psychiatric patients may use their records to control their health journeys in ways they believe are beneficial, even if these actions undermine proper care. Such scenarios are not driven by malicious intent but rather by the distorted perception of what will aid them – a perception shaped by their psychiatric illnesses and specific circumstances.

The findings illustrate practical and theoretical challenges tied to what can be understood as information misuse and its implications in contexts with a direct impact on people's health and wellbeing as with open record access in healthcare. While transparency aims to empower patients and foster trust, it can paradoxically hinder care, strain clinician-patient relationships and complicate recovery. Clinicians also face risks associated with potential information misuse, including harassment due to the accessibility of their personal information.

Additionally, clinicians may ethically be argued to misuse their documentation themselves when using it as a tool to provoke reactions from patients. These findings contribute to a broader discourse on the spectrum of information practices. Misuse, rather than being a binary concept, reflects clashing norms and interpretations. Information practices are context-dependent, where actions seen as resourceful by one group may be viewed as misuse by another (Savolainen, 2007). Similarly, Pasquetto et al. (2024) highlight the complexity of defining data misuse, noting that what one community sees as problematic may be considered best practice in another. These perspectives underscore that misuse is not a binary concept but a reflection of clashing norms, ideals and practices within specific contexts. In healthcare, what constitutes misuse is often determined by context: for example, a pregnant patient seeking to question and control their care through access to medical records is unlikely to be labelled as misusing information; however, a self-harming patient leveraging similar access to resist therapeutic interventions might be seen as crossing into misuse. Such examples highlight the need to evaluate information practices based on intent, purpose and consequences rather than rigid norms.

In psychiatric care, where information carries heightened vulnerabilities, digitalisation has amplified both the opportunities for empowerment and the risks of misuse. The study's findings underscore the need for documentation systems that balance accessibility with safeguards for all stakeholders, in the case of healthcare, supporting both clinicians and patients without undermining care or trust.

By viewing information misuse as a continuum shaped by context, intent and outcomes, we move towards a more nuanced understanding better suited to navigating the ethical and practical challenges of information use in complex environments such as healthcare.

Ultimately, this study reframes information misuse as not merely improper use but as information behaviours that deviate from normative expectations, driven by complex personal, contextual and systemic factors. Perhaps, at its core, information misuse might best be understood as information used in ways that cross established boundaries of what constitutes acceptable or ordinary use, ranging from deliberate exploitation to behaviours driven by misunderstanding or illness.

Acknowledgements

The author expresses her sincere appreciation to her informants for their time and dedication to this research. She also wishes to thank her supervising professor, Isto Huvila, for his support and guidance in developing this paper. Furthermore, she extends her gratitude to the Medical Humanities Graduate Programme, particularly for the philosophical discussions with her closest peer, doctoral student Kristina Humphreys. Finally, the author is grateful to the editors and anonymous reviewers for their insightful and encouraging feedback.

About the author

Camilla Lyckblad is a doctoral student at the Department of Archives, Libraries, and Museums at Uppsala University. Her research interests include vulnerable information, secrecy, medical ethics and moral philosophy. She can be contacted at camilla.lyckblad@abm.uu.se

References

- Bärkås, A. (2024). Patients' access to their mental health records: understanding policy, access, and patient experiences. Doctoral Dissertation, Uppsala University. <https://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-522720>
- Blease, C., Torous, J., Dong, Z., Davidge, G., DesRoches, C., Kharko, A., Turner, A., Jones, R., Hägglund, M., & McMillan, B. (2023). Patient online record access in English primary care: qualitative survey study of general practitioners' views. *Journal of Medical Internet Research*, 25, e43496–e43496. <https://doi.org/10.2196/43496>
- Braun, V. (with Clarke, V.). (2022). *Thematic analysis: a practical guide*. SAGE.
- Caputo, D. D., Stephens, G., Stephenson, B., Cormier, M., & Kim, M. (2008). An empirical approach to identify information misuse by insiders (extended abstract). In R. Lippmann, E. Kirda, & A. Trachtenberg (Eds.), *Recent advances in intrusion detection* (Vol. 5230, pp. 402–403). Springer. https://doi.org/10.1007/978-3-540-87403-4_27
- Chen, A. T. (2015). Information use and illness representations: understanding their connection in illness coping. *Journal of the Association for Information Science and Technology*, 66(2), 340–353. <https://doi.org/10.1002/asi.23173>

- de Lusignan, S., Mold, F., Sheikh, A., Majeed, A., Wyatt, J. C., Quinn, T., Cavill, M., Gronlund, T. A., Franco, C., Chauhan, U., Blakey, H., Kataria, N., Barker, F., Ellis, B., Koczan, P., Arvanitis, T. N., McCarthy, M., Jones, S., & Rafi, I. (2014). Patients' online access to their electronic health records and linked online services: a systematic interpretative review. *BMJ Open*, 4(9), e006021–e006021. PubMed. <https://doi.org/10.1136/bmjopen-2014-006021>
- Denneson, L. M., Cromer, R., Williams, H. B., Pisciotto, M., & Dobscha, S. K. (2017). A qualitative analysis of how online access to mental health notes is changing clinician perceptions of power and the therapeutic relationship. *Journal of Medical Internet Research*, 19(6), e6915. <https://doi.org/10.2196/jmir.6915>
- Huvila, I. (2018). Alternatives to being information literate. In S. Kurbanoglu, J. Boustany, S. Špiranec, E. Grassian, D. Mizrahi, & L. Roy (Eds.), *Information literacy in the workplace* (Vol. 810, pp. 813–821). Springer International Publishing. https://doi.org/10.1007/978-3-319-74334-9_82
- Huvila, I. (2022). Making and taking information. *Journal of the Association for Information Science and Technology*, 73(4), 528–541. <https://doi.org/10.1002/asi.24599>
- Ingold, T. (2017). On human correspondence. *Journal of the Royal Anthropological Institute*, 23(1), 9–27. <https://doi.org/10.1111/1467-9655.12541>
- Jayasundra, C. C. (2004). Ethical issues surrounding the use of information in health care. *Malaysian Journal of Library and Information Science*, 9(1), Article 1. <https://borneojournal.um.edu.my/index.php/MJLIS/article/view/8400> (Archived by the Internet Archive at <https://web.archive.org/web/20250327144057/https://borneojournal.um.edu.my/index.php/MJLIS/article/view/8400>)
- Kari, J. (2010). Diversity in the conceptions of information use. *Information Research*, 15(3), 15–3. <https://informationr.net/ir/15-3/colis7/colis709.html> (Archived by the Internet Archive at <https://web.archive.org/web/20250327143343/https://informationr.net/ir/15-3/colis7/colis709.html>)
- Karlova, N., & Fisher, K. (2013). A social diffusion model of misinformation and disinformation for understanding human information behaviour. *Information Research* <https://www.semanticscholar.org/paper/A-social-diffusion-model-of-misinformation-and-for-Karlova-Fisher/9186ccfb693e2a1e440390f9721562e310199903> (Archived by the Internet Archive at [/web/20250327142610/https://www.informationr.net/ir/18-1/paper573.html](https://web/20250327142610/https://www.informationr.net/ir/18-1/paper573.html))
- Kujala, S., Hörhammer, I., Väyrynen, A., Holmroos, M., Nättiäho-Rönholm, M., Häggglund, M., & Johansen, M. A. (2022). Patients' experiences of web-based access to electronic health records in Finland: cross-sectional Survey. *Journal of Medical Internet Research*, 24(6), e37438. <https://doi.org/10.2196/37438>
- Mamra, A., Sibghatullah, A. S., Ananta, G. P., Alazzam, M. B., Ahmed, Y. H., & Doheir, M. (2017). Theories and factors applied in investigating the user acceptance towards personal health records: review study. *International Journal of Healthcare Management*, 10(2), 89–96. <https://doi.org/10.1080/20479700.2017.1289439>
- Moll, J., Rexhepi, H., Cajander, Å., Grünloh, C., Huvila, I., Häggglund, M., Myreteg, G., Scandurra, I., & Åhlfeldt, R.-M. (2018). Patients' experiences of accessing their electronic health records: National Patient Survey in Sweden. *Journal of Medical Internet Research*, 20(11), e278. <https://doi.org/10.2196/jmir.9492>

- Neves, A. L., Freise, L., Laranjo, L., Carter, A. W., Darzi, A., & Mayer, E. (2020). Impact of providing patients access to electronic health records on quality and safety of care: a systematic review and meta-analysis. *BMJ Quality & Safety*, 29(12), 1019–1032. PubMed. <https://doi.org/10.1136/bmjqs-2019-010581>
- Nguyen, B., & Simkin, L. (2017). Misuse of information and privacy issues: understanding the drivers for perceptions of unfairness. *The Bottom Line*, 30(2), 132–150. <https://doi.org/10.1108/BL-04-2017-0007>
- Pasquetto, I. V., Thomer, A., Acker, A., Chtena, N., & Desai, M. (2024). What does it mean to ‘misuse’ research data? *Proceedings of the Association for Information Science and Technology*, 61(1), 812–817. <https://doi.org/10.1002/prs2.1108>
- Petersson, L., & Erlingsdóttir, G. (2018). Open notes in Swedish psychiatric care (Part 2): survey among psychiatric care professionals. *JMIR Mental Health*, 5(2), e10521. <https://doi.org/10.2196/10521>
- Pisciotta, M., Denneson, L. M., Williams, H. B., Woods, S., Tuepker, A., & Dobscha, S. K. (2019). Providing mental health care in the context of online mental health notes: advice from patients and mental health clinicians. *Journal of Mental Health*, 28(1), 64–70. <https://doi.org/10.1080/09638237.2018.1521924>
- Pool, J., Akhlaghpour, S., & Burton-Jones, A. (2024). Unpacking the complexities of health record misuse: insights from Australian health services. *Information Technology & People*. <https://doi.org/10.1108/ITP-12-2022-0931>
- Savolainen, R. (2007). Information behavior and information practice: reviewing the ‘umbrella concepts’ of information-seeking studies. *The Library Quarterly*, 77(2), 109–132. <https://doi.org/10.1086/517840>
- Savolainen, R. (2009). Information use and information processing: comparison of conceptualizations. *Journal of Documentation*, 65(2), 187–207. <https://www.emerald.com/insight/content/doi/10.1108/00220410910937570/full/html>
- Savolainen, R. (2016). Elaborating the conceptual space of information-seeking phenomena. *Information Research: An International Electronic Journal*, 21(3), n3. <https://eric.ed.gov/?id=EJ1114149> (Archived by the Internet Archive at <https://web.archive.org/web/20250327141617/https://eric.ed.gov/?id=EJ1114149>)
- Sinha, V., & Randall, B. (2022). A theoretical framework for study of information behavior by opportunistic insiders. *Federation of Business Discipline Journal*, 13(3–11), 8. <https://doi.org/10.12794/metadc2137557>
- Smith, M. F. (1998). Privacy, confidentiality and safety of healthcare information systems: better information is needed. *Health Informatics Journal*, 4(3–4), 124–127. <https://doi.org/10.1177/146045829800400302>
- Tapuria, A., Porat, T., Kalra, D., Dsouza, G., Xiaohui, S., & Curcin, V. (2021). Impact of patient access to their electronic health record: systematic review. *Informatics for Health and Social Care*, 46(2), 194–206. <https://doi-org.ezproxy.its.uu.se/10.1080/17538157.2021.1879810>
- Wang, B., Kristiansen, E., Fagerlund, A. J., Zanaboni, P., Hägglund, M., Bärkås, A., Kujala, S., Cajander, Å., Blease, C., Kharko, A., Huvila, I., Kane, B., & Johansen, M. A. (2023). Users’ experiences with online access to electronic health records in mental and somatic health care: cross-sectional study. *Journal of Medical Internet Research*, 25(1), e47840. <https://doi.org/10.2196/47840>

- Wernström, M. (2023, June 5). Sylf vill anonymisera läkare i journal. *Dagens Medicin*. <https://www.dagensmedicin.se/arbetsliv/arbetsmiljo/sylf-vill-anonymisera-lakare-i-journal/> (Archived by the Internet Archive at <https://web.archive.org/web/20250327135214/https://www.dagensmedicin.se/arbetsliv/arbetsmiljo/sylf-vill-anonymisera-lakare-i-journal/>)
- Zanaboni, P., Kristiansen, E., Lintvedt, O., Wynn, R., Johansen, M. A., Sørensen, T., & Fagerlund, A. J. (2022). Impact on patient-provider relationship and documentation practices when mental health patients access their electronic health records online: a qualitative study among health professionals in an outpatient setting. *BMC Psychiatry*, 22(1), 508. <https://doi.org/10.1186/s12888-022-04123-7>

© [CC-BY-NC 4.0](#) The Author(s). For more information, see our [Open Access Policy](#).