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Evaluating the Contextual Integrity of Australia's My Health Record

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Abstract. My Health Record (MyHR) is Australia's national personally-controlled electronic health record. Initially established in 2012, it moved from an opt-in to an opt-out system in 2018. This paper considers the privacy aspects of MyHR shared health summary. Drawing on Nissenbaum's theory of privacy as contextual integrity, we argue that the shift in the event-specific nature of information sharing leads to MyHR breaching contextual integrity. As per Nissenbaum's decision heuristic for contextual integrity, we evaluate this breach through a reflection on the changing nature of health care, including patient empowerment, and the greater complexity of care. It is evident that more needs to be known about the benefits of shared health summaries, as well as the actual use of MyHR by clinicians and patients. Though we focus on MyHR, this evaluation has broader applicability to other national electronic health records and electronic shared health summaries.

Keywords. Medical Records, Online Systems, Privacy, Ethics

1. Introduction

In Australia, My Health Record (MyHR) is a nationally established electronic health record that contains, among other things, a shareable summary of an individual's health information (www.myhealthrecord.gov.au). The transition of the MyHR system from opt-in to opt-out has fueled public concerns about privacy. To understand some of the privacy concerns we draw on the theory of Contextual Integrity. Contextual Integrity views privacy as the appropriate flow of information, which stems from the information norms in a specific context [1]. This contrasts with many definitions of privacy that are concerned with the control of information about oneself [1]. Nissenbaum [2] has proposed a decision heuristic to evaluate whether a new technology breaches contextual integrity, and further evaluation to see if this breach is warranted through a consideration of the moral and political implications of the new technology, as well as the values, goals and ends of the context. MyHR shared health summary which shifts the traditional 'push' method of information sharing to a 'pull' method of information sharing [3] may breach contextual integrity. One may question whether this breach of contextual integrity is justified by the changing nature of health care, as it evolves from a sole clinician model to a shared care participatory model.

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2. My Health Record

At the core of MyHR is a shared health summary (SHS); a summary of a person's health information, including critical information such as medical conditions, allergies and medications [4]. A patient's SHS is created by their regular provider; this may be a doctor, nurse or Aboriginal health worker [4]. Clinicians who are not the patient's regular provider (e.g. a doctor at an after-hours clinic) can upload an event summary detailing information that may be relevant for their regular clinician to know [4]. By 2022 the Australian Digital Health Agency plans for all health professionals to be able to contribute to and use MyHR [5]. Although clinicians are recommended to consult with patient's about what information is uploaded to MyHR, they are not legally bound to do this [6]. MyHR is the first Australia-wide example of a shared record that is set-up to allow a health care provider to view information about a patient that was created by other primary or tertiary care providers. Currently, the main users of MyHR are general practitioners (GPs) who access it through their practice based proprietary electronic patient record systems [7]. Unlike many international examples, MyHR is a way to exchange a summary record rather a way to exchange a full health record. The only comparable example would be the UK's National Health Service summary care record. Patients can access and view any documents uploaded to their own MyHR – and can upload some information themselves - through a national government portal (https://my.gov.au). Patients can also apply a number of privacy controls; however, these are not activated by default [8]. We are specifically interested in the privacy aspects of the SHS component of MyHR, as this is new in the context of primary health care [9].

3. Contextual Integrity

Contextual Integrity is a theory of privacy that views privacy as the appropriate flow of information, where what is appropriate stems from context specific information norms [2]. Privacy as contextual integrity shifts the focus of privacy from control over information to control over the flow of information that is appropriate to the context specific information norms [1]. Information norms that guide appropriate information flow can be mapped out using five parameters [2]. These parameters are the sender, receiver, and subject of the information, the type of information being shared and the constraints on information sharing, known as transmission principles. Transmission principles include constraints such as the need for consent before information is shared [1]. If any parameter is changed with the introduction of new technology, it is considered a breach of contextual information norms, and thus contextual integrity [2].

4. Method

The method for evaluating a potential breach of contextual integrity is outlined by Nissenbaum [2] as a nine-step decision heuristic. This heuristic first describes the new practice and the current context using the Contextual Integrity parameters. Information norms are determined, and any departures from these as a result of the new technology are identified. An initial assessment as to whether the technology breaches contextual integrity is made. It is acknowledged that contextual integrity can be conservative and that norms can change [1, 2]. Thus, if the new technology breaches contextual integrity, it is recommended that the moral and political implications of new technology be considered, as well as whether it aligns with the goals, values and ends of the context [2]. The decision heuristic and its application to MyHR SHS is outlined below.

5. Results

5.1. Describe the Practice in Terms of Information Flow

The MyHR SHS envisages clinicians, mainly GPs, uploading a summary of their patient's information to a national electronic health record that other treating clinicians and the patient themselves can access. When a person attends a GP consultation, at the end of that consultation, their GP will upload a SHS - unless the patient specifically says that they do not want information uploaded. GPs are encouraged to discuss with each patient the information they are uploading to that person's MyHR.

5.2. Identify Prevailing Context

Hitherto, outside of referral and discharge letters written for particular purposes and exchanged by hand, mail or fax, clinicians have not provided a summary of information about a patient that other clinicians can access without notice, that is, without specific contact between the clinicians about the care of that patient [9]. Information exchange is usually done on an 'as required' basis, such as someone visiting their GP in need of a referral to a specialist. In such a case, only the most pertinent health information would be summarised in this exchange, but not a summary of the patient's full record.

5.3. Identify Information Actors

GPs act as gatekeepers in the Australian health care system, with access to specialist care requiring a referral from a GP [10]. Thus, in this context GPs in many cases act as the senders of information. Patients who visit a GP with a health problem, or for routine health care, are the main subjects in this context. Where the complexity begins is in considering the recipient, as there are a number of potential recipients of information from the GP. This could include a range of allied health professionals, medical specialists, or diagnostic services that provide tests such as x-rays or blood tests [10]. The type of recipient (i.e. where the patient needs to go next) will determine the type of information the GP needs to send.

5.4. Identify Transmission Principles

Currently, clinicians are guided both by confidentiality and acting in the patient's best interests [11, 12]. Under Australian privacy law, clinicians can share relevant information regarding a person's health with another treating clinician without that person's consent [13]. Patients tend to have limited knowledge of what information is shared between clinicians and how it is shared, though they appear to trust that clinicians will do what is in their best interest [14, 15].

5.5. Locate Applicable Entrenched Information Norms and Identify Significant Points of Difference

Current information norms are steeped in the trust placed in the clinician-patient relationship, and the values of patient benefit and confidentiality that clinicians balance when sharing information [11, 12]. Because of this, clinicians make decisions based on what they perceive as the patient's best interest when deciding to share information. Clinicians also record information differently depending on the recipient [16]. For example, clinician A pushes information to clinician B based on an event, such as the patient seeing clinician A for a health issue that requires further clinical involvement to address. Clinician A decides two things: what information is clinically relevant to clinician B, and what information should be shared with clinician B in the best interest of the patient. Thus, it could be said that the information is curated for the needs of the event (e.g. the patient's visit to clinician A), and the needs of the receiver (clinician B).

MyHR SHS is a new information practice. This type of record has been described as a shift from a 'push' method (a referral or discharge letter) to a 'pull' method, where a clinician can download information about a patient from that person's MyHR [3]. This information may not be curated, and thus may not be pertinent to the clinician 'pulling' it from MyHR; it may not even be up-to-date regarding the current health of the patient. One anonymous submission to a parliamentary enquiry described MyHR as [17, p. 1] "a glorified dropbox." This is in contrast to something like a management and care plan, which is designed to be used in team-based care of a particular type (e.g. aged care, chronic disease, mental health) and to include information relevant to those providing care.

5.6. Initial Assessment

An initial assessment of MyHR SHS points to a breach of contextual integrity due to the shift from a 'push' method of information sharing to a 'pull' method of information sharing. This is a change from the current curated and event-based nature of information sharing.

5.7. Evaluation I - Moral and Political

MyHR has been claimed to empower the individual by giving them control over their health record [5]. This aligns with a shift towards greater participation by patients, and the democratising of health care through ownership of one's health information [18]. This is seen in the patient's ability to access MyHR and apply security controls, but also in the recommendation that clinicians collaborate with their patients when writing that person's SHS. However, the benefits of this shift are not guaranteed to be experienced equally by all people. People may be marginalised due to issues such as low literacy or limited communication options [19, 20].

5.8. Evaluation II – Values, Goals, and Ends

When we consider the values, goals, and ends of health care, we are faced with a challenge due to the shift towards more complex models of care in the community [12]. Health care traditionally involved seeing a GP who provided treatment or referral on to a specialist with a referral letter; in this context, two clinicians balanced confidentiality and the patient's best interest. The emergence of chronic and complex conditions has led to more collaborative care where several clinicians and services provide integrated aspects of care in parallel [21]. With this has come a shift in the importance of information sharing, and this has required new interpretations of the value of confidentiality [12, 21, 22]. Clinicians and patients may be willing for information to be shared more liberally if there is a benefit to a person's health [11, 15]. The trade-off between benefit to patient health and confidentiality when applied to MyHR is unclear, as we have little evidence to date about the benefits of the SHS. The SHS is supposed to improve the availability of "potentially lifesaving" information according to the Australian Digital Health Agency [5 p. 21]. However, there is a risk with summary records that this essential information will be lost because data are not curated [23].

5.9. Outcome

There is no definitive outcome from this evaluation of MyHR SHS, but it does raise issues for discussion in the shift to a more digital health system. There is a need to reflect on what confidentiality means in the age of complex and integrated care, and how this applies to an individual's electronic health record. Further, the benefit of promoting patient participation in care through their access to their MyHR needs to be considered within the context of power and privilege regarding who will be able to take up this opportunity to participate. Finally, the value of the SHS needs to be backed up with evidence.

6. Discussion and Conclusion

Initial assessment of MyHR SHS points to a breach in contextual integrity due to a shift from a 'push' to 'pull' method of information sharing. This disrupts the event-specific nature of current information sharing. Evaluating the contextual integrity of shared information in an electronic health record is complicated by the changing nature of health care. Team-based care requires greater sharing of information, which challenges traditional values related to confidentiality and privacy. In addition, clinicians' need for information to support individualised decision making is growing, and providing that information in an efficient and effective way is essential. If MyHR proves to have benefits to patients and clinicians, a breach of contextual integrity may be warranted. However, the evidence for summary records is still limited. There appears to be a risk that the promise of better care will be sunk by too much data with too little relevance at the point of care. New values related to patient empowerment pose opportunities for a shareable electronic health record that may justify breaches of contextual integrity. However, this rests on the assumption that patients have the resources to take control of their MyHR. Further evidence of MyHR SHS benefits, and of patients and clinicians actual use, is needed before we can conclusively determine whether MyHR breaches contextual integrity.

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