

Information Continuity in the Digital Age: Co-Developing the Socio-Technical Design Requirements for Integrated Electronic Health Records to Uphold Contextual Privacy

Timothy Kariotis, Brussels Privacy Hub Visiting Scholar

Information continuity, the collection and sharing of information, is becoming increasingly important in fragmented, siloed, and complex health systems. Information continuity is especially important for people with complex mental health conditions who may access several clinical and non-clinical services across the community, have limited capacity to convey their health information, and face trauma from having to retell their stories repeatedly. Electronic health records are one solution to the lack of information continuity between services, with integrated electronic health records (iEHRs) which are longitudinal and contributed to by all services, seen as the gold standard. There are several barriers to iEHRs, including funding, technology issues, and privacy concerns. Privacy and confidentiality concerns are especially pertinent due to the sensitive nature of information shared. Decisions regarding the sharing of information are underpinned by values and norms related to trust, confidentiality and perceptions of promoting health; these can be understood using the theory of contextual integrity. Contextual Integrity views privacy as the appropriate flow of information based on context specific information norms. Contextual integrity provides a lens to understand why an iEHR may pose privacy concerns through breaching information norms. We propose using the theory of contextual integrity, in combination with participatory design research methods to develop ideal norms for an iEHR, and the design principles to uphold these norms in mental health contexts.