

Consumer health informatics for people who use AAC: Views on eHealth records at home.

To date, there is little information in the literature to guide the provision of supports for people who use AAC to use personal electronic health (eHealth) records at home. Personal ehealth records are in digital form, accessible to the person, stored for ease of access and retrieval, for sharing with the person's multiple health providers. In this paper we will (a) outline the rationale for using eHealth records by providing an overview of relevant research on consumer health informatics, health literacy, and legal and ethical issues related to the use of personal eHealth records, and (b) present the findings of three studies aiming to investigate the barriers to and facilitators for personal eHealth record use by people who use AAC and their service providers. Implications for people who use AAC will be explored and discussed in relation to sociotechnical factors affecting participation in health technologies.

In 2014, we obtained ethical approval of the Human Research Ethics Committee at The University and the organisations assisting with recruitment, to conduct this research on use of the personal eHealth records with people who have communication disabilities associated with: cerebral palsy, aphasia following stroke, intellectual disability, and traumatic brain injury. The aim of the three integrated studies was to investigate people's views and experiences of personal eHealth records, so as to identify barriers and facilitators to using these and to inform future policy direction and future research. We based these studies on reviews of the literature on health information at home, in residential care settings for people with disabilities; legal and ethical issues relating to the use of personal eHealth records; and health literacy demands of these records. In this presentation an overview of the literature will be provided as a context to the studies presented, and the findings of the research will be discussed in relation to related consumer health informatics evidence base [1-3].

Study 1: This sociotechnical case study of a young adult with severe cerebral palsy who used AAC, involved observation of her interacting with her own health documents at home, and an examination of her storage and type of home health documents. She used a wheelchair for mobility and a speech-generating device to communicate with switch access control. Her health information was stored in multiple ways: as hard copy documents in an expandable file, and in the computer in a 'documents' folder and attached to emails. She required full assistance to access her health documents in the expandable file, but accessed the computer and Internet independently using assistive technologies, and could retrieve computer-based information independently. Her health information was not stored or organised systematically; there was some ad-hoc duplication between electronic and hard copy information; and there was no reference across sources to integrate elements of the information. This case study suggested that personal eHealth records could benefit people who use AAC, but that a range of supports may be needed to organise and prepare information for storage a systematic and integrated way [1] for improved retrieval and sharing across health providers.

Study 2: We surveyed 12 adults with diverse severe communication disabilities (after stroke, cerebral palsy, brain injury) about using eHealth records (9 by face-to-face interviews and three by online survey). All participants lacked confidence communicating with unfamiliar healthcare providers and considered that eHealth

records would help them by improved 'storing' and 'sharing' of health information that was important to them. As one said: "It is so tiring to continually explain my history and progress. Every meeting with a new health professional requires a lot of work for them to understand" (4). Further information is needed to determine whether the investment of time and effort by people who use AAC and their supporters in using eHealth records will see improved health information exchange when people with these disabilities meet with health professionals.

Study 3: We held five focus groups to discuss barriers to and facilitators for eHealth records by people with severe communication disabilities. Each focus group was 1 hour long and held at each participant's workplace. The groups were audiotaped and transcribed verbatim with identifying information removed, and analysed for content themes. Participants in our pilot study were care workers in supported accommodation ($n = 9$), allied health clinicians ($n = 5$), parents ($n = 2$), medical staff ($n = 2$), and nurses ($n = 6$). Overall, the focus group discussions reflected diverse views and major content themes of: (a) barriers and facilitators; (b) benefits and limitations; (c) ethics, consent, privacy, and accuracy; (d) roles of carers and direct support workers; (e) advocacy and self-advocacy; and (f) health literacy.

Conclusion

The results of our research shows that eHealth record use is not yet integrated into organisational policies for people with severe communication disabilities who use AAC. Key stakeholders, including people who use AAC and their service providers, are uncertain about how personal eHealth records would integrate, duplicate, overlap, or replace existing extensive documentation. While using personal eHealth records might benefit people who use AAC, there are many doubts, uncertainties and limitations put forward in the studies that both form and reflect barriers to the use of eHealth records by people who use AAC. It is not known whether use of personal eHealth records will replace the written information currently prepared for and provided to hospitals at admission. It is vital to match the time and effort 'cost' of using personal eHealth records with evidence of any benefits. Implications for people who use AAC and their families and service providers - particularly in relation to consumer health informatics and health literacy - will be presented and discussed, and directions for future research outlined.

- [1] A. Hordern, A. Georgiou, S. Whetton, & M. Prgomet, Consumer e-health: An overview of research evidence and implications for future policy. *Health Information Management Journal*, 40 (2011), 6-14.
- [2] S. Hill, *The Knowledgeable Patient: Communication and Participation in Health. A Cochrane Handbook*. Wiley-Blackwell: London, 2011.
- [3] J. Asha, et al., Some unintended consequences of information technology in health care: The nature of patient care information system-related errors. *Journ Amer Med Inform Assoc.*, 11 (2004) 104-112.

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