

Understanding What People with Epilepsy and Their Care-Partners Value about an Electronic Patient Portal

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Abstract : Introduction: Providing people with access to their own healthcare information and engaging them as co-authors of their health record can promote better transparency, trust, and inclusivity in the healthcare system. With the advent of electronic health records, there is a move towards involving patients as partners in their healthcare by providing them with access to their own health data via electronic patient portals (ePortal). For example, a recently developed ePortal to the Irish National Epilepsy Electronic Patient Record (EPR) provides access to summary medical records, tools for Patient Reported Outcomes (PROM), health goal-setting and preparation for clinical appointments. Aim: To determine what people with epilepsy (their families/carers) value about the Irish epilepsy ePortal. Methods: A socio-technical process was employed recruiting 30 families of people with epilepsy who also have an intellectual disability (ID). Family members who are a care partner of the person with epilepsy (PWE) were invited to co-design, develop and implement the ePortal. Family members engaged in usability and utility testing which involved a face to face meeting to learn about the ePortal, register for a user account and evaluate its structure and content. Family members were instructed to login to the portal on at least two separate occasions following the meeting and to complete a self-report evaluation tool during this time. The evaluation tool, based on a Usability Questionnaire (Lewis, 1993), consists of a short assessment of comfort using technology, instructions for using the ePortal and some tasks to complete. Tasks included validating summary record details, assessing ePortal ease of use, evaluation of information presented. Participants were asked for suggestions on how to improve the portal and make it more applicable to PWE who also have an ID. Results: Family members responded positively to the ePortal and valued the ability to share information between clinicians and care partners; use the ePortal as a passport between different healthcare settings (e.g., primary care to hospital). In the context of elderly parents of PWE, the ePortal is valued as a tool for supporting shared care between family members. Participants welcomed the facility to log lists of questions and goals to discuss with the clinician at the next clinical appointment as a means of improving quality of care. Participants also suggested further enhancements to the ePortal such as access to clinic letters which can provide an aide memoir in terms of the careplan agreed with the clinical team. For example, through the ePortal, people could see what investigations or therapies are scheduled. Conclusion: The Epilepsy Patient Portal is accessible via a range of devices such as smartphones and tablets. ePortals have the potential to help personalise care, improve patient involvement in clinical decision making, engage them as quality and safety partners, and help clinicians be more responsive to patient needs. Acknowledgement: The epilepsy ePortal project is part of PISCES, a Lighthouse Project funded by eHealth Ireland and HSE to help build an understanding of the benefits of eHealth technologies in the Irish Healthcare System.

Keywords : electronic patient portal, electronic patient record, epilepsy, intellectual disability, usability testing

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