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PISCES: LEARNING FROM PEOPLE WITH EPILEPSY AND THEIR CARE-PARTNERS ABOUT HOW AN ELECTRONIC PATIENT PORTAL CAN IMPROVE CLINICAL CARE

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Statement of the Problem: To learn from people with epilepsy and their care-partners (their families/carers) about how the Irish epilepsy ePortal can improve clinical care. 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.

Methodology & Theoretical Orientation: A socio-technical process was employed to co-design, develop and implement the epilepsy ePortal involving 30 families/care-partners of people with epilepsy who also have an intellectual disability (ID). Participants 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.

Conclusion & Significance: Family members/care-partners responded positively to the ePortal and indicated that it can help improve: information sharing between clinicians and care partners; create a passport between different healthcare settings (e.g. primary care to hospital). Elderly parents of person with epilepsy (PWE) valued the ePortal as a tool for facilitating shared care between family members. Clinical processes that may benefit from implementation of patient portals include: the care of PWE in the ID residential setting; young adults transitioning from paediatric to adult services; cross-sectoral integrated care (e.g. community, primary and hospital-based care); patient and care partner education. ePortals have the potential to promote personalization care by improving patient involvement in clinical decision making, engage them as quality and safety partners, and help clinicians be more responsive to patient needs.

Biography

Kevin Power is the Requirements Engineer and Implementation Manager for the Epilepsy Lighthouse Project (PISCES). The Pisces Lighthouse project is funded by e-Health Ireland and HSE to help build an understanding of the benefits of eHealth technologies in the Irish Healthcare System. He has his expertise in investigating requirements engineering and implementation processes in the Irish health care arena.

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