Power, Kevin 2020 Enabling patient and family-centred care with an Epilepsy Patient Portal.
. *International Journal of Integrated Care, 21(S1)*:A41, pp. 1-8, DOI: doi.org/10.5334/ijic.ICIC20310

## CONFERENCE ABSTRACT

# Enabling patient and family-centred care with an Epilepsy Patient Portal.

ICIC20 Virtual Conference – September 2020

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### *Introduction*

There is an international move towards involving patients as partners in care by allowing them access to their own health data and engaging them as co-authors of their medical record via electronic patient portals (ePortal). ePortal can be a catalyst for patient and family-centred care (PFCC) which aims to: establish co-production partnerships between patients, their carers and healthcare practitioners; empower people to take a more active role in their care; improve understanding of their illness, increase compliance with treatment; and adopt healthier lifestyles. However, factors associated with successful ePortal adoption are not fully understood.

### *Problem Statement*

To explore the role of an epilepsy ePortal in: developing more knowledgeable patients; engaging patients as safety partners; creating a passport of care and enhancing Epilepsy self-management.

### *Methods*

The Irish National Epilepsy ePortal, the foundation for this study, offers functionality for patients to view their epilepsy care summary record, access clinic letters, report progress with their treatment, set epilepsy care goals, and prepare for clinical encounters.

### *Results*

Fifty people with Epilepsy (PwE)/their care-partners together with 15 Healthcare Providers (HCP) are trialling this functionality in a stratified sample of clinical scenarios. Experience with the epilepsy ePortal is captured through surveys, focus groups, one-to-one interviews and ethnographic observations. The ePortal has been applied to mediate epilepsy telephone advice line (TAL); vagal nerve stimulator therapy; ketogenic diet treatment; out-patient clinics; and obstetric care.

### *Discussions*

The Epilepsy Patient Portal provides value for users in terms of integrated care with online access to health information, that is accessible when and where needed to facilitate enhanced self-management of a long term condition

### *Findings*

Findings suggest stakeholder readiness to adopt the ePortal: patients report feeling more in control, a better understanding of the primary-care specialist interface, improved health literacy. Healthcare providers see an opportunity to improve chronic disease management and collaborative care with the ePortal.

### *Conclusion*

This epilepsy ePortal project is consistent with current Irish health service reform (Slaintecare), eHealth and Integrated Care agendas. Patient portal technology has the potential to help move away from simply treating ill people to promoting and maintaining health and well-being.

### *Lessons Learned*

The technical aspects of building and co-designing a patient portal linked to the Epilepsy EPR are not complex. However, the information governance and data protection issues that this research project is dealing with provide important insights for the Irish Electronic Healthcare Record context.

### *Limitations*

Clinicians are already overburdened and fear increased workloads; the portal will not be a helpline or emergency service. The project team are working closely with clinicians and patients to manage expectations about what the patient portal will provide.

### *Suggestions for Future Research*

Future iterations of Epilepsy specific patient portals will focus on facilitating remote clinical appointments, offline access to Health Records, and the process of access to the patient portal for Healthcare Practitioners in different sites in Ireland and abroad.

Acknowledgement: Research funded by the Health Research Board (HRB) reference 2017-011, Health Service Executive (HSE) and Science Foundation Ireland (SFI).