

CONFERENCE ABSTRACT

A Patient Portal Providing Individualised Services and Care in Epilepsy (PISCES)

17th International Conference on Integrated Care, Dublin, 08-10 May 2017

Kevin Power¹, Mary Fitzsimons¹, Maire White¹, Gianpiero Cavalleri¹, Brendan Dunleavy², Richard Corbridge³, Colin Doherty⁴, Norman Delanty⁵, Mark McCormack¹

1: Royal College Of Surgeons, Ireland;

2: ERGO, Ireland;

3: HSE, Ireland;

4: Saint James's Hospital, Ireland;

5: Beaumont Hospital, Ireland

Introduction: The eHealth Strategy for Ireland (DOH, 2013) stresses the benefits of patient access to healthcare records as an enabler to support enhanced population wellbeing. For those with long term conditions, access to their healthcare records can: facilitate better informed clinical encounters; enable capture of patient reported outcome measures; provide an ability to influence and contribute to personalised health care plans; enhance awareness of treatment options and increase chances of medication compliance. Web-based electronic patient records (EPR) create an opportunity to provide patients with access to their own healthcare record to promote active self-management and improved patient-provider partnerships in care.

Aim: The aim of this project is to design, develop, implement and evaluate a patient portal to the National Epilepsy Electronic Patient Record (EPR) in Ireland.

Methods: A socio-technical process based on ethnographic analysis, interviews, focus groups, and joint design workshops was conducted to establish stakeholder's (those who receive and those who provide) needs and inform the design of the patient portal. This iterative co-design process created an understanding of human beings and the nature of their transactions with each other and their surroundings and led system design specifications. Using evolutionary prototyping, the system was fine-tuned by software engineers based on user feedback. The portal was formatively evaluated to assess its utility to different types of users.

Results: Based on the co-design approach, the Epilepsy Patient Portal provides: a view of the EPR Summary Record including seizure demographic information, semiology, medications and clinical investigations; a facility to capture patient reported outcomes measures (PROMS) including seizure severity; quality of life, and patient knowledge of epilepsy. Portal users indicated that a function for patients or their carers to validate aspects of their record would be beneficial. Clinicians identified an opportunity for the portal to support patient

preparation for clinical encounters. Patient portal users are based on three personas: clinician, person with epilepsy and parent/guardian/carer of a person with epilepsy, and residential carers. Depending on the type of user the patient portal responds with appropriate information.

Conclusion: 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.

Limitations: Clinicians are already overburdened; 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.

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.

Suggestions for future research: Future iterations of Epilepsy specific patient portals could 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.

Keywords: epilepsy; electronic patient record; patient portal; self-management; patient access to health care records
