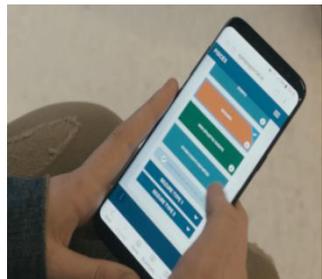**Epilepsy Lighthouse Project**

"it is very empowering to be able to read your own healthcare record"

PISCES
Newsletter

Autumn 2020

FEBRUARY 2020 WORKSHOP IN RCSI STEPHENS GREEN "A GREAT SUCCESS "

DATE 30/SEPT/2020

*We would like to say a big **Thank You** to everyone who has participated in the research thus far contributing to surveys, interviews, being observed at outpatient/virtual clinic, coming to focus groups & workshops. This important research would not be possible without your participation and continued support.*

In FutureNeuro, the SFI Research Centre for Chronic and Rare Neurological Diseases, hosted by RCSI, we are researching topics around eHealth and neurological conditions. eHealth is a term used to describe the use of information and communication technology (ICT) in the delivery of healthcare. Currently we are mainly researching eHealth and epilepsy. This research team continues the work of the Lighthouse Project 'Providing Individualised Services and Care for in Epilepsy' (PISCES).

The PiSCES (Providing Individualised Services and Care in Epilepsy) Epilepsy Patient Portal is integrated with the National Epilepsy Electronic Patient Record (EPR) and can be accessed by authorised and approved users anywhere there is an internet connection, using smartphone, tablet or laptop etc. Pisces provides access to a summary of key epilepsy care information held in the EPR; access to epilepsy clinic letters; tools for patient reported progress and outcomes; epilepsy care goal setting; and preparation for clinic visits.

Patient Portal Update

In our Health Research Board (HRB) funded project, we have been working to understand what people with epilepsy, carers, and healthcare practitioners value about the patient portal. We are trying to understand the reasons why people may or may not use a patient portal, how a patient portal can be used as part of the clinical services and looking at how the portal can help improve continuity of care. Over the past 18 months, we have been trialling the portal with a number of patient groups and in different clinical contexts. We have recruited 72 People with Epilepsy (PwE and/or their 18 care partners (family members, spouses, siblings) and 20 epilepsy doctors, nurses and allied health professional. For example, some people are using the patient portal to access their clinic letters following outpatient or telephone clinics. When a person with epilepsy attends a specialist epilepsy clinic – a letter is sent to their general practitioner outlining their care plan. Some participants are looking at how the portal can be used to monitor response to epilepsy treatments such as Vagal Nerve Stimulator or ketogenic diet;   or how it helps in remote or virtual care, which is of current interest in when we are trying to avoid face-to-face contact and maintain social distancing due to COVID19. Researcher are also examining how the portal can support outreach such as in the

context of obstetric care for women with epilepsy who are pregnant.

"It gives me a sense of ownership of my medical files"

February 21st 2020 Workshop in RCSI Stephens Green

The purpose of this workshop was to explore how the epilepsy patient portal can **help improve patient confidence in care,** provide **clearer information** to patients and their carers, and allow **patients to be genuine partners** with their clinical care providers. The role of the epilepsy ePortal in supporting improved **continuity of care** between the **community and hospital-based services** was also considered. In total 52 participants (PwE and their care partners, allied health professionals, healthcare admin management & IT personnel, community

"This is a really fantastic way for patients to feel more in control of their health and healthcare"

resource officers, patient advocate groups, researchers, software developers and representatives of other chronic condition services took part.

Six focus groups took place with participants debating the role of the epilepsy portal in: delivering holistic patient care, engaging the patient as an expert in their own care, recognizing patient autonomy and shared clinical decision-making between clinician and patient

Next Steps for Patient Portal

In the coming months, we are investigating how the patient portal moves from a research phase into clinical operation. Among other things, we will explore how the portal can facilitate monitoring of quality of life, seizure severity and healthcare goal setting for a new clinic being set up for patients with difficult to control epilepsy who may benefit from surgery. Following is an overview of other eHealth projects.

Ethics of eHealth

eHealth or digital health are terms used to describe any way in which ICT is used to deliver healthcare. Electronic patient records, electronic patient portals, and smartwatches are examples of eHealth technology. The decisions we make when designing or using eHealth technology have ethical implications. For example, the development of patient portals to an electronic patient record can empower patients to help them make more informed decisions about their health and healthcare. This is an ethical opportunity and something worthwhile to achieve. At the same time, digital healthcare information can be used for the wrong reasons. This is an ethical challenge.

We conduct research into the ethical opportunities and challenges resulting from eHealth. These opportunities and challenges can arise at every stage of the technology from its development to its use. Our research informs the people making decisions around the design, development, implementation and use of eHealth. We documented how researchers can use health data in a safe, responsible and secure manner. Another project identified the opportunities and challenges mentioned most often in the literature about the ethics of electronic patient records.

Predictive Data Analytics

The current COVID-19 pandemic has highlighted the growing importance of utilising and analysing collections of electronic health data to understand the health characteristics and statistical trends inherent in patient populations. The Epilepsy EPR is no exception in this regard and gives us valuable data that can be aggregated and analysed to understand our own Epilepsy population in greater detail. Work has been on-going to further develop capacity to aggregate our Epilepsy EPR data for the purposes of both operational analytics (analytics that supports service delivery) and research analytics (analytics that answers specific clinical research questions of interest). The EPIDIVE analytics project is on-going with a view to using analytics to understand the clinical factors that are statistically associated with driving response or non-response to anti-epileptic drug treatments. The PowerBI business intelligence solution has been used to understand how epilepsy services have been impacted by the current COVID pandemic.

Co-Designing eHealth

'From the Outside-In: Co-Designing Tools to Promote Independence and Wellbeing in Epilepsy Care' is a research project being carried out by Prof Colin Doherty, Consultant Neurologist at St James's Hospital and Jack Banks, PhD student at Trinity College Dublin. This study is an exciting exploration into the way people with epilepsy, their carers and healthcare providers feel about using technology or 'eHealth' to manage epilepsy. eHealth supports which currently exist for people with epilepsy include seizure diary apps, medication reminder alerts and wearable seizure detection systems. People with epilepsy and their carers require great self-management skills, as they spend the vast majority of their time living the condition outside of hospital settings. In our increasingly technology based society, the attitudes and behaviours of people with epilepsy towards eHealth have not been widely explored.

Acknowledgments

CONTACT

We value your feedback. Please send your comments or if you require any clarification to
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