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CONFERENCE ABSTRACT

'From the Outside-In' - Co-Designing Tools to Promote Independence and Wellbeing in Epilepsy Care

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Epilepsy is a chronic neurological disease characterised by recurrent seizures. More than 50 . million people worldwide have epilepsy, and almost 80% of this population live in low and middle income countries. In Ireland, it is believed that up to 37,000 people suffer from epilepsy and this number may be increasing.

The way in which people with epilepsy (PWE) receive their care has not changed significantly in more than one hundred years. Typically, once a patient has a diagnosis of epilepsy, the follow up will be in person at predetermined intervals – typically three or more months apart. During these appointments, clinicians educate and counsel patients on their epilepsy. Yet, people with epilepsy spend almost all of their time outside of their clinician's office. Providers cannot support and monitor treatment adherence, mood or enhance their patients' healthful behaviours and quality of life on a daily basis.

The chronic nature of epilepsy means that self-management is of utmost importance to maintaining wellbeing. Self-management allows patients to address these gaps in care and ultimately transfer the 'ownership' of their care from provider to patient.

eHealth is an umbrella term incorporating any area that combines any area that combines healthcare and technology to improve efficiencies and reduce costs. Across many chronic diseases, technological supports have been developed to support patients and their carers to effectively self-manage their conditions remotely. With regard to epilepsy however, the uptake of eHealth supports developed for patients and carers has not been widespread.

'From the Outside-In' is a qualitative research study involving People with Epilepsy (PWE), their carers and families. This project seeks to understand from each of these populations perspectives what supports they feel would help them most self-manage epilepsy, and if eHealth has a role to play for them.

Three qualitative methodologies are being utilised; ethnography, semi-structured interviews and focus groups. Ethnographic observations of participants in their day to day lives allows self-management behaviour to observed in situ. Semi-structured interviews allow participants to air their views on living with epilepsy and provide the chance to tell their patient journey uninterrupted. Focus groups allow PWE, carers and family members collaborate to create a vision of what their epilepsy care will look like in the future,

The ultimate goal of this study is to inform the optimum conditions for PWE, their carers and families to self-manage epilepsy. This research is providing a platform for research participants to shape they way that they receive epilepsy care. Patients can uniquely voice their needs and wants in relation to the eHealth supports they want developed. This will create truly patient-centred epilepsy care for the future.