PISCES
Newsletter

# Easter
2017

39 FAMILIES RECRUITED TO THE PISCES EPILEPSY LIGHTOUSE PROJECT

7/04/2017

78%

Of Adult Lighthouse Patients Recruited

8 Families

Have Participated in Patient Portal co-design Focus groups

16 Families

Recruited from CORK CUH

23 Families

Recruited in Dublin

Providing Individualised Services and Care in Epilepsy (PISCES) is a nationwide project demonstrating how eHealth technologies can improve quality and safety of care for people with epilepsy.
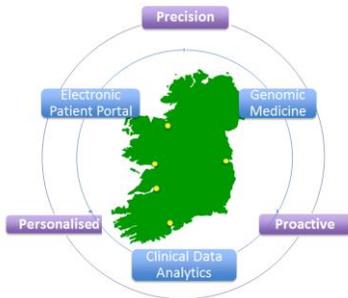
The project is progressing precision, proactive and personalised (3P) medicine by using the national epilepsy electronic patient record (EPR) to embed genomics, patient reported outcomes and analytics into the clinical pathway (*www.ehealthireland.ie/Lighthouse-Projects/*).

Epilepsy EPR and Paediatric

Meetings have taken place at both the Our Lady's Children's Hospital and Temple Street Children's University Hospital with hospital management, IT personnel and clinical teams to plan implementation of the epilepsy electronic patient record (EPR) at those sites which we anticipate will take place in first half of 2017.

Participant Recruitment

Sixty families have been screened for inclusion in PISCES with 39 lighthouse patients now recruited. Families are enthusiastically participating in co-design and implementation of the electronic patient portal. 35 families have provided samples for genetic sequencing and others are scheduled in the coming weeks. During January, PISCES team members spent time in Cork recruiting families from that region recruiting 13 families and have since recruited 3 additional Cork families. Two families have been recruited form Daughters of Charity Outreach Centres with a further 2 planned Saint James Hospital Intellectual disability outreach services.

Adult Patient Recruitment

	Beaumont	Saint James Hospital	Cork UH
Recruited	11	12	16
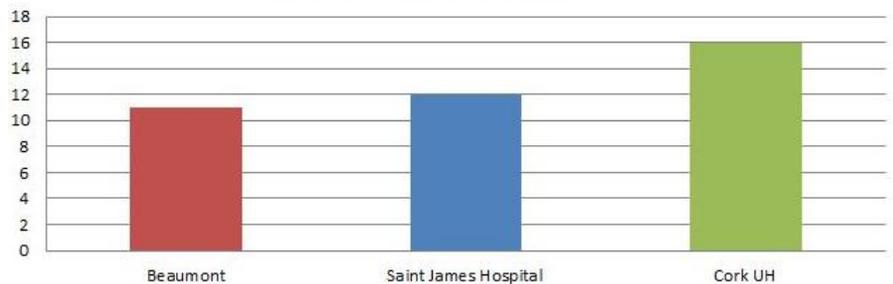
Patient Portal

The patient portal functionality is being evaluated by selected families on a trial basis. For selected families, the portal provides a view of their family member's summary Epilepsy Patient Record and a chance to feedback patient reported outcome measures. ERGO as technology partner, in conjunction with Microsoft Ireland and the HSE have now built the server infrastructure to host the patient Portal.
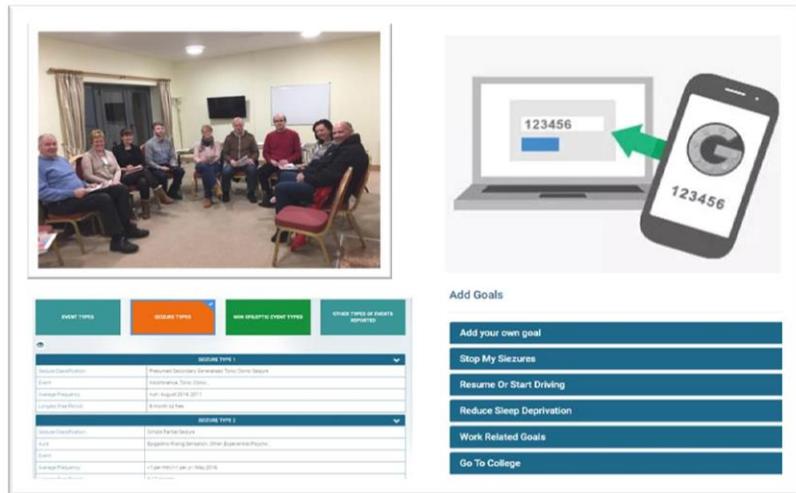
Parent Focus Group Feedback 26th Jan CUH

- A second focus group meeting was held with members of the research team and parents of patients with an intellectual disability, in Bru Columbanus, Co. Cork.
- 3 mothers, 4 fathers and 1 sister of People with Epilepsy and an Intellectual Disability participated
- Questions/Areas of concern which were dealt with include: data security, remote and offline access to health records, seizure tracking, use of videos to identify seizures, and personalisation of the portal depending on the needs of the patient.

Clinical and Residential Care

Co-design meetings have taken place with SJH clinicians to assess the patient portal. The patient Portal will be demonstrated at a Beaumont Hospital Epilepsy Team meeting on 27th April to investigate the impact of use of the patient portal on a clinical appointment. On 5th April lighthouse researchers conducted a site visit to the Daughters of Charity, St Vincent's centre Navan road to investigate facilities for connectivity, wifi, and to engage with residential carers that will use the patient portal.

Data Security

1. The Portal can be accessed by a carer, a clinician or an administrator user.
2. Users can see who was the last clinician to view their record.
3. Two-factor authentication is required to access the portal, this is the gold standard for data security. To login the user must enter a username and password and enter a unique code provided by google authenticator.
4. The Patent Portal is hosted in a Microsoft Azure Data Centre in the Republic of Ireland. This centre conforms to Microsoft's highest data centre security standards.
5. All EPR clinical data stored in the portal is strongly encrypted.

Genomics Module

ERGO software engineers have, in collaboration with a multidisciplinary team of genetic scientists and neurologists designed and developed an enhancement to the national epilepsy EPR. This enhancement facilitates the discussion and interpretation of results of genomic testing, in the context of patient care. An iteration of this functionality to support a multi-disciplinary (MDT) genetics meeting is currently in use by members of the Lighthouse team at Beaumont Hospital. Members of the PISCES research group will be disseminating available findings at the Irish Neurological Association Meeting and the International Conference on Integrated Care in May.

Reporting and Data Analytics

The first phase of the Microsoft PowerBI analytics/business intelligence tool has now been implemented for the Epilepsy Service. This is currently in the evaluation and piloting phase with a number of clinicians. ERGO will host workshops with a wider team of users over the summer to highlight how the tool works and get feedback on additonal unmet reporting needs. This solution allows the secure and efficient interrogation of data within the Epilepsy EPR.

From an operational view it will allow a view of what level and type of clinical encounters are being provided at any point in time and by what type of clinician. This can help for service planning purposes. From a research and population health perspective, it now allows a way to readily interrogate the rich EPR data across all clinical modules to gain insights into the population of people with epilepsy in Ireland.

Where do the patients served by the epilepsy service in Limerick Univ. Hosp. in the past 12 months live?