Providing Individualised Services and Care for in Epilepsy (PISCES) is one of three Lighthouse Projects for eHealth Ireland and the HSE (www.ehealthireland.ie/Lighthouse-Projects). These Lighthouse projects are helping to build an understanding of the benefits of electronic health records (EHR) in the Irish healthcare system. PISCES is demonstrating how eHealth technologies can improve quality and safety of care for people with epilepsy by supporting more: precise diagnosis and treatment (genomic medicine); proactive services (electronic patient portal to own health record); and personalised.

**Update on Research Ethics Committee Reviews**
Ethical Approval for the Pisces Project has been granted by Research Ethics Committees (REC) at: Our Lady’s Children's Hospital Crumlin, Beaumont Hospital, St James’s Hospital, Galway University Hospital, Cork University Hospital and the Daughters of Charity Clonsilla. The project team is currently addressing feedback received following review by the REC at Temple Street Children’s University Hospital.

**Implementation of Epilepsy EPR at Paediatric Sites**
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 early in 2016.

**Participant Recruitment**
Ten patients and their parents (7 from Beaumont Hospital & 3 from Saint James’s Hospital) have been recruited, consented and sequenced for genetic testing. Three more patients are planned to be recruited by Christmas 2016. Seven potential patients have been identified in Cork, with recruitment at this site beginning in January. Engagement with these families through interviews and focus groups regarding their understanding of the epilepsy EPR and the potential quality and safety benefits of an patient portal to the system have commenced.

**eHealth Innovation Showcase Nov 22nd / 23rd**
The patient portal prototype has been showcased as a demonstrator for patient portal access to EHR at the eHealth Innovation Showcase held in the Science Gallery Trinity College. This provided an opportunity for healthcare professionals and the public to interact, see and feel the PISCES patient portal. The event was well attended by HSE officials, Government ministers, industry professionals as well as school children and academics.
Patient Portal

Ergo as technology partner, in conjunction with Microsoft Ireland and the HSE have now built the initial server infrastructure to host the patient portal. This will allow us to make the first iteration of the test portal available to selected patients and carers for evaluation in January. Prototype versions of the patient portal of the Epilepsy EPR have been developed and tested. Co-design meetings are being organized with residential carers and Healthcare Practitioners to assess the patient portal.

Parent Focus Group
15/12/2016

- Parent focus group meeting has been held with members of the research team and parents of patients with an intellectual disability.
- Parents are engaged with the co-design of the portal and gave valuable feedback.
- Parents have asked for functionality to track seizures, personalisation dependant on the needs of the patient, specific functionality for non-verbal patients and access to records offline.
- Parents highlighted the need for a way to validate aspects of their child’s EPR Summary record.

Patient Portal Expectations
1. The project team are working closely with clinicians and patients to manage expectations about what the patient portal will provide.
2. The portal will not be a helpline or emergency service.
3. The portal aims to support patient and residential carers to prepare for a clinical engagement.
4. Be easily understood by a member of the public without a clinical background.

Genomics Module

In collaboration with Ergo software engineers a multidisciplinary team of genetic scientists and clinicians have designed and developed an enhancement to the national epilepsy EPR. An iteration of this functionality to support a multi-disciplinary (MDT) gene-panel meeting is currently being trialled at Beaumont Gene Panel MDT meeting. Kevin Power presented an academic paper on embedding genomics in the clinical pathway at the Health Informatics Society Conference in November 2016.

Reporting and Data Analytics

The aim of the initial reporting and analytics development is to provide a view at both national and hospital level of clinical activity recorded in the EPR. This will allow insights to be gained into how the Epilepsy Service delivers care to patients. This reporting functionality will provide interactive dashboard functionality of both clinical encounters and outcomes. This initial phase will cover all clinician – patient interactions (e.g. OPD Clinic Appointments and Telephone Advice Line calls). The reporting functionality will be developed in partnership with Ergo, using the Microsoft Reporting and Analytics tool suite. It is expected that this first phase will serve as a basis for building significantly more reporting capabilities in later phases.