

Epilepsy Lighthouse Project



75 PATIENTS RECRUITED TO THE PISCES EPILEPSY LIGHTHOUSE PROJECT

Providing Individualised Services and Care in Epilepsy (PISCES) is a pioneering Lighthouse Project using the national epilepsy Electronic Patient Record (EPR) to bring the growing fields of genomic medicine, patient portals and data analytics into the clinical care pathway for people with epilepsy in Ireland. (www.ehealthireland.ie/Lighthouse-Projects/).

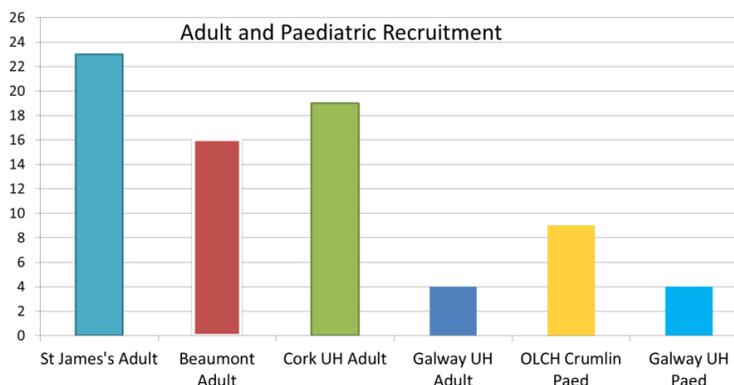
Adult and Paediatric Participant Recruitment

132 families have been screened for inclusion in PISCES with 75 patients now recruited. Families are enthusiastically taking part in the design and roll out of the live Epilepsy Patient Portal which provides patients and/or their carers with access to their epilepsy summary record and tools for managing their epilepsy care. All recruited families have provided samples for genetic sequencing. More families will be enrolled in the project in the new year.

Recruitment of paediatric patients is ongoing, via Galway University Hospital and Our Lady's Children's Hospital Crumlin. EPR records have been created for children enrolled into PISCES. This record will travel along with the child into the adult services offering a more seamless transition from paediatric to adult services. In total 13 paediatric patients have been recruited.

Genomics

To date 67 families have had genomic sequencing, 58 of these cases have been discussed at Genomic multi-disciplinary review meetings. Of those cases discussed 14 have had a positive diagnosis. This means that 14 patients have had a gene identified as being the cause of their epilepsy. The clinical geneticist will meet each family where a pathogenic variant is identified to explain and counsel families on the implications of a genetic variant.



PISCES Newsletter

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Christmas 2017

18/12/2017

Epilepsy Genetics Initiative

Genomic tests for epilepsy often do not identify a clear underlying cause for an individual's epilepsy. This can be down to factors other than genes causing the epilepsy, or because current knowledge does not allow the genetic cause to be identified. In cases where there is no obvious genetic cause from Lighthouse sequencing, patients and families have been invited to have the genetic results forwarded to the Epilepsy Genetics Initiative (EGI) which is based in Columbia University in the United States. EGI conducts regular analysis of the genetic sequence, and provide the infrastructure for continued reanalysis, until a cause is found. The transfer of genetic information from PISCES to EGI has started in recent weeks. Follow this link to find out more on the EGI initiative.

<https://www.cureepilepsy.org/egi/about.asp>



Map of Ireland showing counties where lighthouse families have been recruited in 2017.

Patient Portal

The epilepsy patient portal can be accessed via a desktop computer, smartphone or tablet device. There are now 41 registered authorised users of the portal including patients or family members who care for someone with epilepsy. The portal allows people to view their or their family member's summary epilepsy care record wherever they are. All portal users have had face to face design meetings with members of the Lighthouse team. This has given them an opportunity to say what they would like to see in the portal and how they think the portal can add value in the process of epilepsy care and services.

Users are enthusiastic about the portal and welcome the ability to validate parts of the patient record and it puts them in better control of important health data. For example, one of the PISCES patients had a recent visit to an emergency department due to complications with a new epilepsy medication. The patient's father was able to use the portal to share relevant clinical information with an ED doctor. Without the portal, this important information would not have been so readily available.

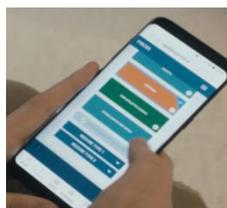
The portal users are engaging in the PISCES project by driving continuous improvements to the technology. Patients and families provide great feedback to help make the portal more user-friendly by, for example, simplifying medical terminology and abbreviations that are displayed in the portal.

They also offer suggestions for adding to the features available via the portal such as including a way to log seizure information into the patient record.



Lighthouse Case Study Video

Recently a video has been released that tells the story of the Epilepsy Lighthouse Study. Follow this link to view: <https://www.youtube.com/watch?v=GcopQge4jmY&t=25> or search Epilepsy Lighthouse in YouTube.



Recent Conferences

Representatives of PISCES actively disseminate experiences and learning from the project. Poster or platform presentations about the project have been presented at the: American Epilepsy Society (AES) Annual Meeting in Washington December 2017; Health Informatics Society of Ireland (HISI) Conference in November 2017; National Patient Safety Conference in Dublin in October 2017; Health Innovation Week in Dublin in October 2017; European Alliance for Personalised Medicine Congress in Belfast in November 2017.

Award Winning Project

Pictured below receiving the Tech Excellence 2017 Public Sector IT project of the Year Award, members of the PISCES team: Sean O'Donoghue (ERGO), Derek Kehoe (ERGO), Graham Frazer (Citrix), Maire White (RCSI), Gianpiero Cavalleri (RCSI), Brendan Dunleavy (ERGO), Wilton Rodriguez (ERGO), and Gemma Garvan (HSE). PISCES also received a commendation at the Irish Healthcare Awards for Best use of Information Technology.



Epilepsy EPR Genomics Module

The Genomics Module of the Epilepsy EPR has been well received. It has been used to support 100% of genomics multi-disciplinary meetings over the past 12 months and is now core to enabling the efficient operation of the meeting. Input from clinicians and scientists involved in the genomics meeting are helping us to design the most up to date and functional genomics EPR module available on a national and international stage. The genomics module has been used to discuss both adult and paediatric patients nationally from the following hospitals: Saint James's, Cork UH, Galway & Our Ladies Children's Hospital Crumlin.

What is Data Analytics?

EPRs allow large sets of patient data to be easily interrogated. This is known as 'data analytics'. PISCES is developing data analytics visualisation features to allow for safe interrogation of data contained within the EPR. There has been huge interest in analytics to assess performance of epilepsy services and gain insight into how epilepsy progresses and responds to different treatments. For example, analytics has been used to identify women of child-bearing age who are currently taking valproate, a potential teratogen. This allows their clinical teams to discuss treatment alternatives. Similarly, when an anti-epilepsy drug (AED) is being taken off the market, the analytics tool allows patients currently on this AED to be promptly identified and therefore proactive medication substitution to take place. Epilepsy EPR users are enthusiastic about engaging in data analytics training and are generating many interesting questions to be addressed.

Individual Health Identifier

Working with the national Individual Health Identifier (IHI) project, the epilepsy EPR can now use the IHI. The IHI is a number that safely identifies anyone who uses health or social care services in Ireland. As the IHI becomes part of more and more electronic health record systems, it will help improve continuity of care by allowing linkage of medical records from different healthcare providers. See a short video about IHI here: <https://youtu.be/AllaRjUwq70>

Next Steps

During 2018, the PISCES project will continue and extend its reach to more people with epilepsy in Ireland. The patient portal will be used to enable better quality and integration of services. We will promote the portal as a passport for adolescent patients as they transition between paediatric and adult epilepsy services. The data analytics will advance so that data can be turned into an asset for the benefit of people with epilepsy across Ireland.

CONTACT

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