



Adopter

Health Service Executive

Type of organisation

National Public Health System

Country

Ireland

Technological supplier

Ergo

Name of the Solution

PISCES (Providing Individualised Services and Care for in Epilepsy)

<http://www.ehealthireland.ie/Lighthouse-Projects/Epilepsy-Lighthouse-Project/>

Video presentation: <https://youtu.be/glcVYDcmMZk>

PISCES (Providing Individualised Services and Care for in Epilepsy) is a cloud based EHR solution, created by clinicians that are involved in the longitudinal care pathway for epilepsy. The solution offers the ability to store and represent the full sequenced genome as well as the geneticist's opinion of the epilepsy and the neurological conditions leading to the type of epilepsy.

The results are best quantified through a real story. A patient over 30 years old who had been under the care of the epilepsy team their entire life, had at least one seizure every single day of their life. A change of diet was suggested for this patient to reduce the levels of calcium intake that were recognised from the sequenced genome. Within a short number of days this patient had the first day of their life without a seizure.

THE PROBLEM THIS SOLUTION TRIES TO SOLVE

Epilepsy has an impact on over 40,000 people in Ireland. The delivery of care is across acute, primary and community care throughout Ireland with a small number of centres of excellence and a single centre of academic study and research.

The healthcare system needs to be able to deliver integrated care to truly change the care pathway for patients and the only way to do this is through access to clearly defined structured information about the delivery of care throughout the care pathway.

A single Electronic Health Record (EHR) focused on the needs of epilepsy patients needed to be available throughout the country. This was introduced to ensure that no matter where care is delivered information can be collected, added to the care record and delivered to the care team regardless of geographic location or care setting. This has to be done in a secure and auditable fashion.

The unique identified need in the care of epilepsy in Ireland is the ability to utilise technology advancements in the field of genomics. The sequenced genome and the genetic analysis of this can have a profound impact on the way in which epilepsy care is delivered. The EHR delivered for epilepsy in Ireland also allows the sequenced genomic data and the geneticists opinion of the sequence to be captured and stored. The EHR is now used as the 'gathering point' for the multi-disciplinary team (MDT). The MDT uses the information on the EHR to make collective decisions about the care of patients across the whole of Ireland, this enables care to be delivered closer to home, it removes duplication of testing and capturing information and enables almost real time information to be available. By adding the sequenced genome to the EHR expert opinion, a single centre of excellence best practice for the country can be applied to care without clinicians or patients having to travel and without having to wait for patient appointments with a limited resource.

Clinical decisions about the care pathway can now be made by the MDT in conjunction with detailed sequencing information and analysis, changes to diet, drug regimes and lifestyle can all be analysed for impact and research into this can be performed as a single consented cohort of patients which can and will have an impact on the larger population.

A further innovation to the EHR is a patient portal that allows patients access to the information and allows patients to write to the record. In the case of epilepsy this is dramatically important to the care record as the frequency, type and severity of seizures has a significant impact on the delivery of care and therefore the patient outcomes. The electronic recording of this information by the patient has both a positive impact for the clinicians who can utilise this information and the patient who can feel a greater sense of control in their condition.

The EHR also offers the first unique possibility to utilise data for population health analytics in this specific disease area. This is an innovation considered for 2017.

INNOVATIVE IT SOLUTION THAT WAS IMPLEMENTED

The solution is a **cloud based EHR solution, created by clinicians that are involved in the longitudinal care pathway for epilepsy**. The EHR is used in all care settings and therefore a cloud based solution enables ease of access regardless of location. **The solution offers the ability to**

store and represent the full sequenced genome as well as the geneticist's opinion of the epilepsy and the neurological conditions leading to the type of epilepsy.

The patient portal enables the patients (and indeed the family) to view the electronic health record securely. It also allows information to be added to the EHR from a mobile device. This allows real time information to be collected into the EHR, in an acute setting and in emergencies the type of seizure, frequency and needs of the patient can be dramatically impactful in recovery times and in the formulation of new and innovative treatment plans.

The solution is innovative in that it allows the sequenced genome and opinion of the multidisciplinary team to become part of the information that informs the care pathway. The deformed element of the genome that can cause different types of epilepsy is acutely meaningful to the type of treatment delivered. For example a dietary change can be suggested based on the genomic sequence, this can have significant impacts on the frequency and type of seizures.

The solution does represent 'cutting-edge' technology and business change as it utilises some of the key and evolving principles of digital health, namely Mobile, Cloud and Analytics. All the processes enable real time, complex and large data to be exposed in such a way as to significantly and efficiently impact on the delivery of care.

The solution makes use of several key innovations in one single deployment of technology including Mobile patient access, Cloud computing for storage, access and super computer power, analytics and Business Intelligence for the delivery of complex data and analysis to clinicians, not to mention patient engagement which has been heralded as the blockbuster drug of the 21st century.

The solution supports a significant change in clinical process, the MDT is able to utilise the solution as a catalyst for new conversations. The solution enables a remote and yet fully informed MDT to take place that feeds back to the patient and all clinicians across Ireland in real time. The process now in place because of this solution no longer requires long and potentially distressing visits for the patient to a single national centre of excellence and also ensures that information is captured once and shared, reducing costs, re-testing and decisions being taken without the full clinical information set."

CURRENT IMPACT ON THE PATIENTS / END USERS

The results are best quantified through a real story. In September 2016 the first cohort of consenting patients had the genome sequenced. One of these patients, a person over 30 years old had been under the care of the epilepsy team their entire life. **This person had at least one seizure every single day of their life.**

The sequenced genome, geneticist's opinion and health record information were now in the same place for the wider MDT to compare and discuss, at the geneticists prompting, a change of diet was suggested for this patient to reduce the levels of calcium intake that were recognised from the sequenced genome.

Within a short number of days this patient had the first day of their life without a seizure.

The academic review of this suggests that this type of information based change could have an impact in around 10% of patients. The cohort of consenting patients to be part of the genomic

sequencing programme is growing and enables a different type of health care planning to take place based on a much richer data set. 10,000 patients now have their information shared via the EHR. Several 100 high acuity patients now access the patient portal in a proof of concept and test basis."

CURRENT SUCCESS

There are around 10,000 of the 40,000 epilepsy sufferers with their information on the EHR. A public information programme and consent activation programme is underway to increase this number. The patient portal is seen as a strong benefit and has seen numbers increase at a significant rate.

There were an estimated 90 children under 5 who lost their lives to epilepsy related illnesses in 2016. The costs associated for trialling drugs in epilepsy in 2016 was 5 million. Other costs associated to the delivery of an integrated care service for epilepsy can be broken into two areas; health system savings and savings to the patient. The system can now save on the cost of travel, patient appointments at the centre of excellence can be reduced as the MDT can come together more easily and with up to date information to discuss and alter the care pathway, this is reducing the need for outpatient appointments. As all information is now available wherever the patient is receiving care and the need to attend specific review appointments is reduced.

The patient portal is also enabling elements of telemedicine to be explored, telephone calls between health professionals and the patient with the record in front of both parties has been seen to be extremely beneficial both in terms of costs and the comfort to the patient and their families. The EHR element of the project is now in large scale use, the genomic sequencing element is with consented patients, in 2017 this cohort will continue to grow. The patient portal is with a large user base but as an evaluation and test phase."

HOW THE PROJECT CAN / WILL SCALE WITHIN OR OUTSIDE THE ADOPTER ORGANISATION

The project is now considering how some of the solutions can be adopted by other neurological conditions; Parkinsons, MND, Thorns Disease and Dementia.

The solution has been built in such a way as to be used and replicated by other jurisdictions that have similar information standards, the Northern Ireland health system is considering how it can have access to the solution as the two countries do have shared clinical pathways for care in this area. Best practices are being shared with other countries such as Spain to collaborate on patient centred design. The implementation of the Individual Health Identifier in Ireland does mean that patient information can be securely shared between nations and therefore this enables the epilepsy EHR to be considered across both jurisdictions.

Through links with Epilepsy Ireland (The charity) and the Royal College of Surgeons in Ireland the solution is being considered as an academic baseline for other countries including the USA.