Providing Individualised Services and Care in Epilepsy (PISCES)

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• 40,000 People with epilepsy in Ireland
• 13,000 (1/3) Poorly controlled epilepsy
  • require ongoing healthcare and services

• HSE National Clinical Programme for Epilepsy
  • 6 Regional Centres
  • Equitable, Quality, Timely care, Value for Money
  • Clinical Information When and Where Needed
  • Supported with a secure web-based Epilepsy EPR
• 7,000 individual patient records
• Supporting over 8,000 clinician-patient encounters per year
  • A unifying force for Integrated & shared epilepsy care
• Types of clinical encounter
  • Out-patient
  • Telephone Advice Line
  • Outreach Clinics
  • Epilepsy Surgery
  • Rapid Access Seizure Clinic
• EPR facilitating clinical Analytics
  • Monitor and evaluate services
  • Plan new services
  • Audit and Research
Components

**COLLABORATION**: Clinical teams from across the country. Analysts, genetic and information as well as technology professionals. Patient groups and the charities and international observers.

**DATA**: Cloud based data access and the analytics capability through Power BI

**OPEN**: Data without boundaries - No hospitals walls. Sensors and remote data capture from the patient.

**PARTNERSHIP**: National example of partnership working with EPR developer organisation and hosting team. New styles of innovation in practice developed.

**ACCESS**: Inter-Disciplinary team access, genetics to nursing to dieticians.

**COMMUNICATION**: Systems to support patient care and service interaction

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**PISCES WORK STREAMS**

**PRECISION**
- **Genomics**
- Identify underlying cause of epilepsy
- Embed genomics in clinical pathway
- Facilitated by EPILEPSY EPR

**PROACTIVE**
- **Patient portal**
- Patient reported outcome measures
- AED & TX Compliance
- Real world Quality of Life
- Seizure Severity

**PERSONALISED**
- **Clinical Analytics**
- Population Health data in EPILEPSY EPR
- Insights into disease risk, progression & TX response
- Informs evidence-based individual plans
PISCES WORK STREAMS

Genome sequencing & clinical care
- Pediatric patients + 100 unaffected parents
- Adults with intellectual disability + epilepsy

Design, Develop & Implement Epilepsy EPR enhancements
- Genome health record module
- Patient portal to capture PROMs (Carer/Parent)
- Clinical Analytics Visualisation/Dashboards

Create conditions for 3P (Personalised, Proactive & Precision) impact assessment
- Impact on course of treatment
- Patient/carer/ Healthcare provider satisfaction
- Pilot/ demonstrator study
GENOMICS TO DATE

39 Trios Recruited
31 Trios Sequenced
21 Trios Discussed at MDT*

List of Variants Identified:
- GRIN2A
- SCN9A
- CHD2
- ALDH5A1
- SSR4/SCN9A

Current diagnostic rate: 24% (5/21 discussed trios)

* MDT = Multi-disciplinary genomic medicine team
PATIENT PORTAL

• Co-designing the Portal
  – People with epilepsy
  – Family members & Carers
  – Clinicians
  – Software Engineers
PATIENT PORTAL

Possible Questions For My Doctor Or Nurse

Press a category below to show some common questions many patients ask. If you press on a question it will be added to your questions list which you can reference for upcoming appointments. Some questions provide links to external resources for further reading.

Knowledge About Epilepsy
- Treatments
- Investigations
- Other Illnesses
- School, College, and Work
- Driving
- Pregnancy

Possible Questions For My Doctor Or Nurse

Knowledge About Epilepsy
- How long will I have to take tablets for?
- If the tablets don’t work what is the next step?
- Are there other medications which could be used?
- Are there any other treatments?

Treatments
- Investigations
- Other Illnesses
- School, College, and Work
- Driving
- Pregnancy

This section will help you to get ready for the next time you have to attend your epilepsy doctor or nurse.
Tree map: Population health in action, co-morbidity profile for sample of 3000 patients represented in EPR.
Thank you!

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