



The development of an epilepsy electronic patient portal: Facilitating both patient empowerment and remote clinician-patient interaction in a post-COVID-19 world

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Abstract

Objectives: The current coronavirus disease 2019 (COVID-19) pandemic stresses an urgency to accelerate much-needed health service reform. Rapid and courageous changes being made to address the immediate impact of the pandemic are demonstrating that the means and technology to enable new models of health care exist. For example, innovations such as electronic patient portals (ePortal) can facilitate (a) radical reform of outpatient care; (b) cost containment in the economically constrained aftermath of the pandemic; (c) environmental sustainability by reduction of unnecessary journeys/transport. Herein, the development of Providing Individualised Services and Care in Epilepsy (PiSCES), an ePortal to the Irish National Epilepsy Electronic Patient Record, is demonstrated. This project, which pre-dates the COVID-19 crisis, aims to facilitate better patient- and family-centered epilepsy care. **Methods:** A combination of ethnographic research, document analysis, and joint application design sessions was used to elicit PiSCES requirements. From these, a specification of desired modules of functionality was established and guided the software development.

Results: PiSCES functional features include “My Epilepsy Care Summary,” “My Epilepsy Care Goals,” “My Epilepsy Clinic Letters,” “Help Us Measure Your Progress,” “Prepare For Your Clinic Visit,” “Information for Your Healthcare Provider.” The system provides people with epilepsy access to, and engages them as co-authors of, their own medical record. It can promote improved patient-clinician partnerships and facilitate patient self-management.

Significance: In the aftermath of COVID-19, it is highly unlikely that the healthcare sector will return to a “business as usual” way of delivering services. The pandemic is expected to accelerate adoption of innovations like PiSCES. It is therefore a catalyst for change that will deliver care that is more responsive to individual patient needs and preferences.

KEYWORDS

COVID-19, electronic health records, epilepsy, patient portal

1 | INTRODUCTION

In response to the coronavirus disease 2019 (COVID-19) pandemic, many aspects of healthcare delivery are rapidly changing.^{1–3} There is increased focus on new technology-enabled care models that reduce the need for in-person contact between clinicians and patients.¹ Outpatient lists are being reviewed to determine which patients need face-to-face encounters and which are suitable for remote or virtual care.² COVID-19 is therefore a catalyst for change that is driving care that is more responsive to individual patient needs and preferences. Much of this will sustain and become the “new normal” of health service delivery in the post-COVID-19 world.²

In the following, an electronic patient portal developed by the Irish National Clinical Programme for Epilepsy (NCPE)⁴ to promote improved patient- and family-centered care (PFCC)⁵ is described. Although this project pre-dates COVID-19, the challenge of the pandemic is expected to accelerate the adoption of innovations like the epilepsy portal, which can facilitate the following: (a) radical reform of outpatient care; (b) cost containment in the economically constrained aftermath of the pandemic; and (c) environmental sustainability by reduction of unnecessary journeys/transport.

The growing adoption of the electronic patient record (EPR) is being accompanied by an increasing international interest in the use of electronic portals (ePortal) to provide people with access to, and engage them as co-authors of, their own medical record.^{6–10} ePortal can enable improved trust, transparency, and patient-clinician collaboration,⁶ and promote a paradigm of PFCC.⁵

PFCC, which is about “putting the patient and family at the heart of every decision and empowering them to be genuine partners in their care,”¹¹ is key to the management of complex chronic conditions such as epilepsy, as it recognizes people within the full context of their lives not just their health condition.^{12,13} It is an approach to healthcare delivery that recognizes and respects the expertise of patients and their families; places an emphasis on patient activation and empowerment; provides care that is responsive to individual patient preferences, needs, and values; and is grounded in mutual beneficial partnerships and continuity of patient-healthcare provider relationships.^{12,13} ePortals linked to EPRs have the potential to facilitate delivery of PFCC by providing patients and their authorized care partners (eg, family members) with secure access to their health information when and where needed; clinic visit summaries, tools for patient-reported outcomes and goal setting; aids for patient

Key Points

- Post-COVID-19 (coronavirus disease 2019), it is highly unlikely that the healthcare sector will return to a “business as usual” way of delivering services
- Electronic patient portals (ePortal) can facilitate radical reform of outpatient care, cost containment, and environmental sustainability
- Here, the development of Providing Individualised Services and Care in Epilepsy (PiSCES), an ePortal to the Irish National Epilepsy Electronic Patient Record, is demonstrated
- PiSCES is enabling improved trust, transparency, patient-clinician collaboration, and patient- and family-centered care
- We must seize the opportunity to sustain health service innovation in the post-COVID-19 world

education; and the means to securely message and communicate with their healthcare providers.^{14–18}

Although reports on the outcomes of ePortal mediated healthcare and services vary, there is a general faith in the promise of the technology to facilitate improved patient engagement and enable innovative models of care.^{14–18} For example, ePortals can support delivery of virtual care, thereby obviating the need for patients to attend the clinic in person.¹² Similarly, the ePortal can act as a passport of care between healthcare providers or healthcare sectors, as the patient or their care-partner will have the ability to share key clinical information as required.^{19,20} Examples include supporting the coordination of care for patients transitioning from pediatric to adult services²¹ or continuity of care between hospital-based and community settings.²² ePortal intervention is associated with improved psychobehavioral patient outcomes (eg, health knowledge, self-efficacy, medication adherence, and preventative health service utilization), although mixed effects on clinical outcomes such as blood pressure, cholesterol, glucose, and weight loss are reported.^{15,23–24} ePortal access is sending a message of inclusivity.⁶ Patients report that accessing clinic notes via an ePortal provides an aide memoir,¹⁸ helps build confidence in their healthcare provider,^{25,26} and allows them to act as safety partners as they can validate the content of their healthcare record.²⁷ In summary, ePortal functionality aligns with PFCC ambitions to actively involve patients and families as direct partners in

care and decision-making, promote patient and family health and well-being, facilitate better communication, and enhance greater collaboration and co-ordination across the health system. This is of critical importance in the epilepsy care domain, where challenges exist in truly realizing integrated PFCC including the need for the healthcare system to partner directly with patients and families to design, develop, and implement new models of care.

For more than a decade, a team of patients, families, nurses, doctors, allied health professionals, computer scientists, healthcare managers, and policymakers have been continuously evolving eHealth technology solutions to facilitate improved quality, safety, and efficiency of epilepsy care in Ireland. Core to this is a bespoke National Epilepsy EPR,²⁸ which underpins the NCPE.⁴ The Epilepsy EPR is a point of care system that currently contains the longitudinal epilepsy care records of approximately 10 000 individuals.²⁹ It supports a range of clinical tasks including in-patient and outpatient care, outreach services, telephone/virtual clinics, epilepsy surgery, and vagus nerve stimulation (VNS) treatment. Continuous evolution of the Epilepsy EPR aims to advance a model of PFCC.^{28–30} A novel genomics module in the EPR is promoting precision care by supporting a multi-disciplinary team of clinicians, geneticists, and bioinformaticians in their interpretation of genomic sequence data in the context of an individual's phenotype.²⁹ Epilepsy EPR-based

clinical data analytics is enabling interrogation of large volumes of population data to derive insights regarding disease progression and response to treatment that can be used in future clinical decision support, thereby personalizing care.^{28,31}

The addition of the ePortal aims to encourage patients and/or care partners (eg, family members) to take a more active role in managing their health care by, for example, reporting outcomes that will allow clinicians to closely monitor individual response to treatment and be more proactive in their delivery of care. In summary, the Irish epilepsy care ecosystem has been growing its digital capacity for many years and has therefore been prepared in the current COVID-19 environment to move quickly to a remote/virtual care model where appropriate.

In this article, we demonstrate the key components of PiSCES (Providing Individualised Services and Care in Epilepsy), the Irish Epilepsy ePortal, and outline its potential to facilitate the delivery of improved PFCC.

2 | METHODS

The PiSCES iterative development process and timeline is illustrated in Figure 1. It was designed using a combination of information sources to elicit requirements and to generate a set of use cases that would describe the ways

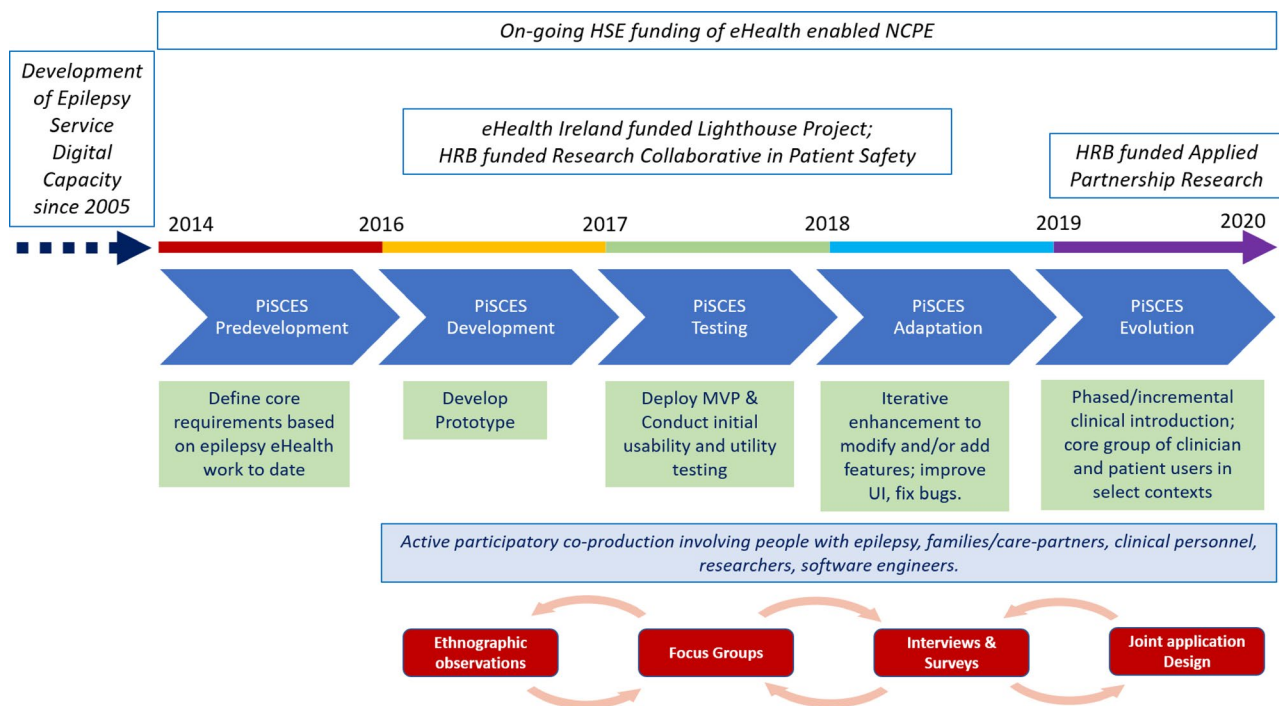


FIGURE 1 Providing Individualised Services and Care in Epilepsy development process involved significant commitment and input from multiple stakeholders over a lengthy period. This was achieved by embedding the initiative in continuous quality improvement of epilepsy services. Various interrelated methods are employed across different phases of the project to engage the people involved in epilepsy care, understand the nature of their transactions with each other and the role technology can play. The project has been enabled through a number of research, health service innovation, and health service delivery funding sources. MVP, Minimum viable product; UI, User interface

in which potential end-users would use the ePortal. From these, a specification of desired modules of functionality was established and used to guide the software development. Information sources included ethnographic research conducted in the Irish epilepsy care domain; analysis of strategy, clinical guideline and patient support documents; and joint application design sessions.

2.1 | PiSCES requirements elicitation

2.1.1 | Ethnographic research

Ethnographic exploration of patient- and family-centeredness in Irish epilepsy care provided significant domain knowledge to inform PiSCES design. Using observations, one-to-one interviews, focus groups and participatory action research, the practice and behavior of epilepsy care was examined through the lens of those who receive (patients, families, and carers) and those who provide (nurses, doctors, clinic support personnel, and community resource officers) epilepsy care and services.^{32–34} These domain experts provided information on their experience of a holistic approach to patient needs; patients treated as experts in their own care; recognition of patient autonomy; clinician-patient partnership and shared decision-making; dignity and respect in the clinical setting; and views on how information technology could support more PFCC.

2.1.2 | Analysis of documents

Strategy, clinical guidelines, and patient support documents provided context about overall health service improvement and reform ambitions, goals of epilepsy care, and the role of the patient in their own epilepsy care. For example, Slaintecare³⁵, Ireland's 10-year plan for reforming its health-care system and the Irish eHealth Strategy³⁶ both acknowledge the role ePortals such as PiSCES can play in supporting patients to proactively manage their health and collaborate with healthcare providers to achieve optimal health outcomes. Similarly, advancing patient self-management is a central goal of the NCPE,⁴ as it has been shown to improve outcomes, promote healthier lifestyles, and reduce health service utilization for people with epilepsy.^{37,38} The Epilepsy Ireland (the main advocate organization for people with epilepsy in Ireland) Living Well with Epilepsy Toolkit,³⁹ a self-management resource, provides a manual journal where patients can record information about their medical team, their medications, seizure management and diary, support network, reminders about clinical appointments, and so forth. These strategy, guideline and patient support documents further informed requirement gathering as they illustrated how

priorities at the level of the healthcare system, organization, and individual might be mediated by using PiSCES.

2.1.3 | Joint application design

Themes emerging from the ethnographic research and the analysis of documents were mapped to desired PiSCES functionality that could address certain goals and ambitions regarding the accomplishment of PFCC. Proposed modules of PiSCES functionality were then reviewed and validated at joint application design sessions attended by software engineers and experts in the provision of epilepsy care. The epilepsy care experts were a subset of those who participated in the ethnographic research and were champions of the national Epilepsy EPR, each with up to 10 years of experience of using the system to support a range of clinical tasks. As such, they were key design informants with significant awareness of how PiSCES might help promote patient- and family-centeredness in epilepsy care.

2.2 | PiSCES system specification and development

To guide the software engineering of the system, elicited requirements were distilled and documented as a set of PiSCES specifications. An agile model was used by the software engineers to break the overall development of PiSCES into a series of iterations, typically of 2-3 weeks in duration. Each iteration was designed to deliver a subset of the specified PiSCES functionality. In this way, the delivery of each increment was used as a stage gate to further validate the defined requirements. Representative end-users, for example, people with epilepsy (PwE), their family members or care-partners (carers), and health care practitioners (HCP), could test the iteration to ensure that it met relevant acceptance criteria and where necessary provide feedback to the software engineers to further enhance the PiSCES solution. This incremental-based development model generates working software quickly and creates the conditions for evolutionary prototyping, where early use of the system in its intended natural environment informs a process of iterative refinement from which an effective application ultimately emerges.

3 | RESULTS: DEMONSTRATION OF PISCES, THE IRISH EPILEPSY EPORTAL

We have developed an ePortal, entitled PiSCES, integrated with the National Epilepsy EPR, which can be accessed by

authorized and approved users from any location where there is an internet connection via a desktop computer, smartphone, or tablet. The requirement elicitation described in Section 2 resulted in the following features being prioritized by stakeholders: Secure Login, User Account Management, Display of Menus, Access to Summary Epilepsy Care Record, Patient-Reported Outcomes, and Self-Management Capabilities. The resulting modules of PiSCES functionality are described below (Figures 2-6; Figures S1-S6). Although developing PiSCES entailed approximately 250 software engineering days, the associated design and implementation aspects necessitated additional people and process costs (Figure 1).

3.1 | PiSCES login and landing page

To meet the highest security standards, PiSCES users must confirm their identity using a two-factor (2FA) authentication process. Following entry of their individual username and password on the login page, the user must verify receipt of a passcode sent by SMS text message to their mobile phone before gaining access to PiSCES. In line with the principle of Privacy by Design,⁴⁰ the system incorporates role-based access control so that users are given permissions related to whether they are a patient, a carer, or healthcare professional

such as epilepsy nurse or doctor. For example, an individual patient can only access their own record, whereas an authorized clinician can access records for patients to whose circle of care they belong.

The PiSCES ePortal landing page provides access to a number of modules of functionality including “My Epilepsy Care Summary,” “My Epilepsy Care Goals,” “My Epilepsy Clinic Letters,” “Help Us Measure Your Progress,” “Prepare For Your Clinic Visit,” and “Information for Your Healthcare Provider” (Figure 2A). Hovering over the “i” icon that appears in the left-hand corner of each module, opens a pop-up box that provides information about the purpose and content of the module. Clicking on any of the modules brings the PiSCES user to more detailed information (Figure 2B). In the following sections, and in the accompanying supplementary file, a selection of PiSCES modules is described. For demonstration purposes, fictitious clinical data are illustrated in some figures.

3.2 | My epilepsy care summary

By selecting “My Epilepsy Care Summary,” the PiSCES user can access a synopsis of information about the patient that is stored in the National Epilepsy EPR (Figure 2B). Links to a summary of the patient's information stored in the epilepsy



FIGURE 2 Screenshots of (A) the PiSCES Landing Page. By selecting “My Epilepsy Care Summary” the user is brought to (B) links to more detailed information

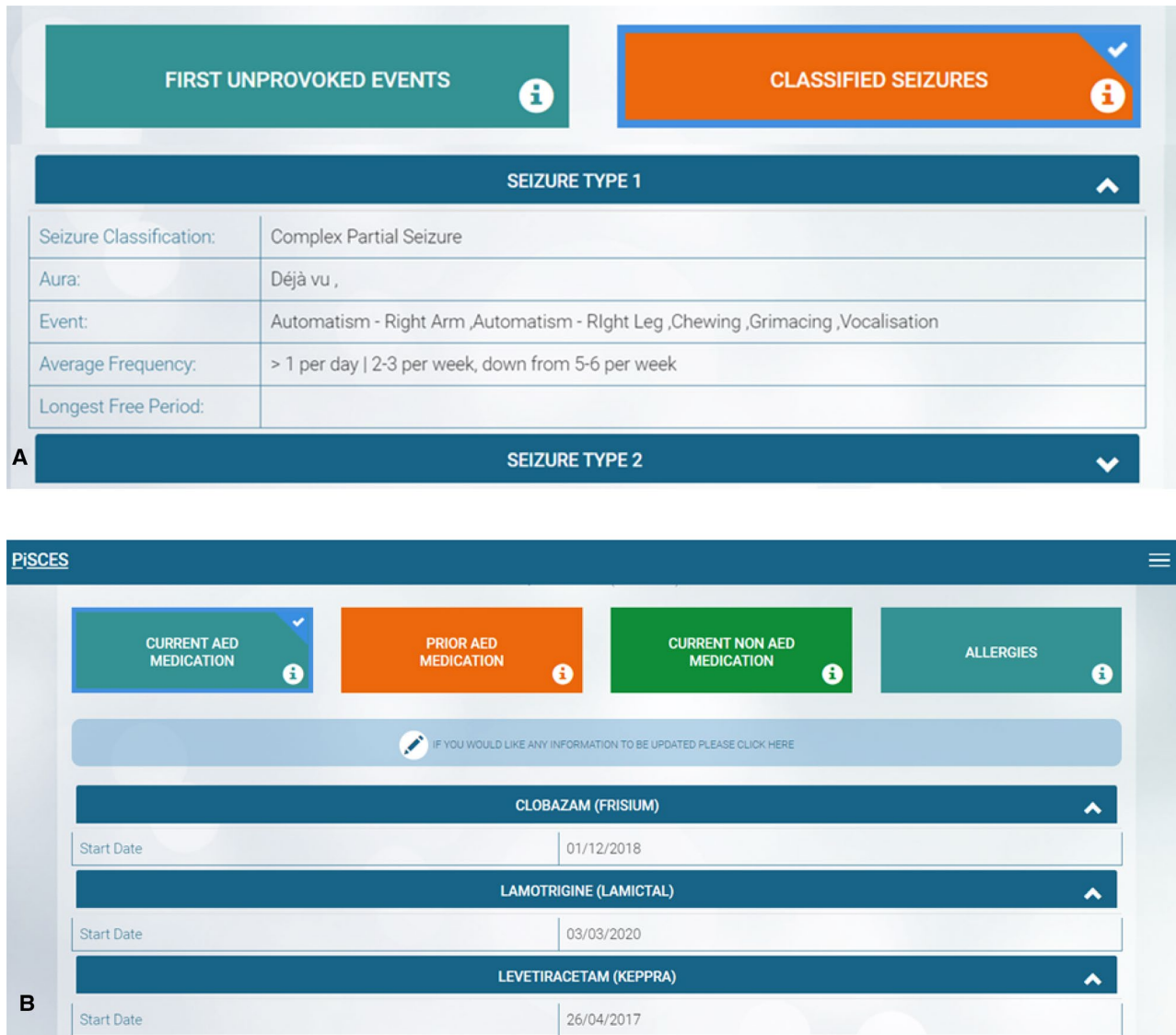


FIGURE 3 Screenshots of (A) the Seizure-Type module and (B) the Medications module, where Current antiepileptic drugs have been selected

EPR including seizure types, medications, investigations, possible causes of epilepsy (etiology), medical and surgical history, and syndrome classification are provided. In addition, a history of people who have accessed this patient's Epilepsy EPR is provided (Section 3.2.7). Selecting any of these reveals further clinical details as illustrated in Figures 3 and 4A,B and also Figures S1-S3 in the Supplementary File accompanying this article. Within this PiSCES module, the facility to allow patients (or their carer) to validate their clinical information is also available (Figure 3 and Figure S7), thus engaging them as a quality and safety partner in the clinical care process. Although the purpose of the “My Epilepsy Care Summary” module is to provide users with an “at a glance” overview of the patient's epilepsy care history, a more detailed version of information can be accessed from the “Information for Your Healthcare Provider” module (Figure S6).

3.2.1 | Seizure types

This section provides the user with access to a synopsis of seizure semiology information in two parts: “First Unprovoked Events” and “Classified Seizures” (Figure 3A). Selecting the former reveals a description of the patient's first seizure-type event including age and date of occurrence, whereas the latter shows information about the patient's classified seizure type(s), for example, aura experienced, event description, average seizure frequency, and longest seizure-free period.

3.2.2 | Medications

The “Medications” module provides information on current and prior anti-epileptic drugs (AEDs), non-AEDs, and drug allergies

(Figure 3B). For example, by selecting Current AED Medication (Figure 3B) a relevant list is illustrated. More detailed information is provided on medication dosage in the “Information for Your Healthcare Provider” module (see Section 3.7 and Figure S6).

3.2.3 | Investigations

A list of diagnostic investigations that have been recorded in the Epilepsy EPR for the patient is provided in the “Investigations” module (Figure S1). Examples include Routine EEG, EEG (Long-Term Monitoring Unit), MRI, and Neuropsychology Assessments, and so on; Information exposed includes the date of the investigation and where it was performed.

3.2.4 | Possible causes of my epilepsy

The Possible Causes of My Epilepsy element (Figure 4A) reveals etiology information documented in the Epilepsy EPR. It lists underlying causes of the patient's epilepsy such as Family History, Genetic, Perinatal Injury, and so on (Column 1), with associated status (Column 2) as evident (Yes/Definite), suspected (Possible/Unknown), or no evidence (No). In a third column, any related explanatory notes documented in the EPR are also shown.

3.2.5 | Medical and surgical history

In the Epilepsy EPR, comorbidities are documented according to the relevant body system: dermatological, endocrine, ENT, gastrointestinal, gynecological, hematological, and so forth. Similarly, previous surgeries are categorised into epilepsy surgery, other neurosurgery, and general surgery. Summary comorbidity and/or previous surgery information documented in the EPR is accessible via the Medical and Surgical History button of the PiSCES ePortal (Figure S2).

3.2.6 | Syndrome classification

Via the PiSCES “Syndrome Classification” button, information about the patient's epilepsy syndrome classification as documented in the EPR can be accessed (Figure 4B).

3.2.7 | Who has accessed my epilepsy EPR?

Audit trails in the Epilepsy EPR maintain a chronological record of transactions made by users of the EPR. Via PiSCES, a list of the last 20 people who have accessed the

A POSSIBLE CAUSES OF MY EPILEPSY

Condition	Status	Notes
Family History	Yes	Father, paternal uncle and paternal first cousins x2
Genetic	Possible	Awaiting results of exome Testing
Perinatal Injury	No	
Febrile Convulsions	Yes	numerous prolonged febrile seizures from aged 2-5
Meningitis	No	
Encephalitis	No	
Traumatic Brain Injury	No	
Mesial Temporal Sclerosis	Left	

B SYNDROME CLASSIFICATION

DIAGNOSIS

Localisation Related Epilepsy Cause Known	Temporal Lobe Epilepsy (TLE) MTS + Left
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FIGURE 4 Screenshots of (A) Possible Causes of My Epilepsy and (B) Syndrome Classification modules

patient's record, together with information about their role and organization and date of access is presented (Figure S3). Information beyond the last 20 accesses can also be made available by request. This function aligns with transparency and privacy principles of data protection.⁴⁰

3.2.8 | Validation


A summary of information documented in the EPR is exposed via the PiSCES ePortal. PiSCES users can request that information be amended. For example, if they notice an omission or an error in a section of the record, they can select “If you would like any information to be updated, please click here” (see Figure 3B and Figure S7). A clinician will review the amendment request and where appropriate update the relevant section of the patient's EPR entry. In this regard, people with epilepsy (PwE) and/or their carers can act as quality and safety partners by validating the content of their epilepsy summary record.

3.3 | My epilepsy care goals

PiSCES provides a space for patients (or their carers) to document their ambitions in relation to both their psychosocial and biomedical epilepsy care needs (Figure 2 and Figure S4). Within the “My Epilepsy Care Goals” module, users can


A

MY EPILEPSY CLINIC LETTERS



- [Clinician Name], Hospital Name, Date ▼
- [Clinician Name], Hospital Name, Date ▼
- [Clinician Name], Hospital Name, Date ▼
- [Clinician Name], Hospital Name, Date ▼

B



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DR TEST
 111 FAKE STREET
 TESTVILLE
 TESTWOOD

Re: TEST EPOTAL PATIENT 1,
 Not a Real Address, Not a Real City,
 Not a Real Town, No Country
 D.O.B: 04/04/1985 (BH) MRN: 99998888

OPD Clinic Date: 03 / 03 / 2020

Epilepsy Diagnosis: Localisation Related Epilepsy Cause Known: Temporal Lobe Epilepsy (TLE) MTS + Left.

Comorbidity: Asthma, Eczema, Hypothyroidism, Mood Disorder(Depression)

Classified Seizures: Test eportal experiences 3 type(s) of seizure. Below are the seizure(s) of note:
 Type 1: Complex Partial Seizure
 Aura: déjà vu.
 Description: automatism - right arm, automatism - right leg, chewing, grimacing, vocalisation, facial distortion.
 Seizure Frequency: Reduced. > 1 per day; 2-3 per week, down from 5-6 per week.
 Type 2: Simple Partial Seizure
 Aura: déjà vu.
 symptoms
 Seizure Frequency: No Change. Weekly, less severe than previously.
 Type 3: Simple Partial to Complex Partial to Generalised Seizure
 Aura: déjà vu.
 Description: automatism - right arm, automatism - right leg, chewing, cyanosis, grimacing, incontinence, tongue biting, tonic clonic, vocalisation, facial distortion.
 Seizure Frequency: Reduced. <1 per mth> 1 per yr; 3-4 per year - last seizure February 2020.

Aetiology: Family History-Yes(Father, paternal uncle and paternal first cousins x2), Genetic-Possible (Awaiting results of exome Testing), Febrile Convulsions-Yes(numerous prolonged febrile seizures from aged 2-5), Mesial Temporal Sclerosis-Left

Current Anti-Epileptic Drugs (AEDs):
 1. Clobazam (Frisium): 5 mg Morning, 10 mg Night.
 2. Folic Acid: 5 mg Morning.
 3. Lamotrigine (Lamictal): 25 mg Morning, 25 mg Night. Target Dosage: Increase by 25 mgs every 1/52 to reach 100 mgs bid.
 4. Levetiracetam (Keppra): 750 mg Morning, 750 mg Night.
 5. Midazolam (): 10 mg PRN, 10 mg PRN.

Current Non Anti-Epileptic Drugs (AEDs):
 1. Citalopram .
 2. Elixon
 3. Paracetamol .
 4. Vitamin B6 .
 5. ventolin .

Dear Dr. Test,
 Test eportal attended OPD Clinic in Beaumont Hospital today accompanied by her spouse. She was reviewed by Prof. [Clinician Name]

Seizure Control Observations: Test continues to have frequent seizures. She has reduced alcohol consumption but despite this seizures continue.

AED Management Observations: As she hasn't tried Lamotrigine in the past we will start it today as outlined above.

Outstanding Investigations/Referrals: Referred today for routine bloods, relevant anti-epileptic drug serum levels and video EEG monitoring.

Advice and Education: During clinic we discussed Seizure Types, Seizure Triggers, Possible side effects of new/increasing AEDs (advised about the risk of a rash while on lamotrigine and advised to stop immediately if rash develops and seek medical attention.), Compliance with AED medications, Alcohol misuse (advised to reduce alcohol consumption.), Activities / Sports (continues to play basketball with local team which she enjoys), SUDEP, Stress, Anxiety and Depression.

Test eportal is not legally entitled to drive as she is less than one year seizure free.

We will see Test eportal in 4 Months.

Kind Regards,

 [Clinician Name]
 Advanced Nurse Practitioner Epilepsy

FIGURE 5 Screenshots of the My Epilepsy Clinic Letter module. (A) A list of available clinic letters showing author, organization, and date can be reviewed. By selecting any of these (B) the clinic letter can be viewed

choose from a list of prompts, for example, Stop my seizures, Resume or Start Driving, Reduce Sleep Deprivation, and/or compose their own objective(s) for their epilepsy care through a “Custom Goals” gateway.

3.4 | My epilepsy clinic letters

During an encounter with the patient, the clinician will update the patient's Epilepsy EPR entry. Functionality can then

HELP US MEASURE YOUR PROGRESS

LIVERPOOL SEIZURE SEVERITY SCALE_Baker et al. (2001)_V3

So we can better understand the severity of your seizures, please complete the following questionnaire

Please answer each question based on the most severe seizure you have experienced in the past 4 weeks.

Pick only one answer for each question.

Part A. Seizure Type - Please enter '0' if you have not experienced seizures in the last 4 weeks and do not complete the remainder of the questionnaire. If you cannot remember the exact number of seizures you've experienced, please estimate based on the number you usually had during a single day or week.

1.1. How many seizures have you experienced during the past 4 weeks?

Part B. Seizure Severity - Please answer each question based on the most severe seizure you have experienced in the past 4 weeks.

1.1. I feel that my most severe seizures have mostly been:

Very severe **Severe** **Mild** **Very mild**

1.2. Most commonly when I blank out/lose consciousness:

- I blank out for less than 1 minute**
- I blank out for between 1 and 2 minutes**
- I blank out for between 3 and 5 minutes**
- I blank out for more than 5 minutes**
- I never blank out/lose consciousness**

be used to automatically generate a clinic letter that will be populated with details recorded in the patient's EPR including patient demographics, referring clinician information, epilepsy seizure and syndrome classification, etiology, current and prior medications, issues discussed during the clinical encounter, and plans for further investigations, and so on. By selecting My Epilepsy Clinic Letters (Figure 5A), a list of EPR-generated letters, with the name and organization of the clinician who created it can be accessed. By selecting any of these, the letter can be viewed via PiSCES (Figure 5B). Such letters are available without delay following the clinical encounter.

3.5 | Help us to measure your progress

PiSCES provides patients functionality to report on their health status or healthcare outcomes. For example, via the "Help Us to Measure Your Progress" module (Figure 6),

FIGURE 6 Help us measure your progress

patients can access standardized epilepsy relevant questionnaires (eg, The Liverpool Seizure Severity Scale⁴¹ and Knowledge of Epilepsy Scale⁴²).¹ In addition, clinicians can implement customized patient questionnaires or status reporting forms via PiSCES. Capturing patient-reported outcomes in this way allows healthcare professionals to more closely and promptly monitor patient response to treatment.

3.6 | Prepare for your clinic visit

PiSCES facilitates PwE/Carers to prepare for encounters with their clinician. The PiSCES "Prepare For Your Clinic Visit" module includes a checklist (Figure S5) of things to do to prepare for the next clinical appointment. It also provides a facility for the patient/carer to document their questions to be reviewed with their HCP at the next clinical appointment.

3.7 | Information for your healthcare provider

The “Information for Your Healthcare Provider” section of PiSCES provides a more detailed version of the patient's epilepsy summary record than is available from “My Epilepsy Care Summary” (Figure 2B). Some examples of the types of information provided here include VNS settings, witness account of seizures, handedness, driving status, hospital name, hospital phone number, and name of consultant neurologist. The intention here is to use this in the context of a passport for epilepsy care. For example, if a patient attends a clinician who is not usually part of their circle of care, they can provide them with access to this additional detail (Figure S6). This need could arise in the context of emergency care.

4 | DISCUSSION

The COVID-19 crisis brings into sharp relief an urgency to accelerate much-needed health service reform. As evidenced by the prompt and courageous changes being made to address the immediate impact of the pandemic, the processes and technology to enable new models of healthcare exist. Around the world, a necessity, and even a moral obligation, for remote care has suddenly been thrust upon clinicians and patients. Similarly, the care of patients with epilepsy during the COVID-19 crisis in Ireland has largely shifted to telephone and video consultation interaction, with little face-to-face direct communication, except in emergency situations. PiSCES completely aligns with solutions that are now being designed and indeed implemented with increasing speed as we find novel and improved ways to communicate with patients and families, sometimes to replace but more often to complement more traditional models of healthcare. We must seize this opportunity to sustain health service innovation in the post-COVID-19 world.

PiSCES is a technical solution designed to promote patient- and family-centeredness of epilepsy care. To meet the wide spectrum of potential end-user needs and use contexts, it provides a range of functional features that can facilitate delivery of more personalized, proactive, and precision epilepsy care. However, it is not envisaged that each individual patient (or carer) would continuously use all of the PiSCES features. Rather they can use those feature(s) that are most relevant at particular points in their epilepsy care journey. For example, as better health outcomes are seen in those with greater understanding of their health condition,^{37,42} patients empowered through access to their epilepsy care record (Figure 2B) and goal setting tools (Figure S4) may adopt the engagement and self-management behaviors that lie at the heart of PFCC. Similarly, where a clinician wishes to more closely monitor a patient's response to a new or recently changed treatment

regimen, the patient may be asked to report their progress (Figure 6) over a given duration using PiSCES.

Healthcare democratization is shifting traditional medical paternalism to more mutual partnerships between HCPs, patients, and their families.⁴³ It is fundamental to realizing the promise of PFCC, where the role of the healthcare professionals changes from “experts that care for patients to enablers that support patients to make decisions.”⁴⁴ PiSCES can help to democratize epilepsy care as it supports people in defining and achieving their health goals collaboratively with their healthcare provider.⁴⁴ Furthermore, across the world, healthcare reform has a quadruple aim of better health, patient experience, provider satisfaction, and value for money.⁴⁵ Objectives include a move away from simply treating ill people to promoting and maintaining health and well-being, a shift from hospital-centric models to better integrated care that treats people at the lowest level of complexity that is safe, timely, and efficient, and as close to home as possible.^{4,35} ePortal-enabled PFCC such as that made possible by PiSCES is at the core of this reform.

However, while the potential benefits of PiSCES may be appreciated, their realization can be more challenging. As illustrated in Figure 1, design, development, and implementation requires commitment of a range of stakeholders, who often have competing priorities, over a lengthy period. Our ability to do this has stemmed from a strategic approach to eHealth-enabled continuous quality improvement (CQI) of Irish epilepsy services that started back in 2005 and continues today. The strategy uses engaged health services research in collaboration with people with epilepsy, their families, and HCPs to understand the role information sharing and exchange plays in facilitating better integration and continuity of care. From this, eHealth solutions are co-designed from the ground up, promoting a sense of participant ownership that drives technology development and enables its subsequent adoption. Execution of the strategy has been made possible with research and development funding (eg, from the Irish health research board) and health services funding of the NCPE to operationalize resultant innovations.

While this article provides a comprehensive illustration of PiSCES functionality, it lacks a detailed description of the technology underpinning the system. However, the corresponding author may be contacted for further information. The current omission of a seizure diary facility in PiSCES is not an oversight. Although this was identified as a requirement, it was intended that the project would collaborate with an existing seizure diary technology provider and integrate it with PiSCES. Inclusion of seizure diary functionality is anticipated in a future PiSCES iteration.

The scope of this article was to illustrate the functionality of PiSCES. The solution is currently being implemented with a core group of PwE and care partners, epilepsy specialist nurses, allied health professionals, and consultant

and nonconsultant epileptologists to examine how PiSCES can lead to more empowered or activated patients; enhance the patient-healthcare provider partnership; facilitate more holistic biomedical and psychosocial care; provide a passport of care between different providers and healthcare sectors (eg, pediatric to adult transition; integrated care between community and hospital settings); and promote appropriate adoption of remote/virtual care models. An important goal of this ongoing research, which we will report in a subsequent article, is to more fully understand how and where PiSCES can be of benefit so that it can be effectively and successfully deployed. We will also be rapidly adopting the lessons learned from the use of PiSCES during the COVID-19 pandemic and translating this learning into new iterations of the system.

Finally, like all eHealth initiatives, PiSCES implementation is not merely a technology project, it is more to do with the people (providers and recipients of care), processes, and associated behavioral change and expectations. We are keen to both share our learning and learn from others who are interested and/or involved in similar projects. Such collaborative learning could be facilitated by the establishment of an International League Against Epilepsy (ILAE) working group on eHealth-enabled epilepsy care.

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CONFLICT OF INTERESTS

None of the authors has any conflict of interest to disclose. We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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ENDNOTE

¹ Liverpool Seizure Severity Scale and Knowledge of Epilepsy Scale used by PiSCES with permission of authors.^{41,42}

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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