Determinants of health and wellbeing in refractory epilepsy and surgery: The Patient Reported, ImpleMentation sciEnce (PRIME) model

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ABSTRACT

This paper offers a new way of understanding the course of a chronic, neurological condition through a comprehensive model of patient-reported determinants of health and wellbeing: The Patient Reported ImpleMentation sciEnce (PRIME) model is the first model of its kind to be based on patient-driven insights for the design and implementation of initiatives that could improve tertiary, primary, and community healthcare services for patients with refractory epilepsy, and has broad implications for other disorders; PRIME focuses on: patient-reported determinants of health and wellbeing, pathways through care, gaps in treatment and other system delays, patient need and expectation, and barriers and facilitators to high-quality care provision; PRIME highlights that in the context of refractory epilepsy, patients value appropriate, clear, and speedy referrals from primary care practitioners and community neurologists to specialist healthcare professionals based in tertiary epilepsy centers. Many patients also want to share in decisions around treatment and care, and gain a greater understanding of their debilitating disease, so as to find ways to self-manage their illness more effectively and plan for the future. Here, PRIME is presented using refractory epilepsy as the exemplar case, while the model remains flexible, suitable for adaptation to other settings, patient populations, and conditions; PRIME comprises six critical levels: 1) The Individual Patient Model; 2) The Patient Relationships Model; 3) The Patient Care Pathways Model; 4) The Patient Transitions Model; 5) The Pre- and Postintervention Model; and 6) The Comprehensive Patient Model. Each level is dealt with in detail, while Levels 5 and 6 are presented in terms of where the gaps lie in our current knowledge, in particular in relation to patients' journeys through healthcare, system intersections, and individuals adaptive behavior following resective surgery, as well as others' views of the disease, such as family members.

1. Introduction

1.1. Implementation science for translating evidence into policy and practice

A clear gap has been identified, across a number of medical fields, between research study outputs and the implementation of scientifically proven health interventions, described as an "ongoing barrier between concept to clinic" [1]. The gap can most usefully be addressed with the application of models of care underpinned by implementation science; the study of strategies to promote intervention uptake that prove effective in routine practice [2].

In the health service and medical research fields, implementation science advocates effective, evidence-based interventions, in targeted settings, to improve health and wellbeing for specific populations [3]. Implementation science seeks to examine a wide range of intervention effects, and the long-term sustainability of new knowledge as it is integrated into clinical practice [4]. As a result, implementation science concentrates on not only evidence translation, but also uptake, acquisition, and dissemination (fidelity, spread, and assessment) [5]. By throwing its net widely, implementation science can strengthen

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uptake such that it is effective, supportive of healthcare professionals, patients, and the systems in which they work [4,6,7].

1.2. Implementation science in neurological and brain disorder fields

For implementation science to be effective, however, across medical fields including neurology and brain disorders, a carefully crafted implementation model is needed. This makes the disease condition accessible to others, can act as a communication device and framework for change, and inform new interventions to bring evidence into practice [8].

Implementation models (also known as 'frameworks' or 'theories' [9]) aim to influence both process and procedure and successfully translate research outcomes into practical solutions for healthcare delivery. They must be contextually relevant and capable of problem resolution [10]. However, selecting an appropriate model is not easy. Choices must be relevant to the scientific or social scientific context [4,11], and effective in addressing a host of complex factors such as how to relate long-term care planning to priority-setting, and shared-care [12]. They must be topic-sensitive [9,13], open to refinement, and include achievable goals [14].

However, to choose a model that will be effective, researchers face a host of complex challenges. They have to weigh up the strengths and weaknesses of different variables, identify their methodological strengths and weaknesses, and decide whether to use a model already in existence or design something new. A multidisciplinary team of scientists and social scientists, methodologists, and healthcare professionals can help with this, examining disease 'fit', sifting through less or more relevant variables, and factoring in key knowledge translation matters.

1.3. Scientific models already in existence in the neurology and brain disorder field

Wensing et al. [15] have designed a model for chronic conditions to examine the determinants of practice. Their model concentrates on healthcare professional-reported practice, and uses clinically-focused interviews and expert professional groups to assess the impact of professional reporting on clinical care. Their model is generic and applicable across chronic conditions. Within the neurology and brain disorder fields there are also bioscientific models in use. These include models that indicate disease phenotypes through advanced neuroimaging [16]; microsimulations of brain disorders [17]; loss of visual acuity in Multiple Sclerosis [18]; drug discovery in Alzheimer's, Huntington, and Parkinson's Disease [19]; and cognitive flexibility in the Autism Spectrum Disorder [20]. There has also been a Toolkit to improve professional practice in brain research in middle- and low-income countries https://www.fic.nih.gov/About/center-global-health-studies/ neuroscience-implementation-toolkit, Quality-of-Life (QoL) profiling for patients with active epilepsy [21], diagrammatic impressions of resilience in the context of epilepsy [22], and illustrations of patient narratives of journeys to surgery [23]. However, Wensing et al.'s model [15] concentrates on clinician-driven data, while the QoL and patient profiling work outlined above concentrates on specific, often singular aspects of a patient's life (such as their degree of activity or extent of physical movement). As a result, these latter models lack scope and the former, Wensing model is not particularly relevant to the current interest. For example, the Toolkit to improve professional practice concentrates on an educational package, and the bioscientific models attend to clinical improvements, while emotional and psychosocial wellbeing is rarely discussed — particularly not in its broader context. Consequently, while focusing on the pathogenesis of a disease, extant models overlook the implications of disease progression for patient experience. While considering how to manage drug tests, models to date have downplayed patient responses to side effects, and while assessing drug-taking, current models ignore the effect of a patient's personal preferences and worries on concordance.

This paper reports on the design of a new model, in which we set out to develop an entry point into understanding more about complex chronic diseases, and in particular refractory epilepsy, from the patient perspective. We also aimed to present a new pathway for patients to surgery, as we recognized that moving between chronic epilepsy and surgical intervention is confusing and daunting for patients.

2. Methods/model presentation

2.1. Designing a model in chronic diseases

In order to develop our model, we considered the work of Rabin et al. [14] and our own writing on Implementation Science [9]. Rabin et al. identified five foundational concepts underpinning implementation science models. They are as follows: 1) Diffusion (models should have the power to spread ideas and change behaviors), 2) Dissemination (models should provide useful, clear evidence for targeted audiences), 3) Implementation (models should not only produce new knowledge but provide harnessable solutions to improve service delivery), 4) Adoption (models should indicate processes and/or practices to move knowledge forward in real-time settings), and 5) Sustainability (models should lead to implementable interventions with long-term scope). We applied these principles as we planned the development of our model and questioned its clarity at both the individual and group level. As the model took shape, we asked ourselves whether its component parts were clearly aligned and coherent, rigorous, based on the data collected; lent themselves to clinical evaluation and assessment [24]; could create knowledge that would inform routine care [25]; ensured patient-reported outcome measures had the same leverage as clinical measures; and could support revelations in theory and practice. While all elements of Rabin's framework are important, their integrative nature, translated into a model can 1) help to overcome system variance, 2) lead to more sustainable intervention uptake, and 3) offer greater opportunity for knowledge spread.
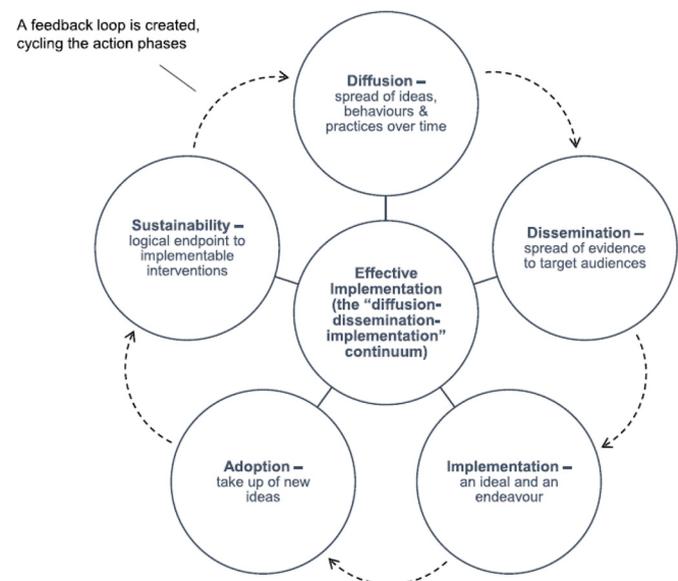

Illustration 1. Foundational implementation science concepts underlying the development of PRIME.
Source: Rapport et al. [9] based on Rabin et al. [14]

The model that we describe was designed to encompass more than just barriers and facilitators to evidence-based, high-quality care, as others have done [26,27], in favor of a comprehensive assessment of

the following: 1) patient-reported determinants of health and wellbeing, 2) pathways through care, 3) gaps in treatment and other system delays, and 4) patient needs and expectations. While others have concentrated on applying models that are already in existence, in order to advance the field of knowledge translation and promote generalizability [28], we see the value in the design of an entirely new model that can contend specifically with patient-reporting in neurological and brain conditions and that maps well to refractory epilepsy and surgery. Thus, the model is of our own making. While we reflected on others' writings on the topic, particularly the literature's extensive evidence-base on foundational concepts in implementation science underpinning model development [2–4], by creating a new model, we hoped to expand on the scope of what current models can offer.

Using refractory epilepsy as the exemplar case, we recognized eight primary conditions that were critical for this model, in line with our previous work [9,29,30]. As follows, the model should:

1. Include clinical and nonclinical factors across the care continuum
2. Foreground patient views
3. Be robust, efficacious and reliable in the face of system change
4. Examine multiperspectival aspects of patient care
5. Fit tertiary care contexts but be adaptable to community and primary care context
6. Indicate new knowledge
7. Have relevance to a wide range of chronic conditions.

2.2. Levels of the model and working methods

The model — from hereon in also known as The **P**atient **R**eported, **I**mple**M**entation sci**E**nce (PRIME) model — can be represented across six levels (Diagram 1).

In effect, PRIME, as an overarching vision and framework to explain the delivery of care, contains six feed-in models. Diagram 1 illustrates this, with the first feed-in level being Level One, the Individual Patient Model, working toward the final feed-in level, Level Six, the Comprehensive Patient Model. As Diagram 1 indicates, as the Model progresses toward Level Six the levels become increasingly more complex and less complete, because of the gaps in our knowledge of Levels Four to Six. The sections below show this while explaining each level in detail.

2.2.1. Level one: the individual patient model

The model's first level, **Level One**, is **The Individual Patient Model.** This reflects patients' real-time knowledge and individual "lived experiences" [31]. While patients' views and experiences guide all six levels, in the exemplar case, they are derived from a research program that triangulated experiential knowledge, with an audit of patients' medical records and epidemiological patient data [29]. The program (reported in detail elsewhere [29]) comprised the following: 1) an assessment of qualitative methods use in epilepsy research [19]; 2) epilepsy service use (including patient mortality, drug use, and emergency department admissions for 66,000 patients with epilepsy across NSW between 2011 and 2016) [32]; 3) patient and clinician characteristics for patients accessing two Tertiary Epilepsy Centers (TECs) in NSW in 2017; 4) patient and clinician interviews and observations (conducted between 2017 and 2018) [30,33]; 5) patient-completed Health-Related Quality-of-Life (HRQoL) surveys; and 6) an audit of medical records across two TECs for 50 patients who were accessing services in 2014 [29] .

The funded program obtained all the necessary ethics and governance approvals from the lead university's Human Research Ethics Committee (HREC), while Site Specific Approvals (SSAs) were obtained from two hospital sites involved. The program followed the ethical principles of the lead university and hospital sites, while fully informed consent was obtained from patients and healthcare professionals before any data were collected. Following collection, all data were anonymized, remained confidential, and were deidentified. All participants agreed to anonymized data being included in study reports, publications, and other study outputs.

The patient and clinician characteristics data and interview and observation data, in particular, helped focus PRIME on patient-reported determinants of health and wellbeing, pathways through care, gaps in treatment and other system delays, patient needs and expectations, and barriers and facilitators to high-quality care provision. Data were analyzed across multiple events, while a random sample of 12 patients (six from each of two TECs offering surgical intervention, and six of their consulting neurologists, three from each TEC, total sample n = 18), provided rich, in-depth narratives about personal, public, and professional experiences (See Box 1 for patient and clinician characteristics). The sample size (n = 18) was enough to reach data saturation, while multiple interviews ensured full member checking against data collected, triangulated with data from patient medical record reviews.

In this research, while interviews and observations were ongoing, interview transcripts and observation notes were assessed systematically, through a combination of thematic and schema analyses [30,34]. These methods are reported in detail elsewhere [35], but in brief, involve consensus-building through analytic group work, around both a thematic framework and its key themes and categories. Thematic analysis was supported by vignette development (succinct schemas) [34], one for each patient, that outlined key aspects of each patient's case (Box 2). The technique is rigorous and enables a verification of datasets. It matches findings to aims and objectives and validates working methods. Ongoing
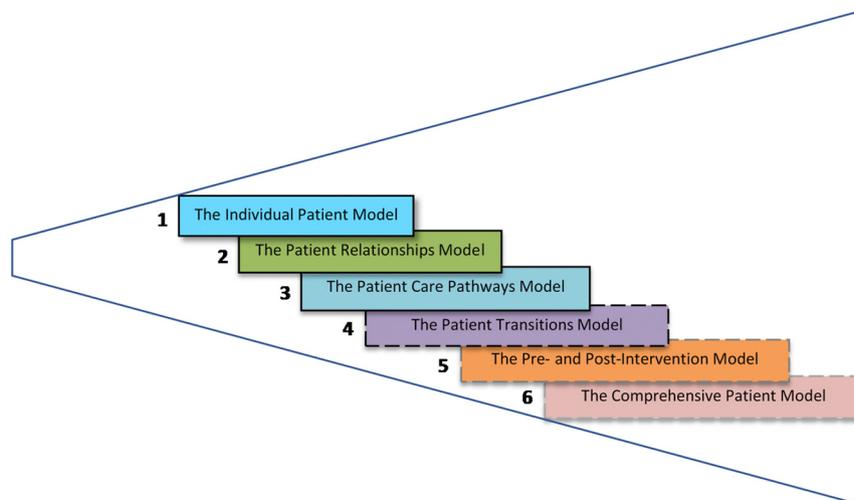

Diagram 1. Six levels of PRIME.

Box 1
Patient and clinician characteristics.

- Twelve patients referred to one of the two NSW TECs for surgical assessment.
- Five females/seven males: mean age 38 yrs., age range 23–67 yrs., SD 12.5 yrs.; mean age of first reported seizure onset 19 yrs., age range 2-37 yrs., SD 9.7 yrs.
- Patients at different stages along the care pathway.
- Patients involved in ongoing observations and interviews + HRQOL survey.
- Three of 12 were recently referred to a TEC for clinical evaluation.
- Four of 12 were undergoing presurgical assessment, one of whom was undertaking a video-EEG, and another of whom was at the late stages of presurgical assessment leading up to neurosurgical consultation.
- Four patients were interviewed postsurgery, with one of those reporting continued seizures, and another preparing for a second surgery.
- Nine were married or in a defacto relationship, four of whom had children, and another was the sole carer of a wife with a disability.
- Seven patients were unemployed, while the remaining five were in either part-time (N = 2) or full-time (N = 3) employment.
- Three clinicians from each study site were recruited. Two = early-career, 2 = mid-career, 2 = senior clinicians. Equal numbers of male and female clinicians.

Box 2
Example of a patient vignette; Patient 11

Patient 11 had refractory epilepsy for 27 years. Prior to TEC-referral her epilepsy was misdiagnosed, and consequently, she was pre-scribed numerous medications, which did not control her symptoms and was finally referred from her community neurologist to a specialist in hospital to assess her condition. She was initially hesitant to seek this second opinion, saying: "*I wasn't going to go to another neurologist because I'd been to this fellow my whole time*". But when she and her family were told about the epilepsy diagnosis she felt such a relief she decided to pursue a hospital referral: "*And now everybody's suddenly putting all the pieces together*". She was shocked when surgery was then offered: "*When they mentioned it I was crying going, 'God no, you're not doing that to me…'*". However, the neurosurgeon consultation reassured her, as the surgeon noted: "*We don't have anything to worry about because I do this every single day*". Her trust in him was reinforced by another patient's recommendation, and through her own background reading: "*I was getting that trust*". She now feels more optimistic about surgery: "*If they can fix it to an extent where it's not going to bother me and it's going to make me a better quality of life that's what I want.*" She had been worried about potential cognitive deficits resulting from surgery but was more concerned about her ongoing seizures: "A*s long as the turns don't happen anymore I don't care*" and her relief at the prospect of having her drugs reduced was palpable: "*I'm probably on about 12 tablets a day. If you can knock me down to about three or four then I'll be happy with that*". During the video-EEG assessment, she felt well-supported and closely attended to, and while she was anxious about being taken off medication and having seizures induced, she still felt positive: "*I was sitting there thinking 'oh my God, it's going to happen'*".

refinement of the method led to group analysis workshops [36] where shared understandings were noted across working groups.

As a result, **Level One, The Individual Patient Model,** came into being. **Level One** emphasized the importance of patient knowledge and understanding not only of the healthcare system, but also of the disease and 'disease type' (group-level or population-level experience), we saw through our research, wanted more detailed and nuanced information about their disease and others' experiences of the disease, in order to feel confident to progress with treatment and care. They also wanted to understand the implications of the disease in the shorter and longer term. Information helped patients manage their own care, and as a consequence, led to less dependence on others such as family members. When knowledge of the healthcare system, disease, and disease type were forthcoming, patients' confidence improved and so did their mood. They felt more supported in pursing their health goals, such as seizure reduction or eradication, evident through three high-level patient domains (external variables) and their associated internal characteristics (Diagram 2).

2.2.2. Level two: the patient relationships model

Level Two is The Patient Relationships Model. Patient relationships are defined according to links with family, clinicians and others in the wider healthcare system (Diagram 3). This is affected by patients' emotional challenges, the personal strengths they find to deal with those, and an ongoing sense of community that is experienced when services are provided by caring others. **Level Two** describes this in terms of four essential, foregrounded component parts: 1) relationships with family, 2) relationships with healthcare professionals and the healthcare system, 3) inner strength and emotional challenges and 4) social connectedness. The internal characteristics are backgrounded but provide the context to the relational qualities.

Level two derived from year-long observations, undertaken in the TEC clinic settings, of clinicians, patients, and family members.

Observations, an ethnographic, 'in-context', enculturated method [38], enabled a study researcher, not directly involved in the events and conversations being observed, to gather an independent perspective. At different times and on different days observations were undertaken
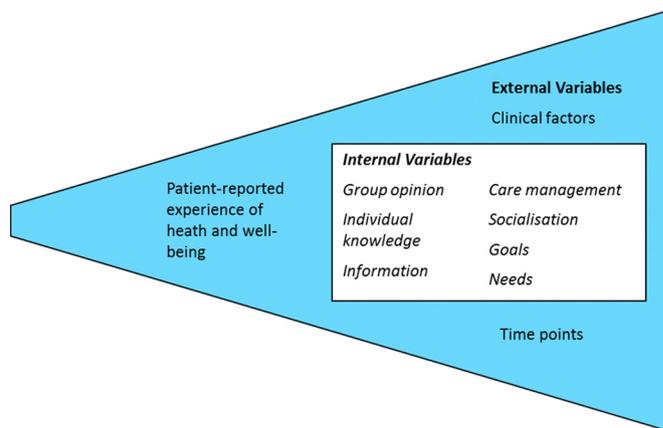

Diagram 2. Level one: core factors in the individual patient model.
KEY: High-level domains in **bold**; internal characteristics in *italics*. 1. **Patient-reported experience of health and wellbeing:** *Personal, group, and societal knowledge of epilepsy; views on health and wellbeing; sense of community belonging, social responsibility, and social activity; self-care and self-management; expressed needs; and future goals.* 2. **Time points:** *Individual care pathways, time lags, key time points, care as a continuum.* 3. **Clinical factors:** *Expert knowledge, clinical information provision (within and outside hospital), service access, and service use.*
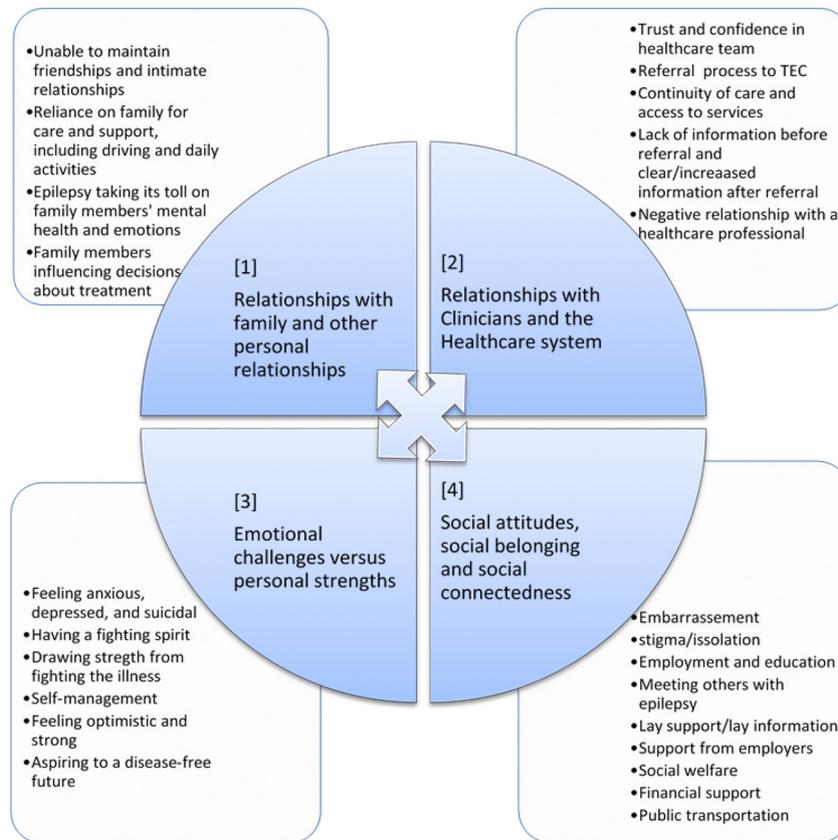
Diagram 3. Relational qualities of PRIME and component parts in the exemplar case.
Source: Reconceptualized from Shih et al. [37].

of clinical consultations, patient interactions with allied healthcare professionals, and decision-making around care pathways. This encouraged an in-depth assessment of patient consultations as patients progressed toward surgical intervention. It included discussions of blood tests, drug treatments and other therapies, surgery, and video electroencephalography (EEG). The researcher considered the timing of discussions, the language used by patients and healthcare professionals, and the intentions expressed. Field notes were taken of the interactive process, emotive expression, environment and setting, and the multifaceted nature of the "social worlds" within which interactions took place [38]. Observations were assessed alongside other data (interview transcripts, field notes, and medical records) using a consensus-building, group work activity used extensively by the team [34], while data triangulation led to an assessment of the relationship between clinical interactions, care delivery, and system complexity. Data revealed that positive clinical relationships help build trust in the system, while optimism and hope reduce a patient's sense of isolation and can alleviate social stigma. Nevertheless, patient and clinician narratives and observations also indicated the extent to which relationships were often in a state of flux, as clinical and nonclinical factors came into play to impact on patient positivity, trust and optimism (Diagram 4).

2.2.3. Level three: the patient care pathways model

Level Three, The Patient Care Pathways Model, exemplifies patient journeys through care, which are always in flux. This is implicit in the way patients report their experience and their understanding of the complex and rapidly adaptive world of healthcare delivery. **Level Three** is the level where patients not only discuss the problems they face as they move through the system, but also the clinical activities undertaken along the way.

While **The Patient Care Pathways Model** might imply linearity, as with other depictions of chronic conditions [33], this is not a linear progression. We have found that linearity does not adapt well to refractory epilepsy, nor does it lend itself to patient narratives or to our observations of patients' progress through the system. Rather, activity centers on the adjustments and accommodations made, and sometimes, the dramatic twists and turns in patient journeys, which result in disjuncture at different time points, such as delayed entry into hospital. Fig. 1 shows Patient 4's journey through care, with a qualifying statement indicating how unexpected changes in patient experience turned a linear journey into a fractured pathway. In Fig. 1, the patient's journey is defined by a number of seemingly arbitrary and changing pathways
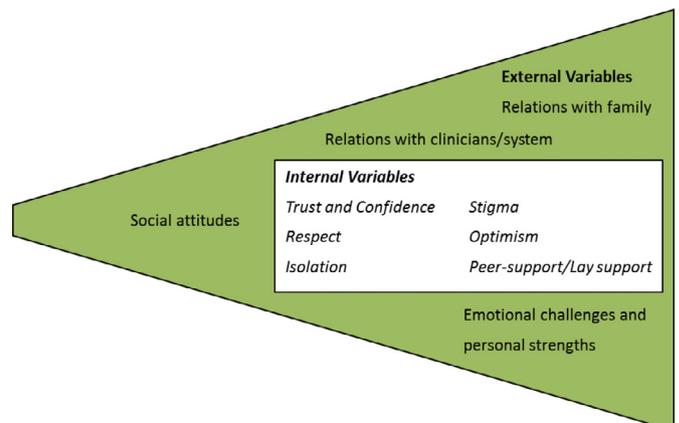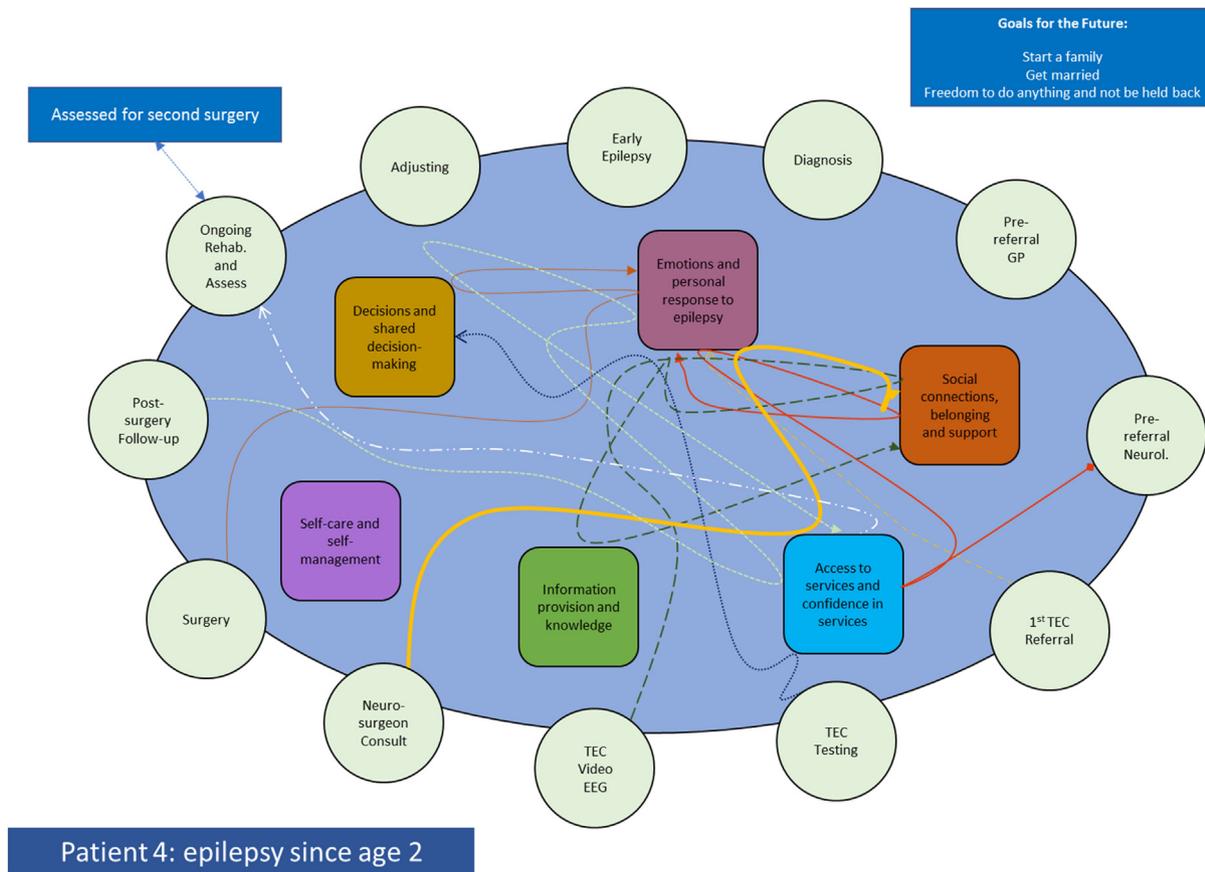

Diagram 4. Level two: core factors in the patient relationships model.

Fig. 1. Patient 4's journey through care.
Source: Authors' own work.

through care (identified by the direction of the meandering arrows), resulting in the patient moving around between systems and services, with little to make sense of, or connect the different colored arrows to each other.

While a fractured pathway is disadvantageous to practice and to clinical teams, in terms of the energy and time needed to manage patients and move them through the healthcare system, we have discovered that these fractures also have their advantages. Firstly, patients have more time to look at new routes through care and to consider whether surgical intervention, as one of a number of options that may be available to them [39], including use of novel antiepileptic drugs, is

the most appropriate option. As they do so, they discuss clinical aspects of care in more detail, such as drug testing, treatment, and assessment, and along with their families, they begin to come to terms with new approaches at emotional, physical, and interactional levels. Secondly, periods of indecision compel patients and healthcare professionals to come together to set a new course, and by so doing, to arrive at an accommodation of one another. There is more time to think through options, ask questions, and discuss decisions with family members and friends. Thirdly, real-time delays can ensure positive adjustments and conformity to system adaptations. Disadvantageously, however, fractured pathways lead to greater surgical lead-in time, greater resource
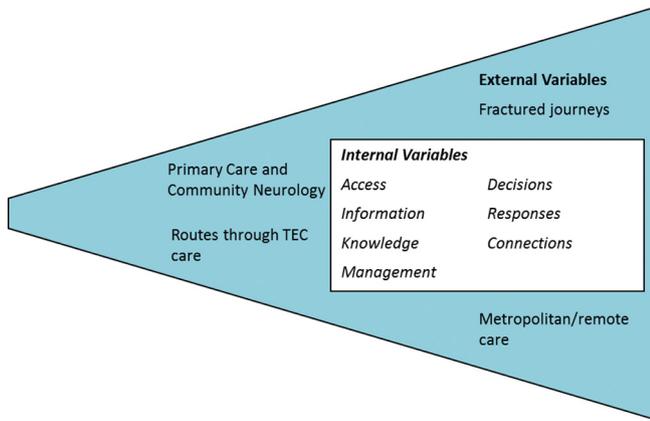
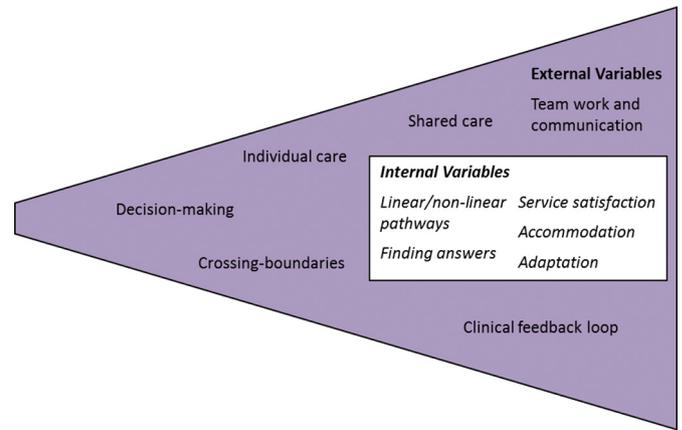Diagram 5. Level three: core factors in the patient care pathways model.

Diagram 6. Level four: core factors in the patient transitions model.

use, and other consequences such as patient indecision, and the possibility that no surgery will take place at the end of a long period of consideration. This can result from logistical complications, such as patients living in remote and rural locations and being unable to access the services they need when they need them, the challenges of delivering comprehensive care packages during a single patient visit, and complications from patients' deteriorating health or a change of heart [40] (Diagram 5).

2.2.4. Level four: the patient transitions model

Level Four: The Patient Transitions Model indicates the way that patients move between primary care, community neurology, and specialist neurology care in the TEC setting (Fig. 2). **Level Four** was derived from a research project undertaken in a community setting (2017–2018, ongoing), where a study researcher spent a year visiting community neurologists at work in their clinic to collect in-depth, rich, and context-driven data. The researcher interviewed patients and their families and community neurologists, examined interactions and discussions with patients, and considered general practitioner (GP) arrangements for care transitions and neurology referrals to TEC specialists. The researcher concentrated on the variety of patient pathways to TEC referral and approaches to shared care, assessing how decisions were made and what information was processed. In epilepsy research, the subjective experience of patients often tends to be considered using quantitative measures that fall short in revealing nuanced experience and expression [41] while our qualitative work indicates that patients project complex thoughts about treatment options that quantitative tools simply cannot capture [30]. **Level Four** is the level

where the gaps that exist in knowledge become apparent, particularly around: models of shared care delivery, approaches to shared decision-making, and boundary-crossing. **Level Four** also identifies where weaknesses manifest in clinical feedback loops, and in the communication between hospital specialists, GPs, community neurologists, and patients.

Level Four is defined according to six external variables: 1) team work and team communication, 2) shared care, 3) individual care, 4) decision-making, 5) crossing boundaries, and 6) the clinical feedback loop. These six variables accord with five internal characteristics that relate to a patient's ability to find the answers to their questions and understand how to manage different healthcare systems, find satisfaction in services, and accommodate change (Diagram 6).

2.2.5. Level five: the pre- and postintervention model

Level Five: The Pre- and Postintervention Model concentrates on intervention, and in the exemplar case, surgical intervention. **Level Five** indicates the vital information that is currently missing about the following: a) time lags between clinical stages of care, b) knowledge of system intersections, complex systems, system adaptations, and system resilience. This has implications for strong clinical leaders and patient resilience [42], in particular, in relation to the external variables: diagnosis or misdiagnosis, drugs and drug-taking, tests, and treatments and assessments, in association with the internal characteristics: early epilepsy, GP, community neurology and neurosurgical assessment, surgical and postsurgical rehabilitation, and follow-up and ongoing adjustment (Diagram 7).
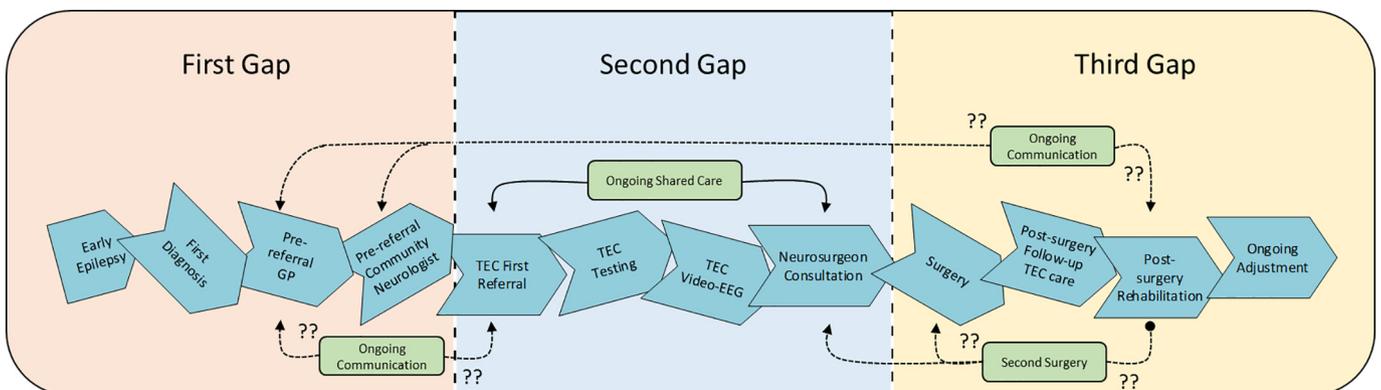

Fig. 2. Patient pathways and clinical time points. Key: ⎯⎯ Healthcare professional communication and shared care that does take place. ⎯⎯⎯ Healthcare professional communication and shared care that may take place.
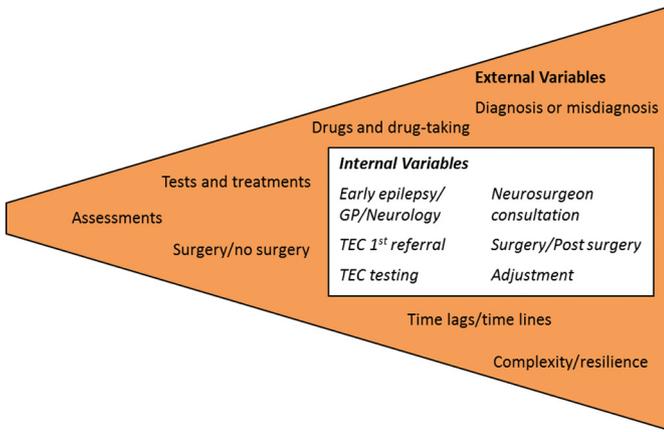
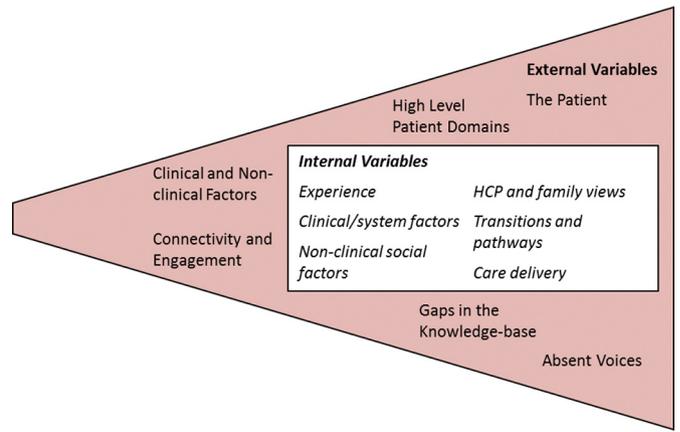**Diagram 7.** Level five: core factors in the pre- and postintervention model.

Diagram 8. Level six: core factors in the comprehensive patient model.

2.2.6. Level six: the comprehensive patient model

Level Six: The Comprehensive Patient Model is the final level of the Model (Fig. 3 shows all six levels in combination, for the exemplar case).

Level Six is also the level where all the other levels come together, indicating their interconnected and relational qualities and how each level leads to the next in terms of: 1) social networks and networking, 2) self-management and drug-taking, 3) information provision and self-knowledge, 4) patient-reported outcomes, 5) clinical and nonclinical factors, and 6) emotional and social aspects of health and wellbeing including patient-reported QoL (Diagram 8).

Level Six also introduces, for the first time, the notion of absent voices. We have little information on the effect of, for example, the clinician's opinion on patient decision-making, and we recognize other absent yet influential voices, such as those of family and friends. This is an underutilized resource [43,44], and yet PRIME is not unusual in being incomplete in this way. Thus, while **Level Six** emphasizes the detailed aspects of each level and overlaps, it also suggests macro and micro-level omissions. While few models present intrafamilial relationships or patient–clinician dyads, Patient 9's vignette (Box 4) indicates that gaining a more rounded understanding of seizure reduction and patient adjustment, by introducing some of those absent voices, may lend itself to richer and more rigorous reporting.

2.3. The utility of PRIME in clinical practice

An extensive evaluation of the model's key internal and external variables at each of the six critical levels is now planned, while a healthcare professional model will help contextualize PRIME's practical and clinical utility; PRIME has been developed to help illuminate how care is delivered in all its complexity, and to drive solutions to patient need and improve clinical practice in refractory epilepsy. Internal and external variables, across all six levels, will be tailored into a guide for practice
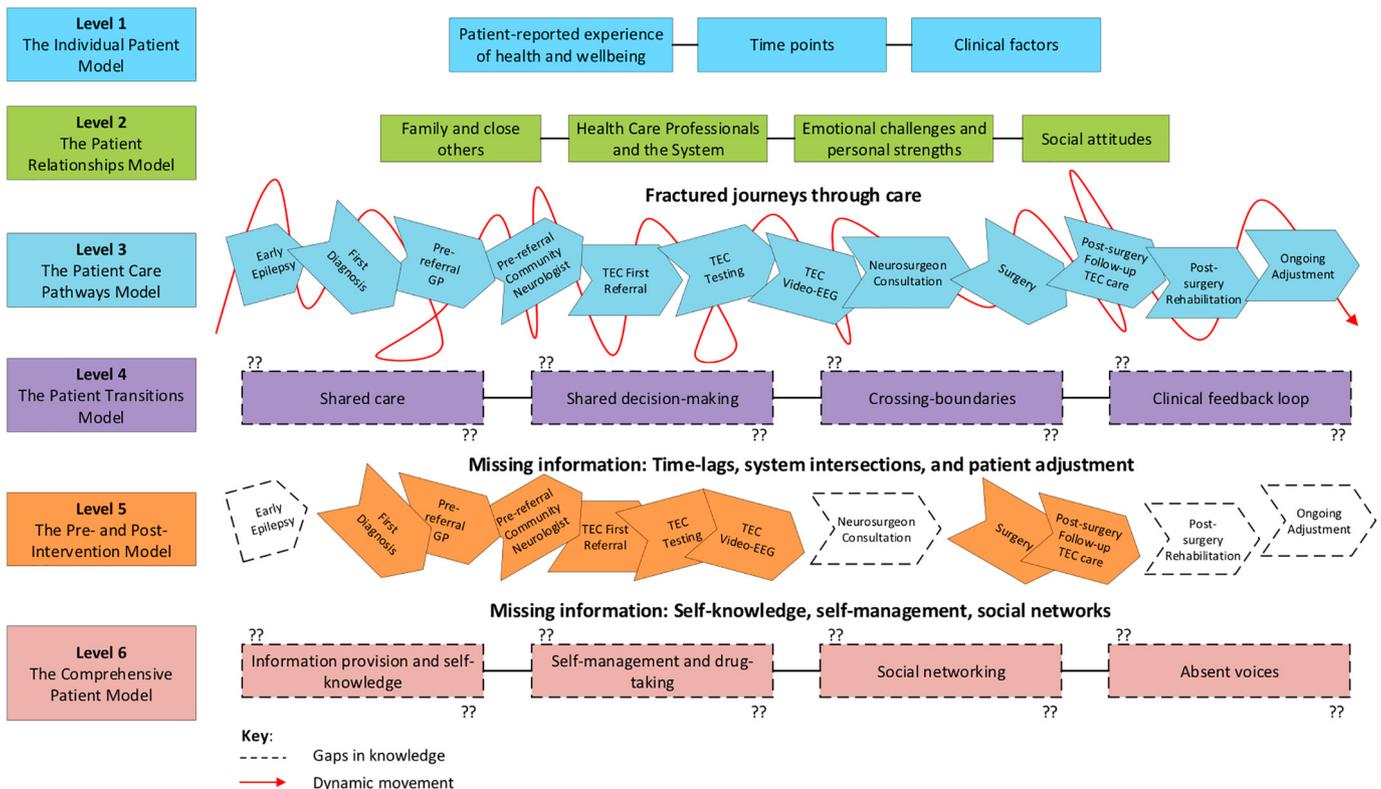

Fig. 3. All six levels of the patient model.

Box 4

Patient 9: patient–clinician dyad.

Twenty-seven years have elapsed since Patient 9 was first diagnosis with epilepsy. Since then he has undergone extensive assessments, tests and treatments affecting his ability to maintain a job. He has had two surgeries, which despite the personalized nature of his care have taken their toll on him, leaving him emotionally fragile, tearful, and disillusioned. This has affected his confidence levels, exacerbated by ongoing concerns about being able to continue to support a disabled wife. Yet there are extensive gaps in our understanding of presurgical experience, including the period between first TEC visit and video-EEG assessment. Did the views he held of excellent care create a sense of optimism during the video-EEG assessment and surgery and can he withstand another surgery? To understand this better, we can consider the views of supporting clinicians. While Clinicians 1 and 2 discuss improvements to patient mood and QoL postsurgery, Clinicians 2, 5, and 6 are much more circumspect, saying people like Patient 9 often find it difficult to adapt, irrespective of surgical results, and often take at least a year to adjust to: *"Not being the centre of attention with their epilepsy. If you remove that from them they can be psychologically stressed"* (Clinician 5). Clinician 6 adds: *"They're so much used to that disabled life, they can't get used to their normal life, and that creates problems"*.

through Nominal Group Technique, (a consensus-building activity that brings key stakeholders together to identify problems with care delivery, generate solutions, and reach decisions) [44]. The guide will directly link to the models' key components to address: improvements to pathways through care, treatment and other system delays, and barriers to high-quality care. It will be created in such a way that proves easily accessible for busy clinicians, and it will take account of resource restrictions and gaps in treatments and services. Each of the guide's component parts will be linked to key strategies and government policy directives making it both topical and evidence-based [15,45]. By providing identifiable features, healthcare professions will be able to engage with the guide to direct their services and behaviors more appropriately. In addition, the model will be modified for patient use, through the development of information leaflets and service-orientation documents, delivered at different stages of care. The model will help to dissect how services can support patients during: early epilepsy (public as member of the community/professional as generalist), prediagnosis to postdiagnosis (primary care); postdiagnosis to pre-TEC referral (community neurology care); postsurgical follow-up to rehabilitation (hospital care, specialist neurologist); and ongoing adjustment (patients returning to the community). The model will underpin the design of an educational template, with the aim of enhancing patient-centered care and patient-focused professional skills [46]. Thus, the versatility of PRIME will help with the translation of research outputs into various practical interventions aimed at improving care standards and care quality. In particular, PRIME's utility will be to better rationalize factors affecting patient progress through care and healthcare professional decision-making, while more directed patient information will ensure greater involvement in long-term disease management and self-care [47–50].

3. Discussion

In this paper, we have presented the PRIME model that will be of benefit to patients, healthcare researchers, and healthcare professionals interested in chronic neurological conditions. We have mobilized PRIME to understand the dimensions of a chronic disease through the exemplar case of refractory epilepsy, and have considered patients' health and wellbeing, system gaps, barriers and facilitators to care and patient need and expectation. The overarching model is patient rather than clinician-driven, making it unique in this field. It is defined according to six interlinking levels (Diagram 1 and Fig. 3), with the entry level being 'The Individual Patient'. The PRIME model embraces clinical and nonclinical information and indicates that patients exist in a tense coexistence with others; PRIME offers the clearest picture to date of a patient-driven model for a chronic condition. It also points to where further information is now needed to make it come alive as a usable service guide, as patient information documentation, as an educational tool and as an evidence-based intervention highlighting resource challenges and system complexity. Key information about epilepsy clinicians' views and experiences is now needed to ensure that the model is populated and demonstrates utility in clinical practice and to ensure better care transitions and reduced disease impact (individual, group, and societal).

The literature emphasizes that there is always an interplay between physical and psychosocial domains in epilepsy [51,52], while the World Health Organization (WHO) (2014) has recommended a thorough investigation of the way that social environments and social connections shape not only physical but also mental health outcomes [53]. The position of the WHO was preceded by the work of Jacoby and Baker [21]. Wilde et al. [54], for example, noted, through a suite of outcome measures, the importance of examining social role participation and patient HRQOL, for proven utility in the care of brain injury. Yuill, Crinson, and Duncan [55] identified six key aspects to this and presented a strong defense of the examination of social support networks alongside personal coping strategies. Yuill and colleagues [55] defined these as critical if we wish to understand social determinants of health and wellbeing, improve population health, address mental health problems, and equalize health discrepancies. The early work of Wilson and Cleary [56], on patient outcomes in medicine, paved the way for a conceptual model that linked patient HRQOL measures to a wide range of clinical variables. They emphasized a clear relationship between different patient outcomes and HRQOL, including general health perception, patient preference, emotional response, and biological, physiological, and symptom factors [56]. Wilson and Cleary noted that to optimize clinical interventions attention should be given to causal pathways, and our model offers a route to achieving this, while bringing attention to both the disease type and the individual. By doing so, PRIME has the capacity to identify "major influences" that impact on patients' health and wellbeing, "and the dynamic relationships among them" [57].

The PRIME model is also the first model to offer insights into the features that will matter when we design and implement initiatives that could improve tertiary, primary, and community healthcare services for patients with refractory epilepsy. As a result, it has broad implications for other brain and neurological disorders and, beyond those, to other chronic, complex conditions; PRIME illuminates how much of what patients value stems from appropriate, clear, and speedy referrals, from primary and community care settings to hospital specialists. This could not only help build confidence and trust in the healthcare system, but also reinforces a patient's belief that the right, patient-focused clinician can steer them toward more effective care, provided in the right setting at the right time. As PRIME highlights, emotional challenges often persist, despite tertiary care referrals, exacerbated by fracture lines in the care system — a system that is forever changing — but this could also lead to new approaches to conflict–resolution, and even acceptance of adaptations to care delivery.

3.1. Limitations

More extensive work on patient perspectives, through surveys or focus groups, and a parallel healthcare professional model would complement the work to date. The healthcare professional model would also lead to consideration of barriers to implementation within the healthcare setting, including resource limitations that affect the busy life of the clinical practitioner, for example clinician time limitations,

the limited numbers of neurologists and nurse specialists on wards, and access to EEG monitoring beds and neuropsychology resources. More information on these limitations and system restrictions would support the value and use of PRIME, as patients enter and exit hospital, approach surgical workup, and contend with follow-on care. We are aware, from PRIME's content, that during a patient's journey, professionals make complex, impactful decisions, while patients face radical life adjustments, and the healthcare professional model would aim to account for this, alongside system intersections at critical time points.

The PRIME model has indicated the importance of emotional resilience in refractory epilepsy [7] as patients face personal challenges and discover inner strengths. We must assess whether emotional resilience is the primary motivating factor for surgical uptake, or one of a number of factors. This will also indicate the capacity for emotional resilience to be a marker of mental health, social cohesion, and social activity. We also need to take account of absent voices — the opinions of clinicians, family members, and others — and how intrafamilial relationships influence patient decision-making.

In its first iteration, we have created PRIME as a model that offers a baseline from which to extend knowledge of the complex care systems that surround chronic conditions' management. To give greater national and international prominence to the use and value of PRIME, the work might be expanded to other populations.

4. Conclusions

This work has offered a new evidence-base for framing the course of a disease condition through the presentation of a comprehensive model of patient-reported determinants of health and wellbeing. The PRIME model can be adapted to other settings, patient populations, and conditions. It provides a unique starting point to understand the experiential knowledge of patients with refractory epilepsy of this debilitating condition, and a complex assortment of clinical and nonclinical factors intersecting across the care continuum. By evaluating the model further and extending it with professional-driven data, we can test it under a range of conditions. That is the next task.

Declaration of interests

None to declare.

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