



Integrated Care in Epilepsy

A rapid review of the key components of health and social care delivery



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List of Acronyms

AEDs	Anti-epileptic drugs
AHRQ	Agency for Healthcare Research and Quality
CAG	Clinical advisory group
CDM	Chronic disease management
CRO	Community resource officer
S/EMP, SAP	Seizure/epilepsy management plan, seizure action plan
ED	Emergency department
EMR	Electronic medical record
ENCT	Epilepsy nurse communication tool
ESN, EN	Epilepsy specialist nurse, epilepsy nurse
GP	General practitioner
ICP	Integrated care pathway
ILAE	International League Against Epilepsy
MDT	Multidisciplinary team
NCPE	National Clinical Programme for Epilepsy
NDIS	National Disability Insurance Scheme
NICE	National Institute for Clinical Excellence
PCC, PC	Person-centred care, person-centred
PDSA	Plan-do-study-act
PLWE	People living with epilepsy
RAC	Rapid assessment clinics
SMART	Standardisation, multidisciplinary, audit, revision, and training
SUDEP	Sudden unexpected death in epilepsy
TAL	Telephone advice line
TSC	Tuberous sclerosis complex
UEC	Urgent epilepsy clinic
UK	United Kingdom
USA	United States of America

1. KEY MESSAGES

- Evidence-based integrated models and elements of care in epilepsy make it possible to overcome fragmentation of care, improving care experiences, and individual and system outcomes.
- Implementation of integrated models of care in epilepsy is an underdeveloped area.
- Contextual barriers and facilitators to implementing integrated models of care in epilepsy need to be understood to improve success and sustainability in practice change.
- The needs of the person living with epilepsy and their family should be central to all changes in service design and delivery.
- Harnessing digital technologies can support integrated care but requires governance support and resources.
- Care coordinators, such as epilepsy specialist nurses (ESNs), have a vital role in linking all stakeholders to ensure value-based, person-centred (PC) integrated care.

2. BACKGROUND

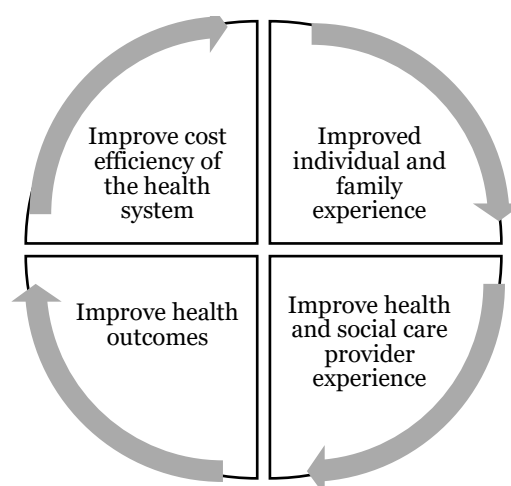
Epilepsy is the most common neurological condition worldwide, causing 0.6% of the total disease burden and impacting people of any age (1). In Australia, there are over 250 000 people living with epilepsy (PLWE). Around two-thirds of people with epilepsy can have their seizures successfully managed with the use of anti-epileptic drugs (AEDs) (2, 3). However, the remaining third of people are living with complex epilepsies that are drug resistant, i.e., not controlled effectively by at least two medications (4, 5). The side effects from AEDs, which may be associated with behavioural, cognitive, psychiatric, and physical impacts, can also further complicate the management of epilepsy and add to the burden of living with epilepsy (4). Consequentially, regardless of whether seizures are controlled or uncontrolled, PLWE can experience psychological, physical, and social concerns, necessitating ongoing access to health and social care across the life course (6). At the same time, there is international recognition that navigating and moving through fragmented health and social care systems can be challenging for PLWE, resulting in unmet needs in receiving timely care and treatment (6, 7). Internationally, there are significant barriers and inequalities in access to healthcare amongst people with epilepsy (8).

Previous research has highlighted the lack of coordinated and shared care between primary, community, and tertiary care in Australia, hindering the provision of efficient and timely care, reducing opportunities for cost-effective services, and negatively impacting on the overall care experience and outcomes for PLWE (9–11). Current management of epilepsy in Australia relies heavily on specialist care in hospitals, rather than in community and primary care settings better suited to ongoing management for chronic conditions, reflecting systemic failures in optimising care (9). People living with drug resistant or difficult to control epilepsy have ongoing chronic and complex needs, which can greatly impact quality of life and health outcomes if not effectively managed. Importantly, there is a higher prevalence of certain comorbidities, such as depression, movement disorders, cognitive impairments, in PLWE as well as greater experiences of social stigma and discrimination, reduced life expectancy, and greater mortality risk (12–14). Considering the complexity of epilepsy care over the continuum of care, developing an integrated person-centred care (PCC) programme could provide a solution to optimise care needs, health, and social outcomes.

Integrated care aims to redress problems in the way care systems are designed, to overcome fragmented care delivery to positively impact on care outcomes and experiences (15). Integrated care represents a coordinated approach to care delivery that is designed in response to PCC and ‘population-based’ health and social needs, under strong leadership and commitment, to ensure equitable care and support for the whole community (15–17). It involves cross-sector collaboration and linking of services to improve access, quality, and continuity of services and holistic care provision (18, 19). The adoption of effective communication practices is required for success in integrated care, and involves building strong interpersonal relationships and information and knowledge sharing between patients, families, care providers, organisations, and sectors (20). Integrated PCC aims to achieve the Quadruple Aim of improving: individual and family experience, health outcomes, the experience of healthcare and social care professionals, and cost efficiency of the health system (see Figure 1) (21). Fundamentally, value-based healthcare is framed on the Quadruple Aim which measures outcomes achieved in relation to cost, therefore supports greater efficiency in healthcare (22).

The **long-term management of chronic and complex conditions** is a challenge shared internationally, with such conditions causing significant economic burden on health and social care (15, 23). The Australian Institute of Health and Welfare reported that almost half of Australians have one or more chronic diseases (24). Rising costs and limited health and social care budgets to provide equitable and cost-effective care globally, have prompted the move to developing and implementing integrated models of care (18). Integrated care has become a leading approach to changing the management of people living with chronic conditions, to take a more holistic, person- and family-centred approach to care and support across the life course (15, 25). Adopting an integrated PCC approach, requires a paradigm shift from focusing on specific disease management, which is often fragmented, non-collaborative,

Figure 1 Quadruple Aim



and too often focuses on reactive medical care to promoting overall health and wellbeing considering the person holistically (15, 25). This approach involves effective coordination of care around PC health and social needs, with cross-sector collaboration, effective communication, and strong interpersonal relationships (9, 15, 26). It also implies an approach where PLWE become partners in care, e.g., through shared decision making with care professionals and being supported to self-manage in ways that promote their independence, health, and wellbeing (27)

2.1 EPILEPSY SPECIFIC ISSUES

The objectives of integrated care are not disease specific, however there are important dimensions of epilepsy that must be recognised in any attempts to improve care and management of this condition. Firstly, the spectrum in manifestation of seizure activity can vary in frequency (one seizure only to several daily) and type from non-convulsive seizures such as a brief lapse in consciousness called absences; atonic seizures that appear as ‘drop attacks’ as a result of a loss of muscle tone; and convulsive seizures such as tonic-clonic, the most easily recognised form of seizure. Specific criteria must be met for a diagnosis of epilepsy, according to the International League Against Epilepsy (ILAE), including: 2 unprovoked seizures more than 24 hours apart, or 1 unprovoked seizure and probability of further seizures, or an epilepsy syndrome is diagnosed (5). This variable and unpredictable presentation can often add to the challenge of identifying and understanding - and therefore effectively managing and treating - epilepsy, especially by non-specialists and in acute care settings such as emergency departments (ED) (9, 28).

Only about half of all epilepsy cases in high income countries have a known cause, while those of unknown causes may be related to currently unidentified genetic anomalies (5). Despite medical advances, the link between seizures and genes is complex and current genetic testing technologies may not identify this link. Some childhood epilepsies may be associated with syndromes which manifest in a range of signs, symptoms, and disabilities adding to management complexity. For example, Dravet syndrome and tuberous sclerosis complex (TSC) have been described by Professor Ingrid Scheffer as “complex puzzles” that require a coordinated, person- and family-centred, holistic approach across a wide range of specialities and throughout the life course (29-31). Epilepsy may also be associated with acquired neurological conditions such as brain injury, neurodegenerative conditions, and stroke, the latter two being more prevalent in older populations (5, 32, 33).

The prevalence of epilepsy is highest in the younger and older age groups (5, 34). This highlights the need for a population-based, whole systems approach to the equitable and timely access to health, social care and support, adjusted to individual needs (35-37). The timing of disease onset and different stages of life call attention to specific issues and needs:

- The needs and experiences of children with epilepsy (who may have genetic conditions/syndromes) and their families must be central to appropriate care and support (38).
- Transitioning PLWE from paediatric to adult care, particularly for individuals with intellectual disabilities and physical, psychological, and social comorbidities require ongoing multidisciplinary coordinated care and support [6, 7].
- The support and information available to pregnant women, relating to the impact of pregnancy on epilepsy and seizure control, risks of certain AEDs during pregnancy and follow-up support after the birth of the baby (39).
- Adult-onset epilepsy and disruption to identity impacts on family life and relationships, managing employment, and financial repercussions (40, 41).
- Epilepsy in older age and access to services, support in residential aged care, and the impact of age-related comorbidities (33, 42).

There are known differences in the prevalence and effects of epilepsy among different population groups. People in lower socioeconomic groups, and culturally and linguistically diverse populations have a greater prevalence of epilepsy and poorer health outcomes (5, 36). Archer et al (2006) noted that Indigenous Australians often present with more complex forms of epilepsy (36). Furthermore, the challenges of providing specialist services to regional, rural, and remote areas in Australia and other countries are well acknowledged. There have been calls for further research for solutions to improve access to epilepsy services in rural and remote regions (43, 44).

Seizures are only the tip of the iceberg in terms of the issues affecting quality of life for PLWE (45). Quality of life is not solely based on clinical outcomes and must also be considered from a social perspective (46). PLWE experience poorer mental health than the general population, this is often related to experiences of social stigma, discrimination, and side effects of medications (47, 48). Medication side effects may be more burdensome to individuals than their seizures, requiring a broader biopsychosocial approach to treatment that recognises seizure control may not be the ultimate aim (49). Mental ill-health is associated with less capacity for self-management of the condition and increased risk of seizures, and poor control of convulsive seizures is the strongest risk factor for premature mortality due to sudden unexpected death in epilepsy (SUDEP) (50, 51). People with epilepsy are also at a greater risk of premature death due to accidents, injury (e.g., drowning), and suicide (51, 52). In addition to mental health problems, memory, and cognitive problems have the greatest detrimental impact on quality of life (44). There is a major need for psychological services to be part of the integrated care pathway (ICP) for PLWE from diagnosis onwards (34, 49).

3. AIM AND RESEARCH QUESTIONS

3.1 AIM

The aim of this rapid review was to identify recommended and/or implemented models or elements of models of integrated care in epilepsy. We wanted to explore the research literature in the area of epilepsy and identify particular factors that could contribute to more effective, efficient, PC integrated care practices in an area where fragmentation of care and heavy reliance on specialist hospital-based services is common. We identified four key questions to guide and structure the review process and analysis.

3.2 RESEARCH QUESTIONS

1. How is integrated care in epilepsy described or envisioned?
2. What models or elements of care are recommended?
3. What are the common elements of integrated care approaches that have been implemented in epilepsy?
4. What impacts, outcomes, or effects of integrated care approaches have been reported for people living with epilepsy?

Terminology

For this review, we broadly define ‘integrated care’ as an approach to care that effectively coordinates services around people’s needs (15). Integrated care is the necessary response to the current fragmentations in care delivery that negatively impact on people’s care experiences and outcomes. Therefore, we included within the scope of integrated care, any models, interventions, and practices with the objective of overcoming, eliminating, or reducing fragmentation of care, even where these attempts are not described in the language or terminology of integrated or PCC.

Integrated care can range from ‘linkages’ through to ‘full integration’ and encompasses both horizontal and vertical integration structures (15). Horizontal integration refers to integrated care between health services, social services and other care providers that is usually based on the development of interdisciplinary teams and/or care networks that support a specific client group across sector. Vertical integration refers to integration within the health sector to link-up primary, community, hospital, and tertiary care services for example evident through best practice care pathways for people with specific health conditions (15).

We consider a ‘model of care’ to be an overarching design for the provision or delivery of health and social care (typically specific to a particular service, and/or health condition), consisting of defined core elements and principles, and a framework for structuring the implementation and evaluation of care (53). The ‘model of care’ may or may not include linkages between health and social care. By ‘elements’ we are referring to the discrete parts of an approach to delivering integrated care, i.e., the tangible interventions, products, processes and so on. Elements may be classified and grouped according to components of care, e.g., information exchange (54). We were guided by potential elements of care identified by Parker et al (2010) in their systematic review on integrated models of care for long term neurological conditions, including epilepsy (55).

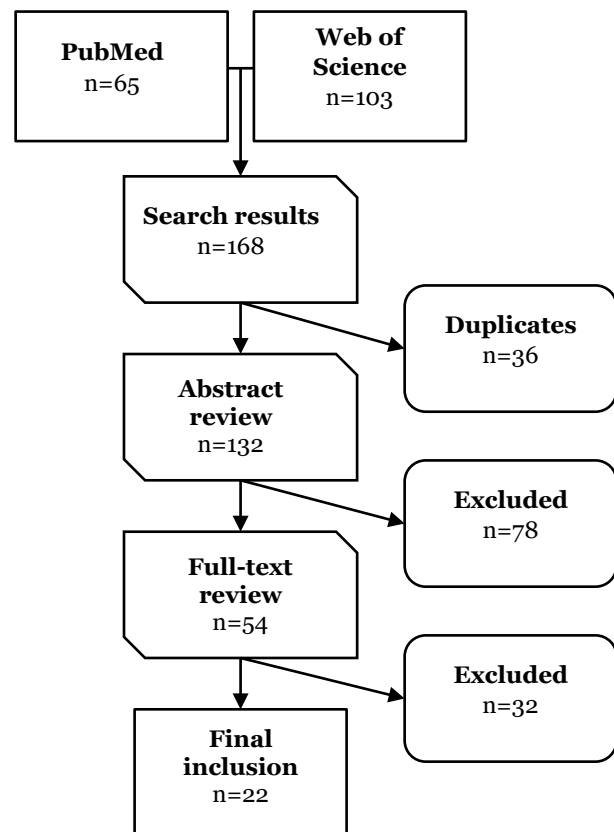
4. METHOD

To identify search terms, we assembled a list of commonly used synonyms and terms relating to integrated care (e.g., coordinated care) found through exploratory databases searches and reading of integrated care literature (54). The objective of the search was not to be exhaustive, but to strike a balance between coverage and relevance, as is appropriate for a rapid review (56). We chose to focus only on articles published since 2010 as the field of research in integrated care is developing rapidly and we were interested in uncovering contemporary perspectives and practices.

Table 1 Inclusion and exclusion criteria

Inclusion criteria
Published since 2010
English language
Peer-reviewed study, report, or literature review
Studies from comparable health systems or contexts, i.e., countries in the Organisation for Economic Co-operation and Development (OECD).
Study details relevant to research questions:
Must include epilepsy as a key focus, although may be applicable to other long-term and complex conditions; AND
Articulate a definition or description of the concept or principles of integrated care (and related terms like coordinated care); AND/OR
Recommends or proposes a model of care, or elements of an integrated approach to improve the organisation and delivery of care in epilepsy; AND/OR
Describes, in sufficient detail, one or more elements of an integrated care approach or model of care that has been put into practice; AND/OR
Reports element(s) of an integrated care approach that have been implemented and evaluated, reports on outcomes of the intervention
Exclusion criteria
Published prior to 2010
Languages other than English
Biomedical, clinical studies, meta-analysis
Conference abstracts, editorials, commentaries
Grey literature
No full text available
Not comparable health system or context

Figure 2 PRISMA diagram



See *Appendix A* for full search strategy and screening process.

5. FINDINGS

The synthesis of findings from the included 22 articles will be outlined according to the four research questions (see page 6). Table 2 provides a summary of the included articles in terms of this rapid review, including study design, aims and objectives.

Table 2 Summary of included articles

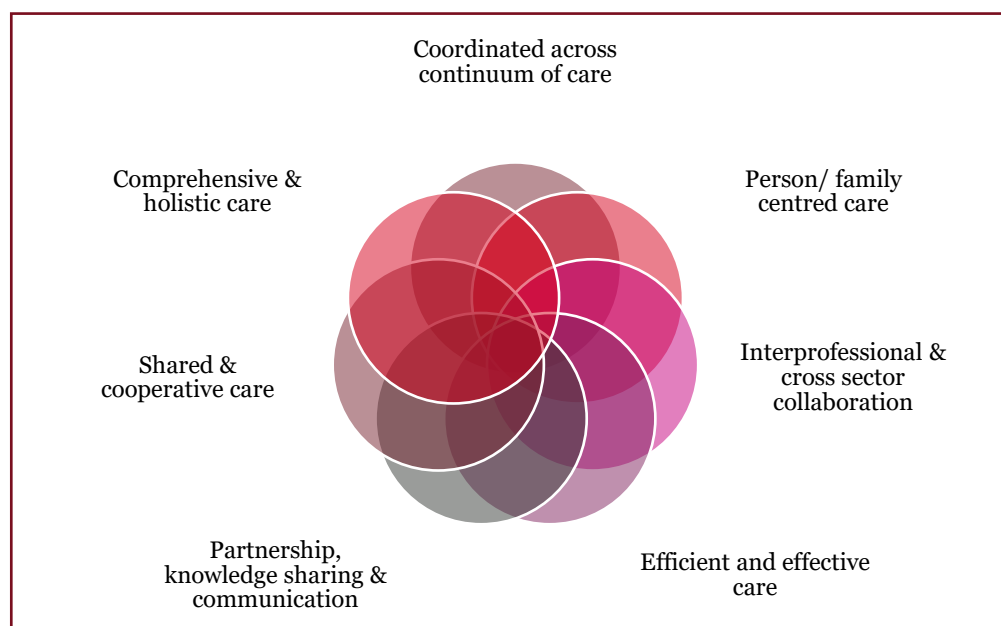
Citation	Country	Study design method(s); objective or aim
Annear et al (2019)	United Kingdom (UK)	Expert recommendation, based on existing models and previous research; proposing comprehensive model for people living with TSC.
Auvin et al (2019)	France	Delphi study; identifying key steps in developing a multidisciplinary team (MDT) in TSC, the key components of the development and function of the MDT.
Bali et al (2016)	UK	Review, non-research article; proposes new model of care for children and young people with epilepsy, aiming to increase multisector integration, facilitate better outcomes and provide lessons for improving care for other long-term conditions.
Bellon et al (2014)	Australia	Survey; exploring the extent to which PLWE and their family members are involved in the development of their epilepsy management plan and the support they receive from the disability sector.
Berg et al (2013)	United States of America (USA)	Review and workshop discussion; identify the greatest problems and current gaps in knowledge and practice that could be the focus of research efforts to improve practice and patient outcomes.
Buelow et al (2018)	USA	Consensus method; development and evaluation of a tool to improve nurse-patient communication and positively affect nurses; approach to care for PLWE using a model of PCC.
Byrne et al (2019)	Ireland	Interviews and observations; understanding the readiness of the Irish epilepsy system to realise the benefits of an integrated PCC model, to inform the implementation of integrated PCC.
Cross et al (2013)	UK	Situation analysis of current practice guidelines, non-research article; explores issues with the administering of rescue medication to children experiencing prolonged convulsive seizures in school settings.
Fitzsimmons et al (2012)	Ireland	Evidence review, using studies included in existing systematic reviews; summary of evidence-based models of care for people with epilepsy, against recommendations of the chronic disease management (CDM) model.
Granata et al (2011)	Italy	Report, consensus statement; considering the problems that influence a patients' and family's life and different stages of disease and the potential role of comprehensive caring that is physician-guided, patient-centred, and built around the children and caregivers.
Hafeez et al (2017)	USA	Qualitative study: interviews and focus group; examining the content of a care coordination intervention for children with epilepsy at an accountable care organisation, and care coordinators' perceptions of facilitators and barriers to improving outcomes in epilepsy.

Higgins et al (2019)	Ireland	Qualitative descriptive design: individual and focus group interviews, observation, and documentary analysis; examine how epilepsy specialist nurses (ESNs) enact their clinical role.
Hutchinson et al (2020)	Australia	Qualitative mixed methods including surveys, interviews, and observations; assessing the barriers to clinical decision making in the diagnosis and management of patients with refractory epilepsy, clarifying referral processes and shared care practices, and the impacts of decisions on patient pathways.
Lewis & Noyes (2013)	UK	Qualitative comparative embedded case study with two cases; exploring communication, information needs, and experiences of knowledge exchange in clinical settings during transition from children to adults' epilepsy services.
Patel et al (2017)	USA	Quality improvement study: plan-do-study-act (PDSA) cycles, economic analysis, interrupted time-series design, five interventions; Aims to lower ED presentations and unplanned hospitalisations, improving quality of care and patient and caregiver experience by providing improved access to outpatient care and education, and subsequently decreasing healthcare costs.
Power et al (2020)	Ireland	Focus groups and interviews; aiming to understand whether and how the perceptions, behaviours, and competencies of people with epilepsy, as they engage with health services, align with the aspirations of a new model of integrated PC epilepsy care.
Tetuan et al (2019)	USA	Retrospective chart review, document analysis; examines clinical pharmacists' roles and current practices in a novel interprofessional telehealth program to improve care for rural-dwelling people with epilepsy.
Tschamper et al (2019)	Norway	Semi-structured interviews; examining parent's experiences of information exchange between a tertiary health service and their child's multidisciplinary local support service using video conferencing and the potential of this tool to support collaborative care.
Varley et al (2010)	Ireland	Focus groups; exploring the perspectives and experiences of health professionals (such as GPs, specialist nurses, neurologists and epileptologists, hospital doctors, as well as learning disability services, and a patient advocate representative) in providing epilepsy care for adult patients.
Varley et al (2020)	Ireland	Participatory action research: regular group meetings and discussions; facilitating ESNs and epilepsy community resource officers (CROs) in gaining a greater understanding of each other's professions and practices, how they impact one another, etc. Exploring opportunities for and challenges to meaningful partnership and intersectoral collaboration in epilepsy care.
Williams et al (2017)	Ireland	Questionnaire; identifying the barriers to use of an evidence-based ICP within an ED to improve utilisation, exploring reasons for low usage rates
Williams et al (2018)	Ireland	Retrospective quantitative evaluation; evaluating the utilisation and implementation of an evidence-based seizure care pathway by ED staff.

5.1 HOW IS INTEGRATED CARE DESCRIBED?

In the literature integrated care is described and envisioned as predominantly person centred and collaborative between and across professionals. Table 3 summarises commonly used descriptors of integrated care in the literature, which is indicative of the challenge in defining integrated care as it means different things across a diverse group of people. Figure 3 highlights the overlap in the way integrated care is conceptualised, requiring all these concepts to make care fully integrated.

Figure 3 Integrated care conceptualised in the literature



The word cloud below highlights the most common words associated with integrated care in the literature review. There were obvious differences in the words predominantly used across countries and continents. For example, comprehensive and coordinated care tends to be used more frequently in literature from United States of America (USA).

Figure 4 Word cloud of common terms



Table 3 Commonly used descriptors of integrated care

Descriptors of integrated care	Relevant articles
<i>Multidisciplinary/interprofessional/interdisciplinary collaboration</i>	Auvin et al (2019), Berg et al (2014), Byrne et al (2019), Cross et al (2019), Granata et al (2014), Hafeez et al (2017), Hutchinson et al (2020), Lewis et al (2013), Patel et al (2014), Power et al (2020), Williams et al (2018), Tetuan et al (2019), Tschamper et al (2019), Williams et al (2017), Varley et al (2010), Varley et al (2020), Annear et al (2019),
<i>Person/ family -centred</i>	Bali et al (2016), Bellon et al (2014), Byrne et al (2019), Buelow et al (2018), Cross et al (2013), Granata et al (2011), Higgins et al (2019), Hutchinson et al (2020), Lewis et al (2014), Power et al (2020), Varley et al (2020), Auvin et al (2019)
<i>Partnership/relationships/interactions/interpersonal</i>	Bali et al (2016), Bellon et al (2014), Buelow et al (2018), Byrne et al (2019), Higgins et al (2019), Hutchinson et al (2020), Granata et al (2014), Power et al (2020), Varley et al (2010)
<i>Coordinated</i>	Berg et al (2014), Byrne et al (2019), Hafeez et al (2017), Higgins et al (2019), Hutchinson et al (2020), Williams et al (2017), Tschamper et al (2019), Varley et al (2020)
<i>Information sharing/exchange</i>	Higgins et al (2019), Hutchinson et al (2020), Patel et al (2014), Tschamper et al (2019), Williams et al (2018), Williams et al (2017), Varley et al (2010),
<i>Continuity of care – spanning condition and life span</i>	Hutchinson et al (2020), Byrne et al (2019), Lewis et al (2014), Power et al (2020), Varley et al (2010),
<i>Efficient care - cost</i>	Bali et al (2016), Byrne et al (2019), Power et al (2020), Varley et al (2010), Varley et al (2020)
<i>Effective care</i>	Bali et al (2016), Byrne et al (2019), Fitzsimmons et al (2012), Patel et al (2014),
<i>Holistic</i>	Annear et al (2019), Auvin et al (2019), Byrne et al (2019), Power et al (2020),
<i>Shared care</i>	Fitzsimons et al (2012), Hutchinson et al (2020), Varley et al (2010),
<i>Cooperative</i>	Tschamper et al (2019)

5.2 WHAT MODELS OF INTEGRATED CARE ARE RECOMMENDED?

Table 4 summarises the recommended models of care for epilepsy that could be adopted, are in the process of being developed, or have been developed and implemented.

Table 4 Recommended and developed models of care

Integrated model of care and relevant article	Adapted or specifically developed	Overview and points to note brief synthesis
<i>Hub and Spoke model</i> Annear et al (2019)	Proposed adapted to TSC	• Need for cross sector and cross disciplinary continuum of care benefits person and their family. • Specialist TSC care provided centrally and undertaken in regional 'hubs'. • Clear pathways necessary for timely and quality care, coordinated and supported centrally.
<i>CDMs</i> Fitzsimons et al (2012)	Adapted to epilepsy	• CDM used with other chronic disease groups to improve health and quality of care and minimise health system burden. • Effectiveness of CDM in epilepsy identified in some areas - patient education, integrated care, clinical guidelines, and clinical information services. • More research on patient outcomes and cost benefits needed.
<i>National Clinical Programme for Epilepsy (NCPE)</i> Power et al (2020)	Developed perspectives of PLWE to the NCPE	• NCPE takes a holistic, integrated PC approach to care for PLWE across biomedical and psychosocial needs. • PLWE believed that access to expert care could only be through the traditional hospital-based specialist services acting as a potential barrier to practice change. • Gap between commitment of policy and achievements in health system. • Health system reform to improve integration of care requires partnerships with service users in the design, development, and implementation of change to ensure readiness and outcome success.
<i>Model of transition (paediatrics to adult)</i> Lewis et al (2013)	Proposed transition model	• MDT and joint care in a combined paediatric and adult clinic with staged transition over months and years, to ensure ongoing engagement with epilepsy services – continuity of care and relationships. • Need to focus on social aspects of epilepsy and real-life issues specific to the PLWE. • Age specific communication and information important. • Parents can continue as partners in young person's care but prepare them to reduce input over time.
<i>Integrated care for children, young people</i> Bali et al (2016)	Proposed model specifically for children and young people (CYP)	• Enablers to improve care: "improve communication, gather better data, tailored individual care plans and whole system strategy to care" (p.1060). • Includes a national epilepsy registry to improve data sharing, develop individual, PCC plans, optimise communication through improved networks and electronic medical records (EMR), cross sector working. • An economic analysis of cost benefits and effectiveness beneficial.

<i>Epilepsy nurse (EN)-led model of care in epilepsy</i> Higgins et al (2019)	Developed as part of the NCPE	• ESN are vital in the MDT and take on a key education role with PLWE, family etc. to support better self-management. • They take on a range of roles across the continuum of care considering health and age specific PCC. • They triage and connect PLWE with services across all sectors which includes the more vulnerable populations. • ESNs practices value “collaboration, participation, relationship-based care, and respect for the voices of PWE and family members” (p.48). • Upskilling management of mental health issues and SUDEP is needed.
<i>ICP of seizure management in ED</i> Williams et al (2017)	Developed care pathways as part of the NCPE	• Evidence-based pathway for seizure management in ED included: evaluation, investigations, management, and follow-up by epilepsy service and rapid access seizure clinic. • Outcome of pathway use: reduction in readmissions, assist in timely decision making, reduce wait times for EEG and supported early discharge. • Implementing change in practice and behaviour needs ongoing “<i>collaboration and commitment</i>” (p.76), across departments and disciplines. Crucial in a fast-paced setting such as ED to have opportunities for information sharing and working across sectors. • SMART principles developed to support pathway implementation and maintenance include Standardisation, Multidisciplinary, Audit, Revision and Training.

Integrated care models adapted or developed for epilepsy care

Hub-and-spoke

Elrod et al (2017) describes the hub-and-spoke model as an organisational model that includes a central site, called ‘hub’, with most resources, and healthcare specialists and services, matched with ‘satellite’ sites, called ‘spokes’, which provide less specialist and limited services (57, 58). General healthcare is provided in the satellite sites, but more specialised healthcare is provided by the central sites. This organisational model linking healthcare services has been described as contributing to building partnerships and relationships, adaptable in building networks, supportive of rural and regional hospitals, and improve referral practices between ‘hubs’ and ‘spokes’ (57, 58). The model has shown value in creating pathways for those living in more rural locations to ensure they receive optimal healthcare (57). Several benefits and risks of using the hub-and-spoke organisational design have been identified and should be considered in relation to context and geography, (Table 5).

Table 5 Benefits and risks associated with the hub-and-spoke organisation design

Benefits	Risks
a. Consistency across operations	a. Congestion at hubs
b. Increased efficiencies	b. Overextension of spokes
c. Enhanced quality	c. Staff dissatisfaction at spokes
d. Enhanced market coverage	d. Transportation disruptions
e. Improved agility	

Table 4 Source: Elrod, J.K. and J.L. Fortenberry, *The hub-and-spoke organization design: an avenue for serving patients well*. BMC Health Services Research, 2017. **17**(1) p. 26-38. Reproduced under the terms of the Creative Commons Attribution 4.0 International License

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Chronic disease management

Chronic disease management (CDM), developed by Wagner et al (1998), focuses on overcoming fragmentation of services and improving health outcomes that is more cost efficient in partnership with the patient and healthcare provider (59). A systematic review conducted on the effectiveness of chronic care models (CCM) was conducted by Davy et al (2015) and highlighted eight key elements (59, 60):

To meet needs of person living with chronic condition:

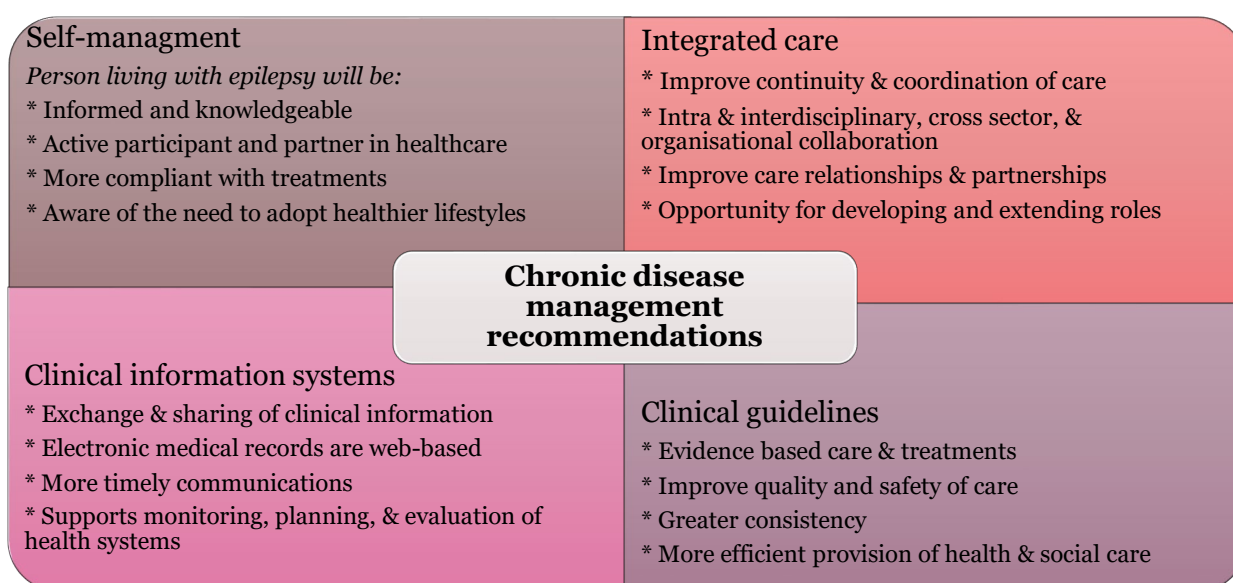
1. Community support
2. Informal family carer support
3. Self-management support
4. Health professional case management support

To meet the needs of healthcare providers:

5. Health system improvement
6. Delivery system design
7. Decision making support
8. Clinical information systems

Elements 2 & 4 are additions to the six elements that are more commonly described (61). Throughout the review improvements were measured by changes in healthcare practice and health outcomes. CCMs vary on elements included, and how the model is delivered and implemented. This review has pointed to the other factors that support the effectiveness of this model, which include reflective practice, reinforcing the benefit of CDM and support from leaders on implementation and sustainability (60).

Figure 5 Adapted from Fitzsimons et al (2012) summary of recommendations for chronic disease management in epilepsy



National Clinical Programme for Epilepsy (NCPE)

A 72 page report outlines this evidence-based Irish epilepsy PC model of care which is multidisciplinary, collaborative, and nurse led (62). Although this review did not include this NCPE specifically three research papers explored different aspects of the programme: Higgins et al (2019) discussed nurse led services, Byrne et al (2019) gained perspectives of healthcare providers readiness for integrated PCC model and Power et al (2020) explored perspectives of PLWE and their families on integrated PCC (25, 63, 64). The three overarching aims of the programme are:

1. The delivery of improved quality of care
2. Improved access to specialist care for patients with epilepsy
3. Delivering value for money through best use of healthcare resources. This will ensure the sustainability of the programme into the future.

This comprehensive programme focussed on specific supports in the community (general practitioner (GP), self-management, health promotion, and seizure management), secondary care (rapid access clinics, outreach services, and telephone/email support for PLWE), and tertiary care (supported surgery programme and evaluation for device implantation) (62). Special group considerations are also included in this programme.

Nurse-led model of care in epilepsy

National Institute for Clinical Excellence (NICE) in the United Kingdom (UK) has highlighted the need for and benefits of epilepsy specialist nurses (ESNs) (65). The ESN “*should be an integral part of the network of care of individuals with epilepsy*” (62, 65)(p.14). The key roles of the ESNs are to support both epilepsy specialists and generalists, to ensure access to community and multi-agency services and to provide information, training and support to the child, young person or adult, families, carers and, in the case of children, others involved in the child's education, welfare, and well-being (65). A Cochrane review conducted in 2016 on the models of epilepsy care highlighted positive outcomes of nurses in improving PLWE and families knowledge and treatment of epilepsy, and self-management, but more research is needed in this area (66). Higgins et al (2018) highlight the important ESN role in leading service change at both patient and system level, through crossing boundaries of care (67). NCPE highlights a specific nurse-led service for PLWE to improve quality and access to right care at the right time (62, 67).

5.3 WHAT ELEMENTS OF INTEGRATED CARE ARE RECOMMENDED OR HAVE BEEN IMPLEMENTED IN EPILEPSY?

Table 6 focuses on specific elements of integrated care that were included in the review. We included both recommended and implemented elements of integrated care in epilepsy as integrated care is a developing area. Table 6 outlines each of the elements and specifies which articles the elements were mentioned. Eleven elements were highlighted with some elements more commonly included across all articles such as crossing sector, organisational and professional boundaries, care coordination, and education and training.

Table 6 Recommended or implemented elements of integrated care in epilepsy

Recommended or implemented elements	Discussion on recommended or implemented elements of integrated care in epilepsy	Articles referenced
<i>Cross sector/organisational/intersector collaboration</i>	• There is a need to shift more epilepsy care and management into the community space due to the dominant provision of care being hospital-based, which can hinder integration of care and delivery of cost-effective services (9, 25, 63). • To overcome fragmentation of care within and across sectors and organisations, collaborative practice, and communication is required to be, as described by Byrne et al (2019), “<i>both within and across professional, disciplinary, organizational, and sectoral boundaries</i>” (p.87), and to be successfully integrated requires removal of these boundaries, “<i>finding a common ground</i>” (p.91), to achieve shared care (12, 25, 35, 63, 68, 69). • Developing partnerships, clear pathways and links are necessary to help navigate across boundaries to improve timely access to appropriate services and treatments (9, 31, 70). • It is important to explore and better understand context specific barriers and facilitators to crossing boundaries, so that desired outcomes can be achieved (12, 25, 63). • Power et al (2020) noted success in health system reform can be challenging and requires a whole systems approach to readiness for change (25, 35). • Some studies highlighted that there are options to facilitate successful information exchange across sectors and organisations through technology such as video conferencing, telephone, and shared EMRs which also supports equity in access to care, irrespective of location (63, 71).	(12, 25, 31, 35, 63, 68-72)
<i>Care coordination</i>	• Care coordination was more commonly recommended or implemented in paediatric epilepsy services, and or with complex epilepsy syndromes focusing on organising and improving care delivery, through ‘multiple points of contact’, sharing epilepsy specific information and improving quality of life (29, 73). • Care coordinators could be from different professional backgrounds but nurses and social workers were often considered in this role (73). • Care coordination role in epilepsy, particularly complex epilepsies, is similar to other chronic and complex conditions, and it is important to build relationships, improve bidirectional communications, develop individual care plans and improve timely access to health	(9, 29, 31, 63, 73)

<i>Multidisciplinary/ interdisciplinary teams</i>	and social care services, “connect the dots”, across the continuum of care or lifespan (9, 31, 73). • Care coordination can begin at diagnosis right through to end of life, palliative care which is often not considered. • Taking on a care coordinator role means being responsive to all medical, social, psychological, and cultural needs and may involve being an advocate and or liaison person across multiple health and social care providers. • The professionals in a MDT team vary across papers and most had the PLWE and their families central to the team to ensure greater influence on their care and access to the right services (35). • Having expertise and knowledge in epilepsy in MDTs is important to achieve optimal outcomes (35, 64). • Many studies highlighted the importance of MDTs in providing a collaborative, coordinated and person- and family-centred approach to managing the complexity of epilepsy and considering the psychosocial impacts (74). • MDTs help to improve opportunities for shared care, communication, and awareness of other comorbidities and medications regimes which could be achieved through developing individual care plans and shared goals (35). • Similar to sector and organisational collaboration, there are boundaries to navigate, and a need for deeper understanding of the breadth and complexity of different professional roles (12)(p.507). • Varley et al (2020) noted for integrated care success, building relationships within and across professions is necessary to improve PLWE health outcomes and overall satisfaction in service delivery (12, 25).	(12, 29, 35, 63, 64, 68, 72, 74)
<i>Education and training</i>	• Education and training can involve health and social care professionals, education sector and employers, PLWE, families and friends and be provided by a range of epilepsy experts, across different settings (72). • Higgins et al (2019) note that outcomes are boosted with informed and engaged PLWE and knowledgeable health professionals (64). • With a greater emphasis on management of epilepsy in primary care then upskilling and training of GPs and community nurses is necessary for this to occur successfully (68). • ENs’ role in several studies included providing information, education and training to PLWE, families and other health professionals in community and healthcare settings, which can improve confidence and reduce anxieties (12, 64, 75). • Particularly relevant to prolonged convulsive seizure management is the timely and appropriate administration of emergency medication wherever it occurs, which requires cross sector and organisational training and education, often delivered by nurses (70). • Routinely training family carers and people across organisations and sectors, including schools, on how to manage seizures is very important and empowering (30). • Sharing of written information which may include safety, driving, and rescue medication is important but needs to	(12, 28, 30, 64, 68, 70, 72, 75, 77)

Telephone Advice lines (TAL)	be appropriate to age and in lay language and other languages (76, 77). - Seizure management plans (SMPs) were also considered an education tool for discussing the approach to emergency seizure management with PLWE, families and healthcare providers (75). - The development of TAL improves access to expert support and care in a timely manner for PLWE, families, and health professionals (63, 64). - This can help with continuity and coordination of care which is appropriate for PCC. - Using the TAL to run virtual clinics makes them accessible from any location, and was considered more cost effective and reduced the focus on hospital-based services as found by Byrne et al (2019) (63). - Varley et al (2010) recommended that telephone advice provided by epilepsy specialists should be accessible to GPs to support them in their role (68). - Despite the effectiveness and efficiency in service delivery reported using this mode of intervention, having adequate staffing and resources to manage this well is vital (63).
Shared EMRs	- Shared EMRs supports the timely access and sharing of clinical information between and across sectors and organisations (69). (35, 63, 69, 71, 75) - Using these shared medical records can be a good platform for developing partnerships, improving communications, shared decision making, standardising care and supporting the following of practice guidelines and pathways of care (35, 71). - In addition they can aid clinical practice and be an education tool for non-epilepsy specialists and junior staff (69). - However fully integrating this into practice can be challenging as reported in the literature, as navigating persistent siloes, with a lack of compatible health information systems, can ultimately affect the effectiveness of shared medical records as a valued element of integrated care (63).
Clinical guidelines and care pathways development	- Despite the international challenges in implementing clinical guidelines and care pathways they can help to standardise, improve quality and efficiency of care, assist with history taking, improve diagnosis, support clinic decisions, and management of seizures, as well as work as an education tool for health professionals with limited experience in epilepsy (69, 76). (28, 69, 75, 76) - Fitzsimons et al (2012) draws attention to the need for a structured dissemination process, considering contextual factors and people involved, to successfully share and implement practice guidelines (28, 69). - Williams et al (2017) implemented an evidence-based ICP in the ED which was recognised by the staff as valuable and improved quality of care for PLWE, but exploring ways to overcome barriers to the routine use of these needs more consideration (28). - The SMART principles were developed by Williams et al (2017) to support the implementation process in epilepsy

	(28). Varley et al (2010) highlighted that with a move to more epilepsy management in the primary care space then clear guidelines are recommended to support the timing and kind of follow-up care that PLWE require (68). • The development of rapid assessment clinics (RAC) or urgent epilepsy clinics (UEC) were new pathways of care which supported more timely access to epilepsy specialists and reduction in ED visits and hospital admissions (75).	
EN services	• Nurses can network across health, community, and primary care sectors, and health and social care providers and nurse led interventions have been demonstrated as having a key role in chronic conditions, including epilepsy, to improve disease-specific knowledge and self-management strategies (64, 69, 78). • ENs often work within a MDT and “<i>complete comprehensive assessments, provide person-centred education and psychosocial care, monitor the impact of care and treatment, co-ordinate care and care-pathways and quality assure patient information</i>” (64). • Despite nurses often being the first point of contact or the ‘go to’ health professional, not all have specialised training in epilepsy so being supported by ENS is important (68). • One option implemented was the Epilepsy Nurse Communication Tool (ENCT) to improve interactions, approaches to care and support and decision making between non-epilepsy specific trained nurses and PLWE (78). • Contact with the nurse could be either be face-to-face, telephone, email, or video conferencing (64).	(64, 68, 69, 78)
Self-management programmes	• The overall principle of self-management of epilepsy is for PLWE and or family members to routinely manage the epilepsy rather than the health professionals (41). • In many cases the collaborative development and use of seizure/epilepsy management plans (S/EMP) or seizure action plan (SAP) improved overall seizure management and outcomes, including appropriate emergency medication use, which as Patel et al (2017) highlighted resulted in reduced ED visits and unplanned hospital admissions (75). • Promoting the self-management approach supported greater choice and control to managing their epilepsy (35, 41). • Bellon et al (2014) noted that children were more likely to have SMP than adults despite being recommended and important for all (41).	(35, 41, 75)
Transition to paediatric to adult services	• This is an area that is an ongoing concern for many working and researching in this area, especially with the increase in disengagement of young people from epilepsy services. • MDTs enable better communication between specialists and services, which can support this transition (29). • Taking a staged approach was implemented to help transitioning from paediatric to adult services with jointly facilitated MDT clinic over an extended period (77).	(29, 31, 77)

Epilepsy Specialist support to other non-specialist health and social care	- Retaining contact with paediatric services during transition was effective in improving ongoing engagement of young people with epilepsy services (77). - Continuity of care, age appropriate, PC communication, and sharing of information supported engagement is important to success (77).	
	Improving and creating opportunities for intra- and interprofessional knowledge flow would be valuable, however issues around clinical autonomy and specialism, particularly prevalent within the medical profession can impact effective communications (9, 63).	(9, 63)
	Mutual knowledge exchange can improve working relationships and partnerships across organisations and sectors.	
	This can in turn help to change clinical practice and PLWEs' confidence in accessing community-based support (9).	

To fully answer question 2 & 3, it is important to draw attention to the diversity of health and social care providers and their roles and responsibilities to ensure PC and connected care for PLWE and highlight the key players. We recognise the importance and value of exploring in more depth the relationships, engagement, and communication approaches adopted between providers; when, how, and with whom do they engage. Table 7 outlines the diversity of people across sectors and organisations and their roles in epilepsy management. We acknowledge the importance of providers to work in partnership with the PLWE and their family members to prioritise health and social outcomes, resulting in a more cost effective and efficient health and social systems, highlighted in integrated care.

Table 7 Health and social care providers involved in integrated care in epilepsy

	Description of the role	Articles referenced
Epileptologists, neurologists	- Epileptologists and specialist neurologists are central figures in epilepsy care. They are typically hospital-based or working within specialist clinics (25, 75, 76) as core members of MDTs (63, 71, 72). - Paediatric neurologists are key actors in the care of children with epilepsy both during the early stages of diagnosis as well as in facilitating the joint care and transition from child to adult epilepsy services (74, 77). - Within an integrated PCC approach, epileptologists may – in addition to supporting patient self-management - occupy a more advisory or consultative role, “<i>equip[ping] other members of the integrated clinical care team to become expert managers</i>” (p.3)(69). The degree of involvement in ongoing monitoring and management would be dependent on the needs and medical complexity of each patient (74). - Power et al (2019) notes many PLWE view their specialists as the central figure in their care, privileging their expertise while devaluing (or not recognising) the role of primary care providers. This perspective does not align with the aspired-to models of integrated PCC and reveals one of the potential challenges in implementing new shared care arrangements (25).	(25, 31, 35, 63, 69, 71, 72, 74-77)
GPs, primary care physicians	The role of primary care physicians or GPs in integrated care in epilepsy is yet to be fully elaborated. To date, there has been a lack of training and support to adequately equip GPs with	(25, 31, 35, 63, 68, 69)

	Description of the role	Articles referenced
	the knowledge and confidence to safely and effectively manage epilepsy in primary care, however they are commonly identified as holding significant potential to improve care outcomes and experiences for PLWE in the community (68). • GPs need to have effective two-way communication and collaboration with hospital-based specialists (31, 63), while acting as the day-to-day, first point of contact for PLWE in all aspects of their care (69). • GPs often have a full medical history of a patient and a closer personal relationship with them, meaning they can be more well placed to address patient needs – both related and unrelated to epilepsy (63).	
Nurses	• Nurses, and ESNs in particular, have received a great deal of attention in regard to PC integrated care in epilepsy. ESNs are often based at hospitals or specialist clinics, working with other health and social care professionals as part of a MDT (72, 75, 77). • Their roles and responsibilities are diverse (12, 64, 69, 70), but can be grouped under the following broad areas: ○ multidisciplinary care coordination ○ liaison between services and sectors (e.g. education, disability) ○ information provision and education to PLWE and families ○ assessment and monitoring of clinical needs ○ support for PLWE self-management ○ counselling and psychosocial care • ESNs may also be qualified as registered nurse prescribers and be involved in managing and prescribing medications. • Higgins et al (2019) describe one of the key roles of ESNs in Ireland as “<i>the coordination of care pathways for PLWE across complex primary, secondary and tertiary services and across a diverse range of professional groups</i>” - the “glue” holding services together (p.47)(64). • In addition to nurses specialising in epilepsy, registered nurses, general practice nurses, paediatric nurses and learning disability nurses were also named in the literature as having a role in the comprehensive and coordinated care of PLWE (31, 63, 70, 71). • Several articles also specified the involvement of advanced nurse practitioners in specialist epilepsy clinics and outpatient centres (25, 64, 75).	(12, 25, 31, 64, 68-70, 72, 75-77)
Social workers	• Social workers are frequently involved in epilepsy care, and are often listed as part of multidisciplinary epilepsy teams (71, 72, 74, 77). • In the USA, social workers in an interprofessional telehealth team facilitate education programs, housing, and transport arrangements for PLWE in rural areas (71). • The UEC described by Patel et al (2017) is staffed by epilepsy social workers who work alongside EN practitioners. Patel et al (2017) highlight that much of the clinic’s time is spent on “<i>education, counselling, and addressing psychosocial risk factors</i>” and social workers may have been critical to the success of their model (75).	(71, 72, 75, 77)

	Description of the role	Articles referenced
Allied health professionals	• These dimensions of care and support also appear to be critical in the transition of young people from child to adult epilepsy services (77). • Meanwhile, in Norway, social workers are available to the families of children with epilepsy being assessed in hospital. These social workers providing advice on their legal rights to benefits and support (72).	
	• Allied health professions (e.g. speech therapy) are mentioned in several articles (35, 63, 71, 74). There is much to be explored regarding shared care practices and communication between allied health professionals and other care providers, and how they engage in PC approaches to meet the needs of PLWE. • In the Norwegian context, Tschamper et al (2019) provide some detail about the involvement of physiotherapists and occupational therapists (72). These professionals are part of the hospital-based clinical team assessing children with epilepsy and disability, but community-based allied health providers are also be engaged as the child's "<i>local support team</i>" and involved in information exchange with the tertiary health service (72).	(63, 71, 72, 74)
Psychiatrists, clinical psychologists	• Like paediatricians, psychiatrists and clinical psychologists commonly figure in the care of children and younger people with epilepsy (74). • Annear et al (2019) list developmental paediatrics, clinical psychology, and psychiatry as involved in the assessment and diagnosis of intellectual, behavioural, and psychiatric conditions associated with TSC (31). Likewise, Tschamper et al (2019) reference the involvement of psychologists and special educators in conducting cognitive assessments of children with epilepsy and disability in hospital (72). Uniquely, Lewis and Noyes (2013) touch on the importance of neuropsychologists for young people with epilepsy experiencing memory problems (77). • Lewis and Noyes also write that clinical psychologists should ideally be integrated into the MDT to help proactively manage behavioural change issues that emerge in long-term conditions like epilepsy (77).	(31, 72, 77)
Educators	• One of the most relevant sectors to integrated care epilepsy outside of health is education (70, 72, 74), with schools described by Berg et al (2013) as "<i>essential in extending and implementing the care and recommendations of physicians and providing additional services</i>" (p. 1168)(74). • School staff spend a substantial amount of time with the children in their care, and thus need to be well informed on the impact of epilepsy and seizures and aware of any management plans in place (74). Educators may also have insight into how well seizures are being controlled and be able to identify developmental or behavioural difficulties (74). • Cross et al (2013) argue that the role of schools and teachers needs to be made clearer, particularly around the scope of their responsibility, and the connection between schools and primary care physicians strengthened to improve the quality of care to children with epilepsy at risk of prolonged seizures (70).	(70, 72, 74)

	Description of the role	Articles referenced
Care coordinators	- The task of care coordination within integrated care can be fulfilled through a dedicated position (72, 73), though it is sometimes subsumed into other roles. - Care coordinators within health may hold “<i>responsibility for coordinating the service, ensuring timely surveillance, and coordinating care between different specialist services, developing individualized plans for patient follow-up, and ensuring continuity of care</i>” (p.3-4)(31). - The other primary tasks of care coordinators is to build relationships with PLWE and families through face-to-face contact and enabling bidirectional communication between care providers and PLWE/families (72, 73).	(31, 72, 73)
Epilepsy CROs	- In Ireland, CROs are community health professionals whose work complements the role of ESNs (12, 63). - Their role is described as involving “<i>offering information and advocacy to people living with epilepsy and their families in the community setting</i>” and delivering services including one-on-one support, self-management training, support groups, seminars, training health professions, and giving epilepsy awareness talks in schools (p. 502)(12).	(12, 63)
Patient support and advocacy groups, charitable organisations	- Patient support groups and charitable organisations have an essential role in the broader scope of epilepsy care and support (31, 70). Annear et al (2019) writes that for children with TSC and their families, links between clinics and patient support groups are vital to ensure families receive “<i>comprehensive support</i>” (31). However, what this means in practice or how these links should be created is not elaborated. - In the UK, charitable organisations have been essential in providing resources to parents and schools (70).	(31, 70)
Disability support workers	- Social care and disability support services were not prominent in the literature in this review (41, 72), possibly due to the search terms used. This is an area which needs to be given particular attention in future work. - Bellon et al’s (2014) research implicitly conveys the important role of support workers and service providers under the National Disability Insurance Scheme (NDIS) in Australia, though they are not the central focus of the article (41). - Likewise, Bali et al (2016) refers to the importance of social care in the UK as a key dimension of integrated care for children and young people with conditions such as epilepsy (35).	(35, 41, 72)
Paediatricians	Paediatric specialists are often listed among the professions involved in hospital or clinic-based MDTs (72, 77) and as participants in the community-based care and management of PLWE. They are, of course, among the core professionals involved in infant or childhood-onset epilepsies (29, 31) and on the transitional period of joint care between child and adult epilepsy services (77).	(29, 31, 72, 77)
Other	In the case of genetic epilepsies and complex syndromes, a broad range of other professionals and specialists may also be involved in the MDT; from geneticists and genetic counsellors, to nephrologists and dermatologists (31, 74).	(31, 74)

5.4 WHAT IMPACTS, OUTCOMES, OR EFFECTS OF INTEGRATED CARE APPROACHES HAVE BEEN REPORTED FOR PEOPLE LIVING WITH EPILEPSY?

The impacts, outcomes and effects of integrated care demonstrated in this review are outlined in Table 8. This overview provides information on how specific targeted innovations can support health system change and improve health and social care providers practice to improve outcomes and advance PCC and integrated care for PLWE. Most of the outcomes or impacts discussed below relate to improving PLWE and health and social care providers experience, improving overall quality of care and reducing healthcare costs which is the principles for value-based healthcare and connects with the Quadruple Aim (21, 22).

Table 8 Consequences of integrated care approaches in epilepsy

	Brief description on impact, outcomes, and effects of integrated care in epilepsy	Article reference
<i>Change in health system utilisation</i>	- Contributing factors to ED visits and hospital admissions were identified and innovations implemented to targeting these factors. - The innovations implemented by Patel et al (2017) were an UEC, also known as a RAC; development of SAP also known as SMP; emergency medication protocols, dosing guide and alert system in EMR and PLWE and family instructive magnet on emergency medication administration; and review high users of ED for epilepsy care to address social issues. - Patel et al (2017) reported on reduced seizure-related ED visits by 28 % and unplanned hospital admissions by 48% resulted in reduction in overall healthcare utilisation and cost savings. - The most beneficial to achieving reduction in healthcare utilisation noted by Patel et al (2017) was the UEC followed by SAP development. - ICPs, Williams et al (2018, 2017), were highlighted as ways of changing health system utilisation.	(28, 41, 75, 76)
<i>Implementation of ICPs</i>	- The review of ICPs in EDs provided a higher quality of care, with less referral wait times for PLWE to see specialist through linking in with ESN phone triage service and rapid assess clinic, rather than by usual discharge process with GP instructed to refer to neurologist. - Follow up wait times were less on the ICP. - Higher rates of completed examination documentation and information provision resulted from the ICP rather with standard care. - Everyone responsible for implementing the pathway need to be considered in the process, included doctors across all levels, nurses, nurse managers and administration staff. - Initial rates of ICP use was about 26.2% but this improved to 61.1% after amending “<i>environmental, operational and user dependant barriers</i>” (p.229). - Changing behaviours and practice remain challenging and needs consideration in implementing care pathways.	(28, 76)
<i>Sharing information through EMRs</i>	- EMR facilitates timely sharing and exchange of information to enable integration of care across sectors and professionals. - EMR can impact continuity and coordination of care. - Challenges were identified in relation to time spent on computers and workplace environments not meeting staff needs.	(63)

	Brief description on impact, outcomes, and effects of integrated care in epilepsy	Article reference
Nurse communication tool	• Breaking down barriers professionally and in siloes and overcoming governance issues remain challenging to success of information sharing and exchange through EMR. • The focus on the PLWE may be impacted by the need to input data and time scrolling though the file to obtain relevant information. • Buelow et al (2018) reported on the ENCT developed by ENs for non-epilepsy trained nurses which can improve quality and guide interactions, discussions and decision making with PLWE, and optimise epilepsy management. • The evaluation of ENCT reported the nurses felt it was useful, easy to use and acceptable. • Evaluation and upgrades are important to ensure ongoing effectiveness and utility in patient-nurse provider communications.	(78)
Knowledge exchange and sharing	• Greater understanding across medical, social, and psychological aspects of epilepsy is achieved when working collaboratively with other health professionals with epilepsy expertise. • The opportunity for learning is increased through creating networks and connections for greater knowledge exchange between epilepsy experts and other non-specialist health and social care to further strengthen relationships and translate knowledge across sectors and organisations. • Using clinical guidelines, EMR, communication tools, adopting coordination roles, technology, SMPs, etc. to support knowledge exchange and sharing.	(75, 76)
Care Coordination	• AHRQ (Agency for Healthcare Research and Quality) care coordination framework can evaluate and monitor care coordination. • ARHQ demonstrated improved bidirectional communication, building of stronger relationships through multiple points of contact and benefit of care coordination across continuum of care. • Other articles mentioned care coordination, but Hafeez et al (2019) was the only one that formally evaluated and monitored this process.	(64, 73)
ESN role	• ESN roles support PCC through getting to know and building relationships and partnerships with the PLWE, family and other health and social care providers, and providing more PC management of epilepsy. • ESNs support PLWE and their family's capacity to self-manage their epilepsy. ESNs' clinical expertise contributes to them adopting a key role in an MDT and key player in overall epilepsy management. • ESNs can work across many settings and sectors including hospital, emergency, and outreach clinics and be the provide information and advice on the TAL.	(64)
TAL	• TAL is a method of delivering care, information exchange and advice when and where needed to PLWE, families, and health and social care providers.	(63, 64)

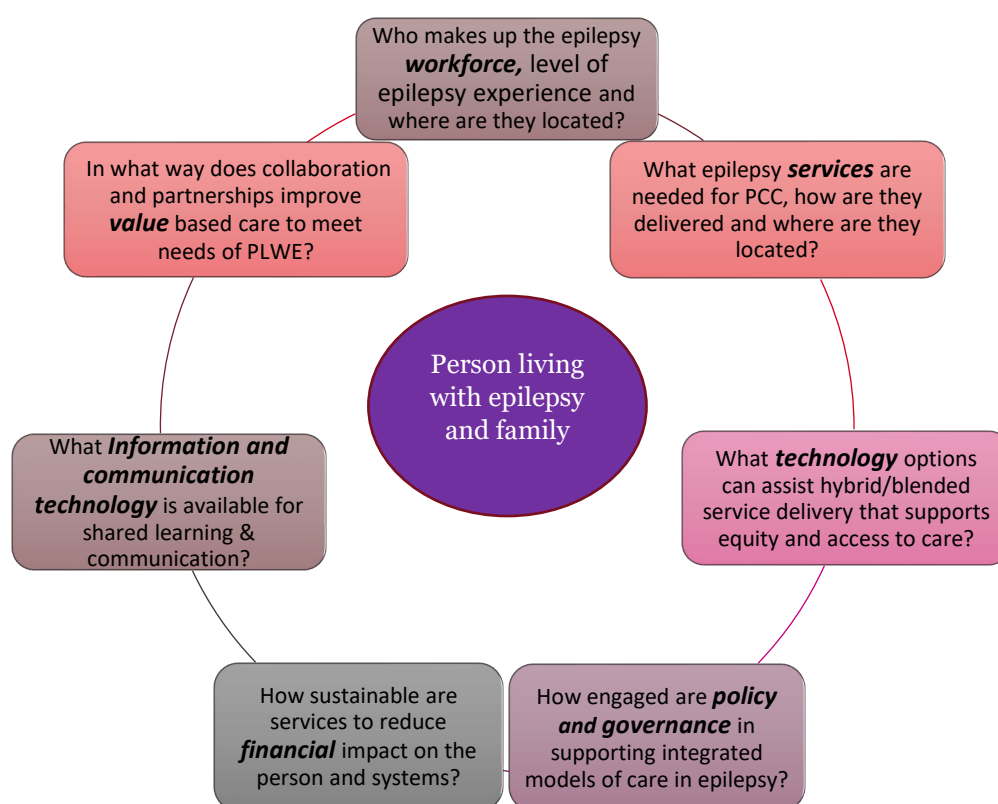
	Brief description on impact, outcomes, and effects of integrated care in epilepsy	Article reference
<i>SMPs</i>	• Often this service was under resourced which impacted the nurse's ability to manage the workload, related to increase demand and expected response times. • The development of individualised seizure management plan is considered extremely useful in more effective PC management of epilepsy. • Well-developed SMPs can impact change in health utilisation, but not everyone has a SMP. Children are more likely to have them than adults. • Those with SMPs usually have greater disability. • PLWE and families wanted more involvement in developing SMPs.	(41, 75)
<i>Interprofessional telehealth service</i>	• Telehealth services can be advantageous to those living in rural and remote areas and may reduce healthcare inequities. • There is flexibility in attending when healthcare team can join from one central place or from different locations. • Tetuan et al (2019) highlighted the value of including a pharmacist into the telehealth epilepsy team, particularly related to the comorbidities and epilepsy related management medications recommended to epileptologists, primary care providers, and nurses. • Further development of the pharmacy role is ongoing.	(71, 72)

6. DISCUSSION

There is an increasing evidence base for integrated care to address the holistic health needs of people living with chronic and complex conditions to support better health and wellbeing (17, 37). The literature identified in this review indicates that while there has been work towards developing integrated models of care for epilepsy, implementation into practice is only in the early stages. Still, interest in the value of integrated care in epilepsy is building. Several articles in this review (12, 25, 28, 63, 68, 76) referred to the NCPE's model for transforming epilepsy care in Ireland through integrated PCC, to achieve *"the best value care for all people living with epilepsy, in the right place, at the right time, sharing the best available information"* (62)(p.9).

With this aspiration in mind, the following discussion centres on seven important domains that have been identified in this review to influence the implementation of integrated care. The seven domains are shown in Figure 6, these are: *workforce*, *services*, *technology*, *policy and governance*, *financial*, *information and communication technology* and *value*.

Figure 6 Mapping guide on equitable, accessible, person-centred, and sustainable integrated care



The articles sought for this review needed to relate to epilepsy and integrated care, but there were no specific criteria limiting population by age or form of epilepsy etc. Three included articles were specific to genetic syndromes which include epilepsy, and almost half concentrated on epilepsy care for children and young people only. There were only a few studies reporting on the outcomes or impact of implementing elements of integrated care into practice, as most articles explored current practice, or proposed or recommended practice change. The prerequisite elements of integrated care described in the literature were: a shift away from health speciality silos towards more collaborative service delivery; building a more cohesive and coordinated workforce; developing effective and timely bidirectional communication approaches between professionals, and utilisation of available technologies to improve PLWE access to support and information. To achieve the full benefits of effective and efficient integrated care in epilepsy requires a team effort, with strong leadership, professional commitment, good management, multisectoral integration, and networking (17, 35, 37).

There are significant challenges to implementing healthcare restructure, including persistent sectoral silos which are often based on service funding models (68), ineffective communication practices among services

and care providers (63), lack of organisational and workforce preparedness, and readiness for change (12, 25), and lack of impetus for improving epilepsy treatment and management in community and primary care settings – including from PLWE and their families who preference epilepsy specialist care (9, 17). Effective collaboration across the healthcare workforce promoting conversations and cohesion, requires “*getting the whole system in the room*” (12) (p.506).

Developing and sustaining an integrated model of care is a long-term ambition (68). As such, there are benefits to achieving political support through governmental policy changes that commit to providing the necessary resources to facilitate change (68). To support provision of adequate resources to deliver a whole systems approach, Bali et al (2016) conducted an economic analysis to demonstrate financial value and cost effectiveness of delivering an integrated model of care (35). However, even governmental support does not ensure that partnerships will be formed easily or run effectively without challenges, as shown in Ireland where there was a government directive for health and social system reform following an economic crisis in 2008 (12). Despite the drive for shared information and communication through electronic medical records (EMRs), overcoming governance issues across organisations and sectors is a difficult task impacting the success of continuity and coordination of care (63).

Workforce readiness for change can be an important enabler, but it requires time and opportunity to build relationships, deepen understandings of the breadth of roles and responsibilities of others, and for knowledge sharing and exchange (12). Building capacity in the epilepsy workforce is a critical area and leverage point for enabling care to be delivered in the right place, at the right time (9, 63, 78). ESNs, in particular, are well placed to network and coordinate care across prevailing sectoral boundaries and have a key role in the provision of treatment, advice and support for PLWE, families and health and social care providers (64, 68, 69). A number of reviewed articles advocated for the coordinating role of ESNs to improve timely, equitable access, and ongoing engagement of PLWE and their families with necessary services (7, 63, 79).

In this review, the collaborative development of PC seizure management or seizure action plans promoted epilepsy self-management strategies, reduced need for unnecessary hospitalisation, supported decision making, and acted as an information and education tool (41, 75). Being referred to and seen at an urgent epilepsy clinic (UEC) or rapid assessment clinic (RAC) reduced referral wait times to see a specialist and linked PLWE to an ESN providing clinical expertise and epilepsy management (64, 75). Blended or hybrid decentralised services which incorporated technology, such as video-conferencing, and face-to-face options benefitted care providers, PLWE, and their families, due to more efficient use of time, greater opportunity for collaboration across sectors, and enabling access to care for people living in rural and remote locations (63, 64). Using guidelines, ICPs and SMPs also contributed to knowledge flow for non-epilepsy specialists and contributed to PLWE and their family’s timely access to care and support and reduced unnecessary hospitalisations (75, 76).

Lastly, integrated care in epilepsy supports the objectives value-based care, i.e. meeting the needs of the person and achieving outcomes relative to cost (22). The volume of unwarranted service use in epilepsy e.g., at the tertiary hospital level, can be lessened by optimising timely access to care across specialities and providers, thereby also reducing financial cost to PLWE and the health system.

7. CONCLUSION

This review demonstrated that the ambition of integrated care models and practices in epilepsy are aligned with the Quadruple Aim and valued-based healthcare to improve experiences of PLWE, families, health and social care providers, increase efficiency and cost effectiveness of care and optimise overall health outcomes, but implementing these changes into practice is currently a developing area. The articles reviewed highlight the benefits of integrating care for the health system and for providers and receivers of epilepsy care, as is true for many chronic and complex conditions. Despite this, there remain barriers to successfully shifting care and treatment preferences from the epilepsy specialist to non-epilepsy specialised health and social care providers. To overcome barriers to collaborative and shared care practices, more opportunities to transfer clinical expertise and improve understanding among primary and community-based care professionals is needed. Routine knowledge exchange and fast access to clinical expert advice were flagged as important measures to ensure care provider readiness, confidence, and capacity to effectively engage in PCC in epilepsy. This groundwork would in turn help facilitate implementation of integrated care into practice.

To ensure success and sustainability in the implementation of valued-based integrated healthcare, the needs of PLWE and their families must be central to any changes in service delivery, provision and self-managing their epilepsy, which was not always considered in the articles reviewed. PLWE and their families must have confidence and trust in the systems' and health and social care providers' ability to manage and support their individual needs and decision making effectively and efficiently. A care coordinator, such as an ESN, can provide the link to PLWE, family and health and social care providers to enable access to the right care, at the right time, helping to overcome the stress and potential harms associated with fragmented care. Additionally, digital technologies have great potential to improve multi-sector collaboration, facilitate shared information and communication, and support the delivery of equitable epilepsy care and support irrespective of location, social and financial situation. However, issues related to provision of sufficient resources and cooperation across governance bodies need to be addressed to optimise the potential of these technologies to support integrated care.

Overall, this review has demonstrated there is movement towards integrated models or elements of care in epilepsy, often adapting and translating evidence-based interventions developed in other chronic and complex disease areas. However, the success in getting the evidence-based interventions implemented into practice, across different contexts, is underdeveloped and requires more stakeholder engagement and implementation planning to understand barriers and facilitators, and to ensure sustainability of changed practices.

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9. APPENDIX A

Search Strategy and Screening

Databases: PubMed (searched 8 August 2020), Web of Science (searched 5 August 2020)

Date range: 2010-2020 (last 10 years)

Language: English

Search string:

PubMed

(epilepsy[MeSH Terms]) AND ("shared care"[Title/Abstract] OR "Integrated care"[Title/Abstract] OR "Coordinated care"[Title/Abstract] OR "Managed care"[Title/Abstract] OR "Person-Centered"[Title/Abstract] OR "Patient-centered"[Title/Abstract] OR "Person-Centred"[Title/Abstract] OR "Patient-centred"[Title/Abstract])

Web of Science

Epilepsy [topic] AND ("Shar* care" OR "Integrat* care" OR "Coordinat* care" OR "Manag* care" OR "Person-Cent* care" OR "Patient-Cent* care") [topic]

Results:

PubMed - 65 results, with date and language limits applied

Web of Science (all databases) - 103 results, with date and language limits applied

Total – 168

Screening process:

All database search results were saved to Endnote and duplicate records removed. Together, three reviewers (KH, TR, CP) screened 132 abstracts for inclusion/exclusion criteria. To improve inter-rater reliability, 25% of the abstracts were screened by at least two reviewers and the team met to compare their decisions. As a result, the inclusion and exclusion criteria were refined and clarified. The reviewers then continued individually screening abstracts and any uncertainties were brought to the team for a discussion until consensus was reached. 78 articles were excluded at abstract screening and 54 went forward to full-text review.

Three reviewers (KH, TR, CP) carried out the full-text review for inclusion/exclusion and the data extraction sheet for included articles. The extracted data included general study characteristics (i.e. year of publication, country of origin, method, population of interest/participants in study) and specific information pertaining to each research question (e.g. for elements or models of care that had been implemented in practice, what setting was it delivered in, who was involved either as primary or auxiliary workforce or as relevant stakeholders, and what sector(s) were involved etc.). 22 articles were included in the final analysis.

Methodological quality appraisal:

A single reviewer assessed the internal validity/methodological quality of the 22 included studies, using Joanna Briggs Institute study design specific checklists (e.g. qualitative research tool) (80) and the Yale non-research appraisal tool for review articles (81). Because the purpose of this to review is to identify approaches to epilepsy integrated care in the available literature rather than to evaluate the effectiveness of particular interventions, all studies are included regardless of quality (56).

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