

## Appendix 2. Summary of articles included in scoping review

| Author                     | Country   | Study design/<br>Article type       | Model or<br>component only | Objective or aim  |
|----------------------------|-----------|-------------------------------------|----------------------------|---|
| Annear (2019)<br>[36]      | UK        | Synthesis of expert recommendations | Recommended model          | To synthesise existing research on models of care for people with TSC and recommend a new comprehensive model of care.                              |
| Auvin (2019)<br>[35]       | France    | Delphi                              | Recommended components     | To identify key steps in developing an MDT in TSC, and the key functions of the MDT.  |
| Bali (2016)<br>[37]        | UK        | Literature review                   | Recommended model          | To synthesise existing research on improving epilepsy care for children and young people and recommend a new multisectoral model of care.           |
| Bellon (2014)<br>[16]      | Australia | Descriptive                         | Implemented components     | To explore the extent to which PLWE and their family members are, and want to be, involved in the development of their epilepsy management plan.    |
| Berg (2013)<br>[25]        | USA       | Descriptive                         | Recommended components     | To identify gaps in knowledge and practice in paediatric epilepsy care, and priority areas to improve care processes and outcomes for PLWE.         |
| Buelow (2018)<br>[17]      | USA       | Literature review, descriptive      | Implemented components     | To develop and evaluate a tool to facilitate communication between nurses and PLWE using a model of PCC.  |
| Byrne (2019)<br>[48]       | Ireland   | Descriptive                         | Implemented model          | To explore the readiness of healthcare providers in the Irish epilepsy care system to adopt and benefit from an integrated PCC model.               |
| Cross (2013)<br>[18]       | UK        | Literature review                   | Implemented components     | To synthesise existing research on managing seizures in children and explore strategies for seizure management in school settings.                  |
| Doran (2021)<br>[41]       | Ireland   | Retrospective cohort                | Implemented model          | To design a new care pathway for homeless PLWE, improve their access to specialist care, and strengthen links between community and tertiary teams. |
| Fitzsimmons (2012)<br>[38] | Ireland   | Literature review                   | Recommended model          | To synthesise existing research on evidence-based models of care for PLWE and apply the CDM model in evaluating the models of care.                 |
| Granata (2011)<br>[26]     | Italy     | Case series                         | Recommended components     | To report on the potential role of PC comprehensive caring  |

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|                         |           |                                |                        | throughout the life course and continuum of epilepsy care.   |
| Hafeez (2017) [19]      | USA       | Descriptive                    | Implemented components | To explore the content of a care coordination intervention for children with epilepsy at an accountable care organization.                       |
| Higgins (2019) [42]     | Ireland   | Descriptive                    | Implemented model      | To explore how epilepsy specialist nurses enact their clinical role in epilepsy management as members of multidisciplinary teams.                |
| Hutchinson (2020) [6]   | Australia | Descriptive                    | Recommended components | To explore clinical decision-making and shared care practices in managing refractory epilepsy, and the impacts of decisions on care pathways.    |
| Jackson (2022) [39]     | USA       | Literature review, descriptive | Recommended model      | To describe the acute seizure care pathway for children with epilepsy, identify gaps in care, and propose interventions to bridge these gaps.    |
| Kirkpatrick (2022) [27] | USA       | Descriptive                    | Recommended components | To explore the perspectives and experiences of women with epilepsy around PC sexual and reproductive health care provision.                      |
| Kluger (2021) [28]      | USA       | Literature review              | Recommended components | To explore the key domains of palliative care relevant to epilepsy that could be adopted to improve models of care for PLWE.                     |
| Le Pichon (2022) [20]   | USA       | Prospective cohort             | Implemented components | To explore telehealth initiatives aimed to improve consumer access to and knowledge about epilepsy services.                                     |
| Lewis (2013) [40]       | UK        | Case study                     | Recommended model      | To explore the communication and information needs of young people and their caregivers during transition from child to adult epilepsy services. |
| Lindhart (2021) [21]    | Denmark   | Descriptive                    | Implemented components | To examine the impact of a personalised discharge letter in facilitating smooth transition from hospital to home.                                |
| Minshall (2021) [29]    | UK        | Retrospective cohort           | Recommended components | To assess the standard of clinical care of PLWE in primary care since the removal of epilepsy from the Quality and Outcomes Framework.           |
| Ogundele (2022) [30]    | UK        | Narrative review               | Recommended components | To synthesise existing research on NDEBIDs and provide recommendations for more integrated approaches to care.                                   |

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| Patel (2017) [43]     | USA       | Retrospective cohort                     | Implemented model      | To implement and evaluate interventions designed to decrease seizure-related ED presentations.  |
| Power (2020) [49]     | Ireland   | Descriptive                              | Implemented model      | To understand the care experiences of PLWE and barriers and facilitators to implementing integrated PCC.                                    |
| Pugh (2020) [44]      | Australia | Prospective cohort, retrospective cohort | Implemented model      | To evaluate a community-based nursing service supporting people with neurological conditions in their discharge from hospital.              |
| Samanta (2021) [31]   | USA       | Literature review                        | Recommended components | To explore the range of interventions available to address the underutilisation of epilepsy surgery.  |
| Satherley (2021) [45] | UK        | Descriptive                              | Implemented model      | To understand family perspectives about a new integrated epilepsy care service for children and young people.                               |
| Saxena (2022) [32]    | USA       | Literature review                        | Recommended components | To synthesise evidence on the biopsychosocial model to facilitate PCC for neurological conditions across outpatient and inpatient settings. |
| Scavasine (2022) [24] | Brazil    | Retrospective cohort                     | Implemented components | To evaluate the efficacy of a store-and-forward teleneurology system in general practice.   |
| Tetuan (2019) [22]    | USA       | Retrospective cohort                     | Implemented components | To evaluate a novel interprofessional telehealth program designed to improve care access for rural-dwelling PLWE.                           |
| Tschamper (2019) [23] | Norway    | Descriptive                              | Implemented components | To evaluate videoconferencing as a collaborative information exchange platform for MDTs and families.                                       |
| Tumiene (2022) [33]   | Lithuania | Narrative review                         | Recommended components | To synthesise existing research on PC integrated care approaches for people with inherited metabolic diseases.                              |
| Varley (2010) [34]    | Ireland   | Descriptive                              | Recommended components | To explore the perspectives and experiences of HCPs in primary and specialist epilepsy care services.                                       |
| Varley (2020) [50]    | Ireland   | Descriptive                              | Implemented model      | To explore challenges and opportunities for community-hospital partnerships in epilepsy care.   |
| Williams (2017) [47]  | Ireland   | Descriptive                              | Implemented model      | To identify the barriers to implementing an ED integrated care pathway for seizure  |

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|-------------------------|---------|----------------------|-------------------|---|
|                         |         |                      |                   | management.   |
| Williams (2018)<br>[46] | Ireland | Retrospective cohort | Implemented model | To evaluate the utilisation and implementation of an ED integrated care pathway for seizure management. |

UK, United Kingdom; USA, United States of America; TSC, tuberous sclerosis complex; MDT, multidisciplinary team; PLWE, people living with epilepsy; PCC, person-centred care; CDM, chronic disease management; ED, emergency department; NDEBIDs, neurodevelopmental, emotional, behavioural, and intellectual disorders; HCPs, healthcare professionals.