

# Each and Every Need

A review of the quality of care provided to patients aged 0-25 years old with chronic neurodisability, using the cerebral palsies as examples of chronic neurodisabling conditions

SHORT REPORT



NCEPOD

Improving the quality of healthcare



Swansea University  
Prifysgol Abertawe

# Each and Every Need

**A review of the quality of care provided to patients aged 0-25 years old with chronic neurodisability, using the cerebral palsies as examples of chronic neurodisabling conditions**

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# Introduction

In 2013 the Royal College of Paediatrics and Child Health published their 'Overview of Child Deaths in the Four UK Countries' report.<sup>1</sup> This highlighted a number of key issues, one of which was that 71% of children who died had a chronic condition, most frequently neurological, reflecting the shift in survival combined with more effective prevention of perinatal deaths. The report was the first of the next generation of child health reviews, based on earlier work by the Centre for Maternal and Child Enquiries (CMACE) formerly the Confidential Enquiry into Maternal and Child Health (CEMACH).

The report presented here is a natural follow-on to the four nation death review, by looking in detail at chronic neurodisability to identify areas of care that could be improved for all patients up to the age of 25 years. A parallel study which is published at the same time by NCEPOD fulfils an additional need identified within the

2013 RCPCH report to examine the care of young people and young adults receiving mental health care in the UK.

## What is disability?

The definition of disability from the World Health Organisation brings together the 'medical model' of disability, which considers health conditions, body structure and function, with the 'social model' of disability, which considers factors in the environment that can be disabling, such as physical factors and peoples' attitudes (Figure 1). Disability is thus something that can affect anyone at any time and can vary over time.

There are numerous causes of chronic neurodisability in children and young people, in some cases the cause or precise diagnosis remains ill defined.

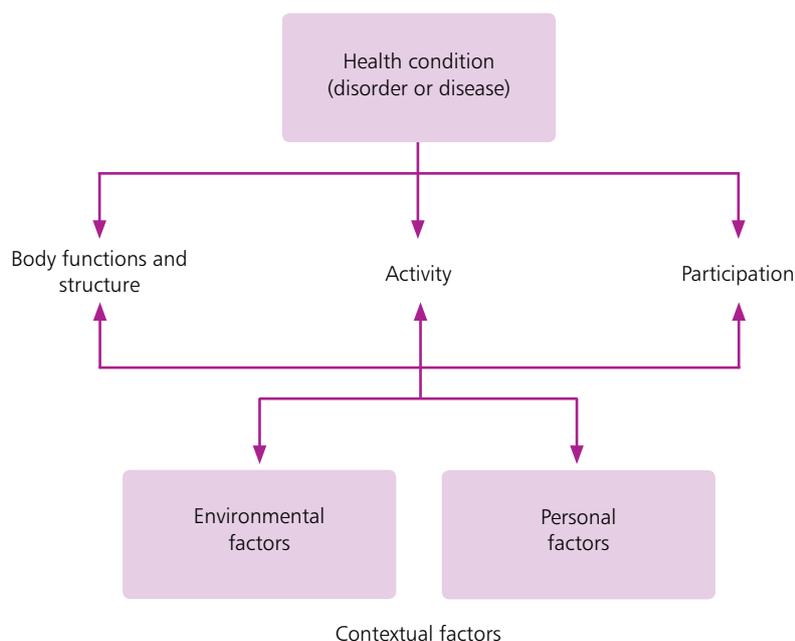


Figure 1 WHO model of disability

### Why the cerebral palsies?

'Cerebral palsy' is an umbrella term for a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy and by secondary musculoskeletal problems.

Together the cerebral palsies are the most common cause of physical disability in early childhood, affecting around three per 1000 live births. The majority of children with a cerebral palsy will be diagnosed within the first two years of life. In those with milder symptoms diagnosis may not be possible until four-five years of age and sometimes occurs even later. Infants with severe brain damage, for example associated with prematurity or perinatal complications, may be diagnosed soon after birth.<sup>2</sup>

Cerebral palsies are a common cause of chronic neurodisability in children and young people and were chosen for this project as exemplar disabling conditions. The cerebral palsies encompass a broad spectrum of severity and can be associated with a wide range of other impairments, including any combination of the following: epilepsies, special communication needs, learning disabilities, hearing impairment, vision impairment, chronic pain, behavioural, emotional and mood issues, autism spectrum conditions, eating, drinking and swallowing issues, drooling, constipation, continence issues, disordered sleep, and skeletal deformities.<sup>2,3,4</sup>

Additional comorbidities lead in many to an increased incidence of urgent and planned medical and surgical interventions, as well as in some dependency on technologies such as artificial feeding and assisted ventilation. Children and young people with a cerebral palsy are also vulnerable to all of the medical and surgical conditions that can affect anyone else, but these conditions can be more difficult to diagnose and manage in the presence of a cerebral palsy. Those who are least mobile and

most dependent on others for all of their care may develop neurological, respiratory, digestive, musculoskeletal and nutritional complications that require hospitalisation.

Healthcare for children and young people with cerebral palsies is therefore delivered in a range of settings, including emergency departments, acute inpatient wards, critical care units, outpatient clinics, community-based clinics and home visits by many different healthcare providers, including allied health professionals, doctors, surgeons, general practitioners, nurses and healthcare assistants. Studying healthcare in this group reflects this complexity, necessitating multiple organisational and clinical questionnaires to capture the range of settings and professional viewpoints across the age spectrum.

It is well documented across the developed world that service provision for those with cerebral palsies becomes fragmented after adolescence and that service users and their carers can feel 'lost in transition'.<sup>5,6,7,8</sup> Transition from paediatric to adult services is a complex process, and ideally throughout the transition process healthcare should be delivered in a coordinated and uninterrupted manner. Challenges to successful transition include limited access to adult services, differences between paediatric and adult healthcare systems, inadequate preparation, and changing family roles.<sup>8</sup> Suboptimal transition to adult services has been linked to a decrease in the utilisation of services by adolescents and deterioration in overall health.<sup>9</sup>

The study presented here has used multiple data sources to collate an overall picture of the services available and the care provided to children and young people with a cerebral palsy. The analysis of routine national datasets has used their potential to provide population based quantitative summary information about NHS utilisation for children and young people with the cerebral palsies in comparison with children and young people without cerebral palsies, showing trends by age, social economic status, inter-country comparisons and comorbidities over time. Analysis of data from clinical questionnaires, case review and organisational data have provided a detailed picture of current practice across healthcare services.

# Recommendations

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The overarching aim of this report is to improve the care provided to children and young people aged 0-25 years with a chronic neurodisability. The cerebral palsies have been used in the study as examples of neurodisabling conditions.

The recommendations with a shaded background relate only to patients with a cerebral palsy.

The term 'clinician' has been used to encompass all healthcare professionals, although individual specialties have been listed where appropriate.

The text in italics after each recommendation is a suggestion as to who should be aware of / lead on the recommendation, but this will vary locally so please include all groups who need to be involved.

The **PRINCIPAL RECOMMENDATIONS** have been ranked by all involved as those recommendations of primary importance.

## **Improving clinical coding and quality of routine data**

### **1 PRINCIPAL RECOMMENDATION**

Clinical coding of neurodisabling conditions in all healthcare records and routinely collected datasets must be accurate and consistent if data are to be meaningful, comparable and useful to inform health outcome reviews and patient care.

- a) Cerebral palsy and other chronic neurodisabling conditions should be added to the standard list that *"must always be coded for any admitted patient care episode (including day case patients) when documented in the patient's medical record for the current hospital provider spell, regardless of specialty."*<sup>[i]</sup>
- b) Standardised healthcare data should be captured by clinicians each time a patient is seen, in ALL settings (to include community based organisations)

- c) Data collection about patients with neurodisabling conditions must include measures of clinical severity and functional abilities to enable detailed analysis
- d) Clinical coding systems should be harmonised across routinely collected datasets in England, Wales, Scotland and Northern Ireland to enable data analysis throughout the UK
- e) Patient records and routine data collections across different healthcare providers (community care, primary care, secondary care and mental health) should be linked to provide the greatest potential for quantifying healthcare utilisation and patient outcomes on a population basis. *(Responsibility for action rests with Clinicians to capture data about needs at the point of care; Chief Executives to provide easy to use electronic data capture interfaces for clinicians to achieve this; Commissioners to ensure the above are in place and the Governments or those with responsibility in England, Scotland, Northern Ireland, Wales, Guernsey, Jersey and the Isle of Man to ensure that the system specifications for electronic records are adequate for the task in all settings where clinical activity occurs.)*

*As hospitals move to electronic patient records, this should facilitate better data linkage between healthcare providers. Work is underway to include SNOMED CT (Systematized Nomenclature of Medicine - Clinical Terms - a standardised vocabulary of clinical terminology) into the routine coding system for UK NHS data. SNOMED CT already captures the 'Surveillance of Cerebral Palsy in Europe' preferred diagnostic terms (including measures of disease and functional severity). These are incorporated into the Community Services Data Set in England and the Community Health Activity Data in Scotland, and NHS providers are mandated to report these diagnostic data at each non-inpatient healthcare contact. However, introduction of SNOMED CT is*

## RECOMMENDATIONS

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*taking a phased approach, neither SNOMED CT nor the Community Services Data Set/ Community Health Activity Data is used across the UK.*

- 2 Access to existing routinely collected national datasets needs to be improved. The governance and application process to the four nations should be harmonised to promote data linkage and encourage the use of population datasets more effectively and efficiently. *(NHS Digital, NHS England, NHS Scotland, NHS Wales, Northern Ireland Statistics and Research Agency, Guernsey, Jersey and the Isle of Man)*

*Recommendations 1 and 2 should therefore be considered as hospital systems are planned to ensure a seamless transition from one coding system to another.*

- i. National Clinical Coding Standards ICD-10 5th Edition

### **Clinical care - diagnosis and management**

#### **3 PRINCIPAL RECOMMENDATION**

Patients suspected of having a neurodisabling condition should have an expert assessment by clinicians who have the competences to consider the range of possible diagnoses. For those patients with a cerebral palsy, the clinician must be able to recognise and describe the tone variation and distribution pattern of motor impairment, as informed by 'NICE Guideline 62' **[ii]** and the 'Reference and Training Manual of the Surveillance of Cerebral Palsy in Europe' **[iii]**. *(Clinicians, Medical Directors, Commissioners, Regulators, Royal Colleges and Specialty Associations)*

- 4 Patients with a cerebral palsy should have the pattern of their motor impairment (e.g. unilateral/bilateral) and tone variation (spasticity, dyskinesia, dystonia, ataxia or choreoathetosis) assessed and recorded in the clinical notes by the clinician undertaking the assessment. *(Clinicians, Regulators)*
- 5 Patients with a cerebral palsy should have their level of motor functioning described and documented in every clinical communication, using the Gross Motor Function Classification System. *(Clinicians, Regulators)*

- 6 Clinicians offering assessments to consider neurodisabling conditions as possible diagnoses should have timely access to magnetic resonance neuroimaging (MRI), including facilities for sedation and/or general anaesthesia if required. These may be within a network of care. MRI should not be provided without appropriate neuroradiological expertise to inform the imaging protocols used and to accurately interpret the images obtained. *(Clinicians, Medical Directors, Commissioners, Regulators)*

#### **7 PRINCIPAL RECOMMENDATION**

Patients with a neurodisabling condition should have access to an appropriate multidisciplinary team to proactively monitor their health status when their needs are complex and/or when there is a change in their functional status, physical condition or environmental situation. For those patients with a cerebral palsy, this access should reflect 'NICE Guideline 62' **[ii]**. *(Medical Directors, Clinical Directors, Clinicians, Commissioners, Regulators)*

- 8 Patients with neurodisabling conditions should have their weight and nutritional status considered at every healthcare encounter and assessed and recorded based on clinical need. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 9 As for all patients, those with a neurodisabling condition who also have a learning disability should have this clearly documented in their clinical records by all healthcare providers (e.g. in primary and/or specialist healthcare). *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Regulators)*
- 10 Oral health and dental care for patients with a neurodisabling condition must be considered as a matter of routine by their lead clinician. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*

**11 PRINCIPAL RECOMMENDATION**

All patients with complex needs and, where appropriate, their parent carers or legal guardians, should be offered the opportunity to develop a patient-held Emergency Health Care Plan/Emergency Care Summary to facilitate communication in the event of a healthcare emergency.

**[iv]** This should include as a minimum:

- a) information about the patient's health conditions and treatment;
- b) who to contact in a range of scenarios and what to do;
- c) a statement about what has been discussed and agreed about levels of intervention including palliative care planning; and
- d) the existence of any advance directives (for those over 18 years), lasting power of attorney or any other measure.

The existence of this Emergency Health Care Plan/ Emergency Care Summary must be recorded in all communication and case notes and this should be subjected to local audit. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators)*

- 12 Patients with a neurodisabling condition should have an assessment completed by their lead clinician to determine their risk of respiratory compromise. This should be reviewed as appropriate for the complexity of the patient's needs. Those patients at significant risk of respiratory compromise should be assessed by clinicians with expertise in respiratory medicine, in order to discuss with the patient and their family the range of interventions most likely to lead to the best outcome. 'What to do' and 'who to contact' in the event of respiratory symptoms should be documented in the patient-held Emergency Health Care Plan. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 13 As for all patients, those with a neurodisabling condition admitted to an acute general hospital as an emergency should have timely assessment and senior review within 14 hours of admission by a specialist relevant to the emergency as recommended by the Royal College of Paediatrics and Child Health in 'Facing the Future' **[v]** and the Royal College of Physicians of London in the 'Acute Care Toolkit 4' **[vi]** *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*

- 14 Patients should undergo timely review prior to major surgery and/or if they have complex co-morbidity by key team members to ensure optimal preparation and planning. This must include senior members of the surgical, anaesthetic and medical teams. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 15 Pain scoring tools should be understood and used in the peri-operative/peri-procedure period for patients with a neurodisabling condition. Healthcare staff should be trained in their use. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians)*
  - ii.** *NICE Guideline 62 - Cerebral palsy in under 25s: assessment and management*
  - iii.** *Reference and Training Manual of the Surveillance of Cerebral Palsy in Europe*
  - iv.** *Emergency Health Care Plan – Council for Disabled Children and Emergency Care Summary - Scotland*
  - v.** *Facing the Future and Emergency Care Summary - Scotland – Royal College of Paediatrics and Child Health*
  - vi.** *Acute Care Toolkit 4 – Royal College of Physicians*

**Clinical care - clinical leads and care plans**

- 16 Patients with a neurodisabling condition who need ongoing medical and therapeutic input should always have a named lead clinician to co-ordinate care across healthcare services and all age groups. Any change in lead clinician should include planning and a thorough handover. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators)*
- 17 Patients with a neurodisabling condition should be on an appropriate care pathway. For those with a cerebral palsy this should include arrangements for surveillance of hips, spine and growth until skeletal maturity and in the longer term, nutritional surveillance and the identification and management of pain. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*

**18 PRINCIPAL RECOMMENDATION**

Patients with a neurodisabling condition should have a clear care plan that describes and addresses all of their needs. For those with a cerebral palsy this should specifically include pain, growth, nutritional status, safety of eating and drinking and other medical conditions such as seizures or mental health or behavioural issues. This care plan should be reviewed and updated when in hospital and on discharge to the community. Where the patient has complex needs this should be readily accessible to patients, their parent carers and clinicians e.g. as part of a patient-held patient passport. **[vii]** (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators*)

- 19 All medically frail patients with a neurodisabling condition, and where appropriate, their parent carers or legal guardians, must be offered the opportunity to discuss with their lead clinician, their care wishes in the event of serious illness or sudden collapse. This should be recorded in their patient-held Emergency Health Care Plan. This may include discussing Do Not Attempt Cardio Pulmonary Resuscitation decisions and palliative care plans, which should be validated at each point of care according to the existing legal requirements and professional guidance. This is particularly important to have in place at handover during transition to adult services. (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators*)

**vii.** *Example of a patient-held passport*

**Transition and age appropriate care**

- 20 To facilitate transition to adult services there must be a clear, documented plan developed between the young person with complex needs and their multidisciplinary team. NCEPOD supports 'NICE Guideline 43' **[viii]** that transition planning should have begun by the age of 14. (*Clinicians, General Practitioners, Commissioners, Regulators*)

- 21 Healthcare organisations must better consider the needs of young people in the organisation, planning and delivery of healthcare. Age appropriate care must include dedicated physical space as *well* as agreed policies and procedures to be used in all clinical areas to facilitate patient privacy, dignity and inclusion. (*Medical Directors, Clinicians, Commissioners, Regulators*)

**22 PRINCIPAL RECOMMENDATION**

The transition plan between children's to adults' services should be co-ordinated by the lead clinicians and integrated within other multiagency plans e.g. health education, social care planning and mental healthcare services. The patient's team in primary care must be part of the planning process (*Clinicians, General Practitioners, Commissioners, Regulators*)

- 23 Care pathways for adolescent patients should promote dignity and independence when a hospital stay is needed and include ready access to single room accommodation, space for special equipment and the facility for parent carers to stay on-site when required **[ix]** and as recommended by the Royal College of Physicians of London in the 'Acute Care Toolkit 13'. **[x]** (*Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators*)
- 24 General Practitioner Networks, Federations, Clusters, Health Boards and Partnerships, should consider developing Clinical Champions for neurodisabled patients to lead and help 'bridge the gap' between specialist neurodisability teams and primary/community care. Leads could be engaged in care from the early teens and function as an essential link with the wider paediatric multidisciplinary teams. (*General Practitioners, Royal College of General Practitioners, Commissioners, Regulators*)
- viii.** NICE Guideline 43 - *Transition from children's to adults' services for young people using health or social care services*
- ix.** 'You're Welcome' Standards
- x.** Royal College of Physicians of London in the 'Acute Care Toolkit 13'.

**Clinical care – communication**

- 25 As for all patients, those with neurodisabling conditions should have their preferred method of communication clearly documented in their clinical records (electronic and/or paper) across all healthcare providers (e.g. in primary and/or specialist healthcare). *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, Regulators)*
- 26 Each consultation with patients with a neurodisabling condition should be used as an opportunity to enquire whether they and their family have the information and support they need. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Regulators)*
- 27 All healthcare professionals who might work with patients with a neurodisabling condition should be able to make a range of reasonable adjustments to accommodate them, such as providing support for a range of communication, learning and physical access needs. ‘Disability Matters’ is a key resource that should be embedded in the training of all healthcare professionals. **[xi]** *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 28 Patients with a neurodisabling condition, and where appropriate, their parent carers or legal guardians should have access to information and training in optimum self-management, problem-solving and how to get the right help and support as required in line with ‘NICE Guideline 62’ **[ii]** *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- 29 Clinicians should be aware of, and comply with, the ethical and legal requirements for consent to surgery as defined by the General Medical Council and requirements for mental capacity assessments which will vary depending on UK country in which they live. These requirements must be communicated clearly to patients and parent carers and documented in the case notes. *(Clinicians, Commissioners, Regulators)*
- 30 Patients with a neurodisabling condition should be involved in all communications and decision-making about their care and management where possible, and where appropriate, with adjustments in place to support their involvement, including specialist speech and language therapists as required. Parent carers or legal guardians must also be included in these conversations as appropriate. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators, Patients)*
- 31 After a period of inpatient care patients with a neurodisabling condition should have their ongoing function and daily needs assessed and documented. Any significant change which would necessitate a planned alteration to day-to-day care must be clearly communicated in discharge plans. The discharge plan should be sent to the patient and their parent carers and their multidisciplinary team including their GP. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, Commissioners, Regulators)*
- ii.** NICE Guideline 62 - Cerebral palsy in under 25s: assessment and management
- xi.** Disability Matters
- 32 Clinicians should be trained to be able to communicate effectively with patients with a range of communication needs. They must be able to make a structured assessment of overall needs alongside management of the presenting condition. *(Medical Directors, Directors of Nursing, Clinical Directors, Clinicians, General Practitioners, Commissioners, NHS Scotland, Regulators)*

**Organisation of care**

- 33 All providers of healthcare for patients with a cerebral palsy or other chronic neurodisability should have clear care pathways described for patients, parent carers and referrers which are easily available e.g. on the hospital website with named contact details. **[xii]** *(Medical Directors, Directors of Nursing, Clinical Directors, General Practitioners, Commissioners, NHS Scotland, Regulators)*

## RECOMMENDATIONS

34 To accommodate patients with neurodisabling conditions all healthcare facilities should:

- a) Be fully accessible;
- b) Have appropriate high quality equipment available including hoists, weighing scales, height measuring facilities, places to allow changing and wheelchairs to support participation in everyday activities and proactive independence. These should be easily available and maintained regularly. *(Medical Directors, Directors of Nursing, Clinical Directors, Commissioners, NHS Scotland, Regulators)*

35 Hospitals should review their day-case facilities and policies to ensure they are inclusive for neurodisabled patients with complex needs. *(Medical Directors, Directors of Nursing, Clinical Directors, Commissioners, NHS Scotland, Regulators)*

**xii. British Academy of Childhood Disability – Quality Principles for Paediatric Disability Services**

Whilst each recommendation should be read to determine if it is relevant to you or your organisation, the table below summarises a quick glance view of which ones should be looked at depending which ‘audience’ you are. A gap analysis tool, by audience is available on the report study page at [www.ncepod.org.uk](http://www.ncepod.org.uk)

Audience	Recommendation number(s)
Chief Executives	1
Clinical Directors	7,8,9,10,11,1,13,14,15,16,17,18,19,23,25,26,27,28,30,31,32,33,34,35
Clinicians	1,3,4,5,6,7,8,9,10,11,12,13,14,15,16,17,18,19,20,21,22,23,25,26,27,28,29,30,31,32
Commissioners	1,3,6,7,8,10,11,12,13,14,16,17,18,19,20,21,22,23,24,25,27,28,29,30,31,32,33,34,35
Directors of Nursing	8,9,10,11,12,13,14,15,16,17,18,19,23,25,26,27,28,30,31,32,33,34,35
General Practitioners	11,16,19,20,22,24,25,32,33
Guernsey	1,2
Isle of Man	1,2
Jersey	1,2
Medical Directors	3,6,7,8,9,10,11,12,13,14,15,16,17,18,19,21,23,25,26,27,28,30,31,32,33,34,35
NHS Digital	2
NHS England	1,2
NHS Scotland	32,33,34,35
NHS Wales	1,2
Northern Ireland	1,2
Patients	30
Regulators	3,4,5,6,7,8,9,10,11,12,13,14,16,17,18,19,20,21,22,23,24,25,26,27,28,29,30,31,32,33,34,35
Royal College of General Practitioners	1,2
General Practitioners	24
Royal Colleges	3
Specialty Associations	3

## Summary

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The overarching aim of this study was to review the quality of care provided to patients with a cerebral palsy, as examples of a neurodisability condition. The interfaces between different care providers was assessed as well as transition from child to adult services. Children and young people with a cerebral palsy have many complex needs and whilst areas of good practice were seen, much room for improvement was identified.

At the very point of diagnosis, the term recorded in medical records to describe the cerebral palsy was often incorrect and frequently did not include specific information about the type of cerebral palsy or tone variation. From routinely collected population datasets, it was clear that although the cerebral palsies are chronic conditions, they are not coded at every contact point with NHS services.

As part of the clinical assessment to determine the cause of the cerebral palsy, the study highlighted variation in access to Magnetic Resonance Imaging, including facilities for sedation and/or general anaesthetic. There was also variation in access to neuroradiological expertise to interpret the images obtained. Important clues to other diagnoses, including developmental brain anomalies and neurometabolic conditions, will be missed if neuroimaging is not undertaken. Accurate diagnosis informs accurate management.

Despite being an internationally recognised system for describing gross motor function that informs clinical management, the Gross Motor Function Classification System (GMFCS) level of fewer than one in three children, young people and young adults with cerebral palsies was documented in their case notes.

Good communication underpins all clinical practice and is encouraged by the General Medical Council and professional bodies, but there was lack of sufficient efforts seen to have been made to communicate directly with this group of patients in a third of the sample. There was

room for improvement in the documentation of inclusion of these patients in discussions and decision-making in four out of ten cases reviewed. There was poor communication in relation to needs, support, emergency health care planning and consent for procedures.

Multidisciplinary team working is key for this group of complex patients, yet this was viewed as inadequate in 137/285 (48.1%) inpatients from the cases reviewed. Discharge summaries about episodes of inpatient care were not copied to lead clinicians for cerebral palsy care in almost half of cases and were only copied to the community physiotherapist in 30% for day case patients and 38% for admitted patients. If the wider team do not know what is happening for the patient, there can be no proactive, joined-up care. Good multidisciplinary team working depends on quality team leadership; however, our study evidenced considerable variation in clarity about who was leading multidisciplinary teams, this being especially the case for young adults with cerebral palsies.

Routine national data showed that children and young people with cerebral palsies had similar trends of 'consultation' with primary care across the age groups to those without the conditions. However, those with cerebral palsies had a higher rate of consultation and number of consultations per year compared to other children and young people in all age categories. It is important for GPs to be aware of the potential multifaceted needs of this patient group, how to manage what they can in primary care and how to access clearly published care pathways when more specialist opinions or care are needed. The data suggested that children and young people with cerebral palsies attended primary and secondary healthcare settings significantly more frequently than those without cerebral palsy. Whilst the rate of outpatient attendances increased over time outpatient attendances decreased significantly with age whilst primary care attendance increased markedly between 15-25 years of age.



# Method

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## Study aims

The overarching aims of this study were to:

- Review the quality of care provided to children and young people with a chronic neurodisability, using the cerebral palsies as exemplar conditions
- Examine the interface between care settings; and
- Assess the transition of care from paediatric to adult services.

Data were collated from a number of sources to allow the aims to be met. These are described below.

## Method overview

### **Participation**

For the organisational and clinical reviews National Health Service hospitals in England, Scotland, Wales and Northern Ireland were expected to participate as well as public hospitals in the Isle of Man, Guernsey and Jersey. Within each hospital, a named contact, referred to as the NCEPOD Local Reporter, acted as a link between NCEPOD and the hospital staff, facilitating case identification, dissemination of questionnaires and data collation.

### **Organisational survey**

An organisational questionnaire was divided into 10 parts with the aim of collecting data from many different providers of care.

### **Patient and parent carer survey**

Short questionnaires were made available on the NCEPOD website to enable children and young people with chronic neurodisabilities, and parent carers, to give their experience of the services they had encountered. Patient and carer support organisations were contacted to promote the survey. Local Reporters in hospitals were asked to display posters encouraging participation in the survey. Small cards were distributed with a brief explanation of the survey and the link, to be handed to patients and parent carers.

### **Clinical review using questionnaires and case notes**

At a local level, questionnaires were sent to lead clinicians involved in a patient's care and copies of case note data were requested. These questionnaires and case notes were anonymised and put to a multidisciplinary group of clinicians to peer review the quality of care provided.

### **Review of routine national datasets and data linkage**

At a national level, and by UK country, datasets were collated that included secondary healthcare data from England, Northern Ireland, Scotland and Wales. The Clinical Practice Research Datalink (CPRD) provided a 6.9% sample of primary care data from all four countries and linked secondary care data for a sample of GP practices in England.<sup>12</sup> In Wales linked primary and secondary healthcare data were also available. Data from the only remaining national cerebral palsies register and intensive care were also included where available.

Where possible anonymised data linkage was performed between datasets for individual children and young people. Data were analysed for the time period 2004-2014. The CPRD dataset was cleaned, analysed and accessed at Cardiff University. All other datasets were housed in the Secure Anonymised Information Linkage (SAIL) databank at Swansea University where the datasets were cleaned and prepared for analysis which then took place at Swansea and Cardiff University via a secure link.

**All analysis relating to these data will be displayed on a grey background throughout the report.**

### **Study Advisory Group**

To help design the study and to act as a study steering group for all data collections and analysis, a Study Advisory Group (SAG) was formed. This group comprised a multidisciplinary group of clinicians as well as a family liaison officer and a carer. The clinicians represented physiotherapy, community and hospital paediatrics,

anaesthetics, neurosurgery, nursing, endocrinology, orthopaedics, palliative care medicine, rehabilitation, and general practice. The SAG identified the objectives that would be used to address the aims of the study. These are summarised under the detailed method sections below:

### Method detail - organisational survey

#### Objectives

- To review access to healthcare services, including pathways of care and clinical leadership
- To review how healthcare services were delivered, including uni/multidisciplinary care, outreach clinics and co-location of services.

At the start of the study, a short questionnaire was sent to every trust/health board to identify which services were provided there and the lead clinician who would be responsible for completing an organisational questionnaire. The links to complete the questionnaire were then sent to the identified clinical leads for completion.

An organisational questionnaire was sent to all hospital trusts/boards where children and young people with a cerebral palsy may have been cared for. Data collected included information around pathways of care, transition, policies and protocols in place, and communication. Data were collected both electronically, and using hard copy questionnaires. Due to the complexity of the service structure, the organisational questionnaire was split into 10 sections:

1. The emergency department
2. Inpatient care - paediatrics
3. Outpatient care - paediatrics
4. Community paediatric care
5. Inpatient care - young adults
6. Outpatient care - young adults
7. Allied health professionals - paediatric inpatient care
8. Allied health professionals - paediatric clinics
9. Allied health professionals - young adult clinics
10. Allied health professionals - young adult inpatient care

### Method detail - patient and parent carer survey

#### Objective

- To understand the views of the service users, so as not to second guess what their experiences had been.

A short patient questionnaire was circulated electronically via NCEPOD's network of Local Reporters and via patient networks to gather data on young people and carers' views on the services they used. This questionnaire was also made available on the NCEPOD website.

### Method detail - clinical peer review using questionnaires and case notes

#### Objective

- To gain an in-depth view of the care received by patients, to highlight where improvements could be made as well as examples of good care.

#### ***On a case by case basis the following areas were assessed:***

- Clinical services; including access to professionals with the required expertise, procedures and interventions, and access to equipment
- Symptom management; including pain, posture and movement, associated conditions, communication support and technology dependencies
- Support services; including family support and support at transition to adulthood
- Communication; at diagnosis and in preparation for adulthood
- Training for children and young people with cerebral palsies, families, and professionals (for those providing direct care and those across workforce sectors)
- Safeguarding and social care
- Transition to adult services
- Decision making with children, young people and families; including capacity and best interest decision making.

**Table 1.1 ICD10 codes for a cerebral palsy used as inclusion codes**

G80.0	Spastic quadriplegic cerebral palsy	G81.9	Hemiplegia, unspecified
G80.1	Spastic diplegic cerebral palsy	G82.3	Flaccid tetraplegia
G80.2	Spastic hemiplegic cerebral palsy	G82.4	Spastic tetraplegia
G80.3	Dyskinetic cerebral palsy	G82.5	Tetraplegia, unspecified
G80.4	Ataxic cerebral palsy	G83.0	Diplegia of upper limbs
G80.8	Other cerebral palsy	G83.1	Monoplegia of lower limb
G80.9	Cerebral palsy, unspecified	G83.2	Monoplegia of upper limb
G81.0	Flaccid hemiplegia	G83.3	Monoplegia, unspecified
G81.1	Spastic hemiplegia		

**Study population and case ascertainment**

Patients aged 0-25 years with an ICD10 code for a cerebral palsy (Table 1.1), who were admitted to hospital between Monday 7th September and Sunday 18th October 2015 inclusive were included in the study.

**Case identification**

The NCEPOD Local Reporter, based in each hospital was asked to populate a spreadsheet which detailed all patients who were admitted to the hospital during the study period with one of the included ICD10 codes. The spreadsheet included patient identifiers (hospital and NHS/CHI number, date of birth, gender), date of admission, ICD10 code for that admission, date of discharge, discharge destination and the details of the clinicians who were involved in the care of the patient. Details of any previous admissions in the four weeks prior to the study period were also requested.

Once uploaded to the secure study database, a maximum of ten cases per hospital were sampled for inclusion in the questionnaire and peer review process. Sampling was based on:

- A maximum of two day case patients per hospital
- At least two patients with multiple admissions (prior to and during the study period)
- At least three surgical patients with any length duration of stay
- At least three medical patients who had an admission for  $\geq 48$  hours.

Although the sample was identified based on a hospital admission, where possible, details were also collected on the community care the patient had received in the three year period prior to the hospital admission.

**Clinical questionnaires and case notes**

Three clinical questionnaires were used to collect data for this study:

**1. Admitting clinician**

This questionnaire collated data on the care provided during the patients identified admission. This questionnaire also captured whether the patient had a 'usual' lead for neurodisability care, or whether 'overall neurodisability care' was provided through the general practitioner.

**2. Lead clinician for neurodisability care**

Where the details of this clinician could be identified, a questionnaire was sent. This questionnaire collated information on the ongoing care provided to the patient in the community, in the three year period prior to the identified admission.

**3. General practitioner (GP)**

This questionnaire collated information on the last three years of primary care provided. It was sent to the GP if they were known to be the 'usual lead' for the patient's ongoing neurodisability care, or if the 'usual lead' was not known as it could not be ascertained from either the admission questionnaire or the case notes, in which case the GP was asked to indicate who the relevant clinician was.

### Case notes

Extracts of patient case notes were requested for each included case.

#### **Acute care notes**

These case note extracts were requested, where applicable, from the time of the patient's arrival in hospital until the time of their discharge, day 30 or death:

- Emergency department records
- Clinical notes, both paper and electronic
- Operation/procedure notes and consent forms
- Nursing notes
- Any separate orthopaedic notes
- Emergency Health Care Plans /Emergency Care Summary
- Passports of care
- Discharge summary
- Community therapy notes
- Outpatient appointment correspondence
- The most recent community discharge summary
- Copies of GP letters
- Clinical notes from any previous admissions (including discharge summaries) (between the 10th August – 18th October 2015)

In addition to the extracts for the admission at the time of inclusion into the study, previous notes for the three years prior to the study admission were requested which included

- Clinic letters
- Discharge summaries for any previous hospital admissions

#### **Community care notes**

These were requested for the three years prior to the included admission:

- Community multidisciplinary summaries
- Relevant allied health professional notes
- Clinic letters

### **Clinical peer review process**

A multidisciplinary group of case reviewers was recruited to peer review the case notes and associated clinician questionnaires. The group comprised: paediatric surgery, anaesthetics, orthopaedic surgery, paediatrics, physiotherapy, speech and language therapy, neurology, occupational therapy, intensive care and nursing.

All patient identifiers were removed prior to review. Neither the Clinical Co-ordinators at NCEPOD, nor the case reviewers had access to patient identifiable information.

After being anonymised, each case was reviewed by at least one reviewer within the multidisciplinary group. At regular intervals throughout the meeting the Chair allowed a period of discussion for each reviewer to summarise their cases and ask for opinions from other specialties or raise aspects of the case for further discussion.

To standardise the peer reviews, case reviewers used a semi structured electronic questionnaire and were encouraged to enter free text commentary at multiple points.

The overall quality of care of each case was summarised using the NCEPOD grading system:

**Good practice:** A standard that you would accept from yourself, your trainees and your institution.

**Room for improvement:** Aspects of **clinical** care that could have been better.

**Room for improvement:** Aspects of **organisational** care that could have been better.

**Room for improvement:** Aspects of both **clinical and organisational** care that could have been better.

**Less than satisfactory:** Several aspects of clinical and/or organisational care that were well below that you would accept from yourself, your trainees and your institution.

**Insufficient data:** Insufficient information submitted to NCEPOD to assess the quality of care.

## Quality and confidentiality

Each case was given a unique NCEPOD number. Data from all questionnaires received were electronically scanned into a database. Prior to any analysis taking place, the data were cleaned to ensure that there were no duplicate records and that erroneous data had not been entered during scanning. Any fields that contained data that could not be validated were removed.

## Data analysis

Following cleaning of the quantitative data, descriptive data summaries were produced. The qualitative data collected from the case reviewers' opinions and free text answers in

the clinician questionnaires were coded by themes where possible to allow quantitative analysis. The data were reviewed by NCEPOD Clinical Co-ordinators, a Clinical Researcher and Researcher Assistant to identify the nature and frequency of recurring themes. All data were analysed using Microsoft Access™ and Excel™ by the research staff at NCEPOD.

Case studies have been used throughout this report to illustrate particular themes.

## Method detail - review of routine national datasets

### Objective

Routinely collected national datasets in this project were used to determine the extent to which they could contribute to an assessment of the health needs and the quality of care that children and young people with a cerebral palsy receive.

A four month project scoping period (July-October 2015) was completed, which included a literature search and consultation with data providers, project advisory group and the study advisory group to identify:

- Potential data sources in England, Wales, Northern Ireland, Scotland, the Channel Islands and Isle of Man. (*Data from the Channel Islands or Isle of Man could not be identified as the data were either 'not collected or would have to be obtained from a wide range of sources, making its reliability questionable'*)
- Potential questions that could be addressed from the available datasets
- The approaches to data linkage that had the potential to address these questions
- The facilitators and barriers to data linkage between routinely collected datasets
- The process for gaining permission to access datasets
- Implications from data scoping for the methodological approach
- Revisions and finalisation of project protocol.

A series of descriptive cross sectional analyses of the datasets were designed to address the key questions. All had the potential to be addressed but the results were limited by data availability and factors such as data completeness, availability within the time frame of the project and the cost of the data.

The study population included children and young people aged 0-25 years who had a cerebral palsy, were resident in England, Wales, Scotland, Northern Ireland over an eleven year period (2004-2014) compared to children without a cerebral palsy over the same time period. All analyses were stratified in five year age bands (0-4, 5-9, 10-14, 15-19, 20-24 completed years) and results were compared between children and young people with and without a cerebral palsy and between participating countries, where possible (Figure 1.1).

METHOD

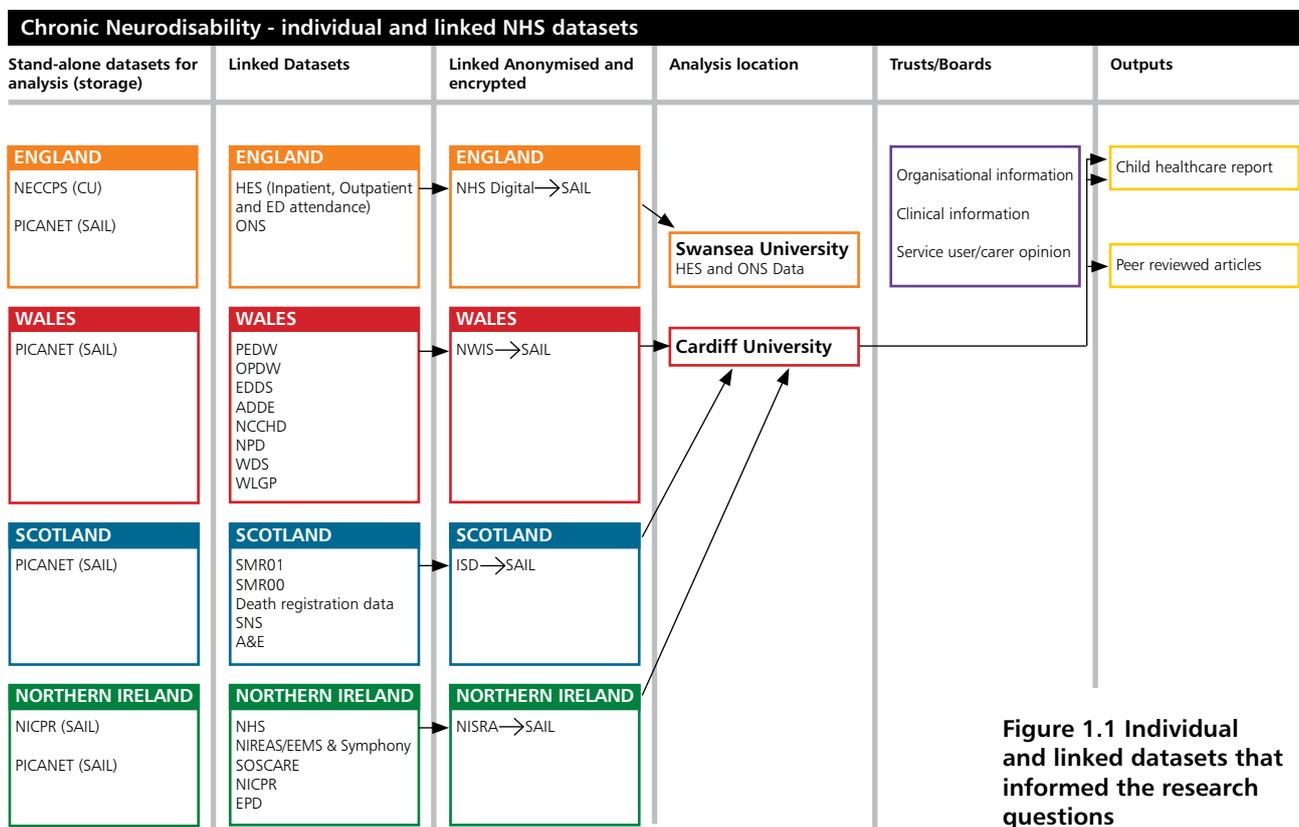


Figure 1.1 Individual and linked datasets that informed the research questions

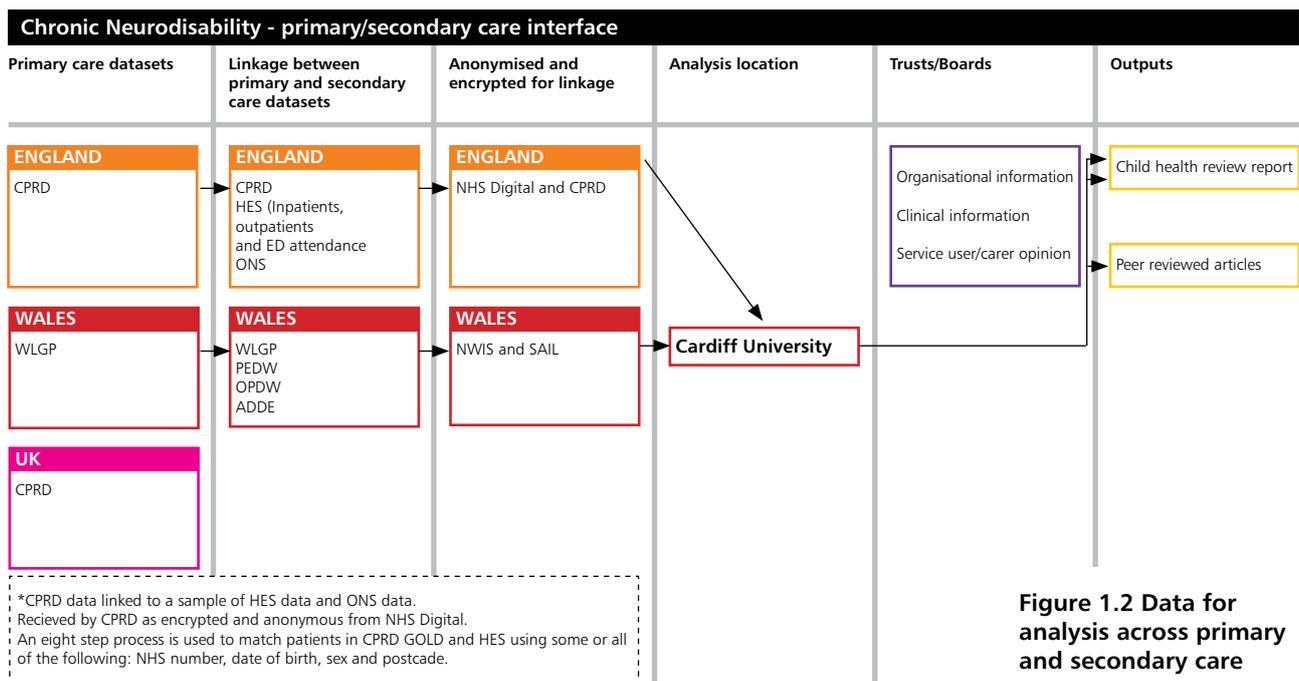


Figure 1.2 Data for analysis across primary and secondary care

## Research questions

### ***Hospital admissions and outpatient attendance***

The following questions were addressed from secondary care datasets in England, Northern Ireland, Scotland and Wales: (2004-2014) and CPRD HES linked data for England. Analyses were compared between children and young people with a cerebral palsy and undertaken by age group, year of admission or attendance and deprivation of area of residence where available.

- What was the rate of hospital admissions, outpatient attendances (per 100 person years at risk) for children and young people with and without one of the cerebral palsies?
- What proportion of hospital admission episodes/ outpatient attendances were attributed to children and young people with one of the cerebral palsies?

The following features were described and compared between children and young people with and without a cerebral palsy:

- Median length of stay by age group
- Median number of outpatient/inpatient attendances per year
- Type of hospital admission (emergency, elective)
- Reason for hospital admission/outpatient attendance by clinical specialty/disease type/procedure undertaken (where possible)

### ***Intensive care admissions***

The following questions were addressed from the PICANet dataset, a clinical audit that collects critical care data across all 34 paediatric intensive care units (PICUs) in the UK and Ireland and six specialist transport organisations. PICANet data were analysed for all admissions (2008-2014):

- How many children and young people with a cerebral palsy were admitted to PICU's across the UK?
- What proportion of PICU admissions were for children and young people with a cerebral palsy?
- Age distribution for those admitted to a PICU
- Clinical diagnosis (reason for admission defined post admission)
- Length of stay
- Place of discharge

### ***Primary care attendances***

The following questions were addressed in England, Wales, Scotland and Northern Ireland separately from the CPRD dataset and, for Wales, from Wales Primary Care GP dataset (2004-2014). Data were compared between children and young people with and without a cerebral palsy and undertaken by age group, year of attendance and deprivation of area of residence where available.

- What was the rate (per 100 person years at risk) of primary care consultation for children and young people with a cerebral palsy (by age and deprivation of area of residence)
  - Reasons for primary care attendances
  - Referral patterns to secondary care
  - Median length of stay in days

### ***Transition***

- What was the pattern of utilisation of adult and paediatric inpatient and outpatient healthcare facilities for children and young people with and without one of the cerebral palsies during transition?
- What were the reasons for outpatient attendance and inpatient admissions by age group during transition?

### ***Cerebral palsy register analyses***

It was originally planned that a cohort of children with a cerebral palsy could be identified in each nation and data-linked into routinely collected data. However the North of England Collaborative Cerebral Palsy Survey (NECCPS) dataset was disbanded during the study period and so this was not possible. The data linkage was pursued for the Northern Ireland Cerebral Palsy Register, however issues that arose surrounding the accurate linkage of individuals' data were not resolved within the timescale of the project; access to the individual CP registers was available and included relevant data to address the following key questions for the five age groups and included information on Gross Motor Function Classification System (GMFCS) severity and Index of Multiple Deprivation (IMD) where possible.

## METHOD

- How many children in each age group received an MRI scan at diagnosis?
- What were the associated functional impairments (analysed with respect to GMFCS level where possible)?
  - Vision
  - Seizures
  - GMFCS level
  - Type of cerebral palsy
  - Communication
  - Hearing
  - IQ
  - Feeding

### Data sources

The data sources, to address the key questions are described in Table 1.2.

**Table 1.2 Routinely collected healthcare data across NHS in England, Wales, Scotland and Northern Ireland sources and other useful data sources.**

	England	Scotland	Wales	Northern Ireland	United Kingdom
<b>Inpatients</b>					
<b>Name</b>	*HES APC	SMR01	PEDW	PAS	
<b>Source</b>	NHS Digital	ISD	SAIL	HBS	
<b>Data timescale</b>	2004-2014	2004-2014	1979-2014	2004-2014	
<b>Coverage</b>	Total population	Total population	Total population	Total population	
<b>Outpatients</b>					
<b>Name</b>	*HES Outpatients	SMR00	OPDW	Outpatients Dataset	
<b>Source</b>	NHS Digital	ISD	SAIL	HBS	
<b>Data timescale</b>	2004-2014	2004-2014	1979-2014	2004-2014	
<b>Coverage</b>	Total population	Total population	Total population	Total population	
<b>Primary care</b>					
<b>Name</b>			WLGP	EPD	*CPRD
<b>Source</b>			SAIL	BSO	CPRD
<b>Data timescale</b>			1979-2014	2010-2014	1979-2014
<b>Coverage</b>			348 (73%) GP practices	Primary care prescriptions sent to BSO for total populations	> 11.3 million patients from 674 practices in the UK- approximately 6.9% of the UK population

**Table 1.2 Routinely collected healthcare data across NHS in England, Wales, Scotland and Northern Ireland sources and other useful data sources. (continued)**

	England	Scotland	Wales	Northern Ireland	United Kingdom
<b>Emergency department</b>					
<b>Name</b>	HES Accident and Emergency	A&E Datamart	EDDS	Symphony-Belfast, Northern & Western Trusts	
<b>Source</b>	NHS Digital	ISD	SAIL	HBS	
<b>Data timescale</b>	2007-2014	2007-2014	2009-2014	2011-2014	
<b>Coverage</b>	Total population	Total population	Total population from 2012-Prior to 2012, only major (24 hour, emergency led) A&Es submitted data	Symphony covers Belfast, Northern & Western Trusts EEMS covers Eastern & Southern Trusts	
<b>Intensive care</b>					
<b>Name</b>					PICANet
<b>Source</b>					PICANet
<b>Data timescale</b>					2008-2014
<b>Coverage</b>					Total UK population
<b>Mortality</b>					
<b>Name</b>	*ONS Mortality	Death Registration Data	ADDE	Death Registration Data	
<b>Source</b>	ONS	ISD	SAIL	Northern Ireland Statistics and Research Agency	
<b>Data timescale</b>	2004-2014	2004-2014	2004-2014	2004-2014	
<b>Coverage</b>	Population linked to HES	Population registered with a GP	Total population	Population in the GP Patients Registration Index	
<b>Cerebral Palsy or Special Needs Registers</b>					
<b>Name</b>	NECCPS	SNS		NICPR	
<b>Source</b>	Regional Maternity Survey Office	ISD		Queens University, Belfast	
<b>Time Scale</b>	Those born 2004-2014	2004-2014		Those born 1981-2011	
<b>Coverage</b>	North East and North Cumbria children and young people with cerebral palsy	Implemented at different times and with different completion rates in 12 NHS Boards		Northern Ireland population of children and young people with cerebral palsy	

\*CPRD provided data linkage between primary and secondary healthcare for an estimated 5.34% of the population of England.

**Key to acronyms**

<i>A&amp;E</i>	<i>Accident and Emergency</i>	<i>NICPR</i>	<i>Northern Ireland Cerebral Palsy Register</i>
<i>ADDE</i>	<i>Annual District Death Extract</i>	<i>OPDW</i>	<i>Outpatients Dataset Wales</i>
<i>BSO</i>	<i>Business Services Organisation</i>	<i>PEDW</i>	<i>Patient Episode Database for Wales</i>
<i>CPRD</i>	<i>Clinical Practice Research Database</i>	<i>SAIL</i>	<i>Secure Anonymised Information Linkage</i>
<i>EDDS</i>	<i>Emergency Department Dataset</i>	<i>SMR00</i>	<i>Scottish Morbidity Records - Outpatients Attendances and Appointments</i>
<i>EPD</i>	<i>Enhanced Prescribing Dataset</i>	<i>SMR01</i>	<i>Scottish Morbidity Records - General Acute Inpatient and Day Case</i>
<i>HES APC</i>	<i>Hospital Episode Statistics Admitted Patient Care</i>	<i>SNS</i>	<i>Support Needs System</i>
<i>HBS</i>	<i>Honest Broker Service</i>	<i>WLGP</i>	<i>Wales Primary Care GP Dataset</i>
<i>ISD</i>	<i>Information Services Scotland</i>		
<i>NECCPS</i>	<i>North of England Collaborative Cerebral Palsy Survey</i>		

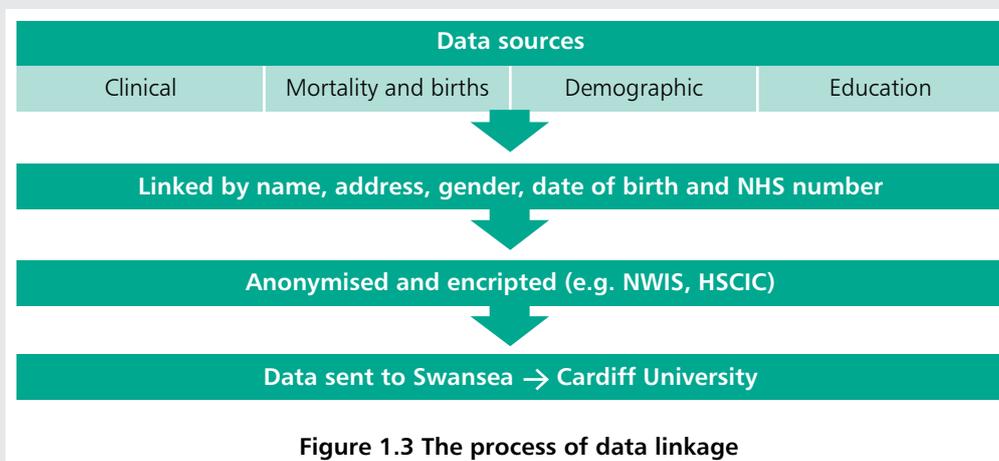
**Data acquisition**

Detailed application forms were completed and submitted to each data host stating the purpose for which the data would be used, the variables required, the datasets to be linked, and explaining how the data would be stored securely.

The duration between sending the application and receiving the data varied widely across data providers due to different procedures for assessing applications. There was a continuous need to update and address information governance throughout the project for the timeline appertaining to the application submission, approval dates, dates when data were received and costs (Appendix 2). The duration from first contact to receipt of data was longest for NHS Digital data for England. Special negotiations with the Northern Ireland Cerebral Palsy Register were approved and data were received June 2017.

**Data linkage**

The process for linking data is summarised in Figure 1.3. Once applied for and permissions to access data were granted, datasets were linked remotely (NHS Digital in England, SAIL Wales, ISD Scotland, HBS Northern Ireland) and provided to the Secure Anonymised Information Linkage (SAIL) Databank for data cleaning. The typical process for data linkage relied upon National Health Service number for England, Wales and Northern Ireland and the Community Health Index: (CHI) in Scotland. A matching algorithm of combinations of potential patient identifiable fields accounted for individuals with missing NHS numbers (estimated at 17% of the population).<sup>13</sup> A description of data linkage process within SAIL for the Wales datasets can be found in Appendix 3.



**Figure 1.3 The process of data linkage**

CPRD provided GP data that was linked to HES and ONS data for 77% of subscribing GP practices in England (an estimated 5.34% of the population of England). CPRD received HES data as encrypted and anonymised from NHS Digital. CPRD use an eight step process to match individual patients in CPRD GOLD and HES using some or all of the following; NHS number, date of birth, sex and postcode. Each individual was included in the study for a period dependent on the patient's dates of birth, death (if relevant) and registration with a GP, and the dates of the last collection of data from the GP where the data met CPRD's quality standard.

### Data cleaning and preparation

Time-scales to prepare these large datasets for analysis varied from 6-10 months per dataset. Several analysts were employed in Swansea to undertake this process (for all datasets other than those from CPRD, PICA Net and the NECCPS). Such data cleaning and preparation involved:

- De-duping based on encrypted codes, dates of health episodes, multiple admissions on the same date for the same individual, diagnostic codes, age, data that fell outside age range or time period of interest, incorrectly linked cases etc.
- Designing and creating a cohort of children and young people with a cerebral palsy in Wales taken from multiple datasets and ensuring consistent treatment of variables e.g. prioritisation of gender/week of birth/date of death from across various datasets in which they are found.
- Creating a list of clinical code groups of interest – diagnostic (ICD-10 and READ v2), operational (OPCS 4), product (READ v3), prescribing (BNF Chapter codes) and treatment specialty (specialty codes within HES, PEDW, OPDW, PAS, SMR00/01)
- Familiarisation and data quality assessment on datasets received
- Agreeing the handling of data anomalies/data quality issues identified
- Identification and flagging of children with one of the cerebral palsies

- Flagging morbidity codes (Codes are available on request)
- Defining and creating four nations person spells (hospital admissions) to enable comparison of hospital admissions across countries
- Calculation of denominators.

### Identification of children with one of the cerebral palsies

Children with one of the cerebral palsies were identified from routine datasets using a disease diagnostic coding algorithm adapted from Meeraus et al.<sup>14</sup>

ICD-10 codes G80-83 (in any coding position at least once) were used to identify children and young people with a cerebral palsy within secondary care data sets.

Read Codes v2 and v3 were used to identify children with a cerebral palsy in Primary Care datasets and PICA Net. Where relevant, in order to explore the interface between datasets that use Read codes and those that use ICD10), Read codes were mapped to ICD-10 codes (Available on request).

The cerebral palsies are chronic conditions, however they are not coded consistently at every contact point with NHS services. The CPRD and Welsh data were searched for data between 1st January 1979 to 31st December 2014 to identify patients in the older age groups at the start of the study period who may not have had a cerebral palsy code recorded for a number of years.

Within English (HES), Scottish, and Northern Irish data, only the date range 1st January 2004 to 31st December 2014 were searched as data were not provided for earlier years and relevant cases were only identified from hospital related data as no primary care datasets were available. Disease codes were poorly recorded in outpatient and emergency department datasets therefore case ascertainment was primarily from inpatient datasets which is likely to be biased towards the more severely affected children and young people with one of the cerebral palsies. Case ascertainment therefore varies across datasets.

A suite of disease related codes (ICD-10 and Read codes) were used to identify morbidity:

- the common causes or reasons behind hospital admissions e.g. respiratory disorders, epilepsy and neurological, cardiovascular, endocrine and metabolic, gastro intestinal conditions, infections and injuries. (Read codes mapped onto ICD-10 Chapter codes)
- procedures undertaken (e.g. gastrostomy, botulinum toxin, tendon release) adapted from Meeraus et al<sup>14</sup>
- medications prescribed (e.g. anticonvulsants, laxatives, neuromuscular relaxants) adapted from Meeraus et al.<sup>14</sup>

### Validation of codes

It is not possible to validate the case ascertainment from individual large datasets. However the case ascertainment for the case note review provided some insight about the accuracy of coding for a cerebral palsy based upon confirmation of diagnosis from cases identified for case note review.

### Definition of hospital admissions (hospital spells)

CPRD generate hospital spell numbers from HES Admitted Patient Care (APC) data to identify a continuous inpatient stay in a single hospital. A transfer from one hospital to another will lead to the creation of a new spell number. Thus, CPRD spells will reflect the number of hospital admissions correctly but counting the spells will overstate the number of 'person spells', i.e. continuous inpatient spells of care within the NHS, regardless of any inter-hospital transfers which may take place. On the other hand, the calculation of the length of a person's stay in a hospital will, for those patients transferred from one hospital to another, underestimate their total length of stay under hospital care.

Analysis of the four nations' inpatients (non-CPRD) data has used a different derivation of hospital spells developed at Swansea University and named the four nation person spell (4N person spell), aiming to approximate 'person spells'. (Available on request)

Throughout the report the term 'hospital admission' has been used to equate to hospital spells as defined above and identified the data source. Care needs to be taken,

therefore, when comparing statistics based on CPRD hospital spells or admissions with statistics based on the person hospital spells of admissions defined for the four nations' inpatients data.

### Calculation of denominators

For CPRD, the basis for the calculation of person years at risk was CPRD's anonymised list of patients who had data of an acceptable standard for research purposes who were aged 0 up to 25 years at any point during the study period of 1 January 2004 to 31 December 2014. An individual's total time at risk within the study was then broken down by year and age band.

Denominators used for linked English data included only those individuals (within CPRD) marked as eligible for linkage.

For the 'All Wales' datasets a file of [anonymised] patient identifiers comprised the cohort of patients aged 0 up to 25 resident in Wales at any point during the study period of 1st January 2004 to 31st December 2014. Not all GP practices in Wales contributed data to SAIL but SAIL's coverage of NHS secondary care outpatient and inpatient activity is complete. Calculation of person years at risk was broadly similar to the approach taken with CPRD. For GP denominators, patients in the overall cohort were only included for those time periods when they were registered with a GP practice contributing to SAIL.

### Data analysis

Data are presented for key questions in simple graphical form for trends across age groups, gender, time and IMD (where possible). Population rates according to person years at risk were calculated for key outcomes and compared by age group, year of event and IMD (utilising CPRD and Wales SAIL data). Reasons for attendance are described by proportion of attendances by diagnosis or treatment specialty where relevant confidence intervals were calculated to enable statistical comparisons. When interpreting the results, consideration must be given to the possible effects of the size and nature of the datasets, the variation in definitions, case ascertainment rates and methods and variation of case mix within and between datasets.

# Study limitations

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## Case note review and questionnaires

Part of the reason for doing this study was the concern that pathways of care for this group of patients were not clear and somewhat fragmented. This appeared to be confirmed quite early on as it was harder to identify leads to ask questions of and case notes did not tell the whole story as they were not linked across healthcare providers and it was challenging to glean the extra sections needed.

Ideally this study would have been conducted by identifying patients in the community and following their various pathways including access to healthcare. However, it was not possible to identify patients this way due to the complexity of identifying community links or contacting general practitioners. A pragmatic approach was therefore taken to identify patients through hospital coding and trace their pathways out into the community. Although this was a compromise as a study method, it should be borne in mind that this is what should be achievable, as a patient attending a hospital will not be carrying their notes with them.

There were some specific issues encountered:

- Not all NHS healthcare providers participated in this study – although it was ensured that all countries were represented and provided a representative sample
- Case notes received were not all complete (e.g. acute care notes were not always supplemented by the community care notes and vice versa)
- Although NCEPOD did request electronic medical records as well as those on paper, it was not always easy for the reviewers to work out what information would have been accessible to the clinician at the point of presentation of the patient to the hospital.
- Response rates from General Practitioners were lower than we would have hoped for as were response rates from the parent carer and patient surveys, but data from other sources was used to enhance what was available
- Responses to the community care part of the case reviewer assessment form were sometimes based on limited information from the case notes, as not available or not documented
- Organisational leads for the different areas of care were difficult to identify.

## Routine national data

- The processes around obtaining data for the data linkage elements of the study, data cleaning for analysis proved to be complex and time consuming
- The various organisations that hold the data required different application processes and different governance requirements. Further applications for updated data were required and data application systems changed within the time frame of applying for datasets
- After the considerable time that was required to clean and prepare data for analysis, there were strict criteria to destroy datasets. The time frame available for detailed analysis was limited by the conditions of the data sharing agreements
- UK countries differed in the extent and type of data availability, whilst standard ICD-10, READ codes v2 and

- v3 are used, the variables that were collected differed between countries and different definitions and coding systems were used (e.g. for admission, discharge, transfer, A&E). The data quality and types and definitions of data fields included also differed. All contributed to making comparative analyses difficult
- Some of the data obtained lacked the level of detail necessary to get a full understanding of the range of needs and service utilisation of children and young people with cerebral palsies
- The extent to which data sources could be linked and the nature of the questions that could be addressed from each set of linked data varied and limited the ability to make comparisons across the UK. However different data linkage in different regions had the potential to reflect different components of healthcare

## STUDY LIMITATIONS

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- The consistency, timeliness and accuracy of coding varied and affected the quality of data analysis. Completion of data fields (missing data) affected the potential for detailed analysis
- Children with cerebral palsies are largely managed within the community and outpatient settings. Routine data collection in these settings was poor and the amount of NHS involvement is likely to be under estimated
- Hospital case records are coded and data entered into routine healthcare datasets by operators who are not clinically trained. Coding will therefore be affected by the quality of data recorded within healthcare records, and the vigilance and interpretation of the data by the coder
- Cerebral palsy is associated with varying levels of severity both in terms of motor and cognitive impairment. These data are not currently collected routinely and confound detailed analysis of service utilisation and quality of care according to clinical need.

## Data returns and study populations

### Organisational survey

Where a service was provided, the Local Reporter at the hospital was asked to provide the name of the service lead, and contact details so that an organisational questionnaire could be sent for completion. Table 3.1 shows the number of questionnaires included in the analysis.

### Clinical review using questionnaires and case notes

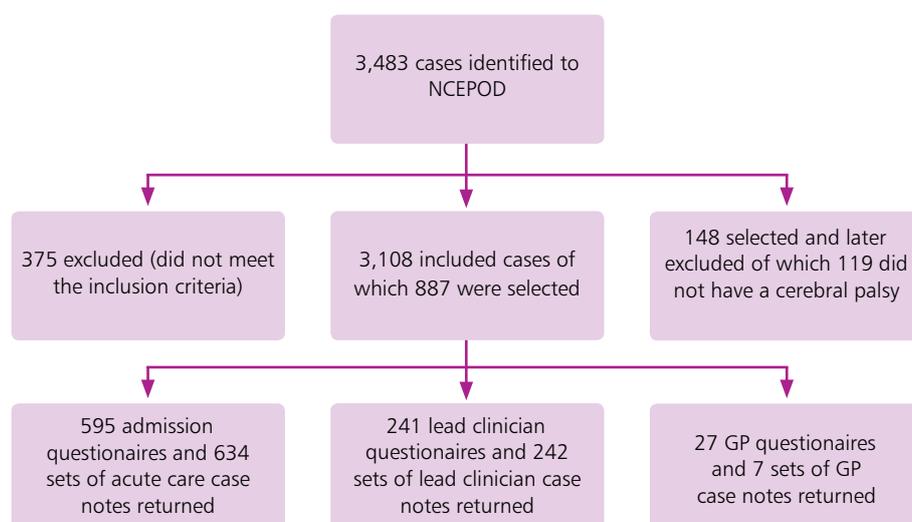
For the study period 3,483 patients were identified as meeting the study inclusion criteria. Figure 3.1 details the return of the cases included.

Of particular note were the 148 patients who were subsequently excluded. In most instances this was because despite having had one of the included ICD10 codes applied, clinical review of the available information revealed that a cerebral palsy was not the correct diagnosis. Of the 634 sets of admission case notes, some included community notes and 242 sets of separate community case notes were

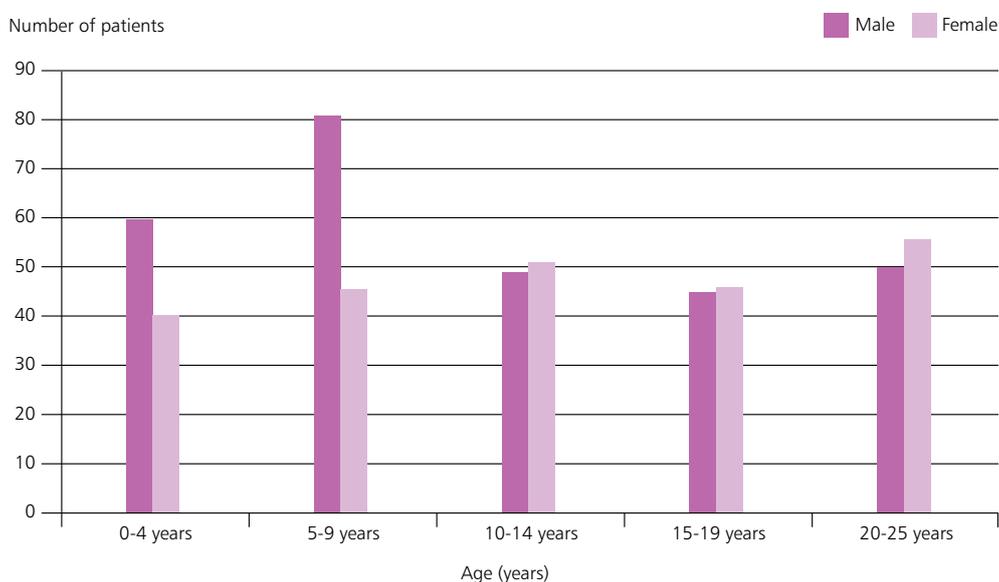
**Table 3.1 Number of questionnaires included in the analysis**

	n=
Emergency department care	92
Paediatric inpatient care	90
Paediatric outpatient care	84
Paediatric community care	81
Adult inpatient care	66
Adult outpatient care	53
Allied health professionals paediatric inpatient	63
Allied health professionals paediatric outpatient care	67
Allied health professionals adult outpatient care	41
Allied health professionals adult inpatient care	52

returned giving 350 sets of community notes; although not all were of good enough quality to assess. For 199 patients a complete set of case notes and questionnaires were received.



**Figure 3.1 Data returns**



**Figure 3.2 Age and gender of the study population**

Please note that the denominators throughout the report will reflect the number of different data sources that have been used, such as the various questionnaires, or case notes. The text around the data will provide context to numbers that have been used.

**Study population**

From the questionnaire, 290/531 (54.6%) patients were male; the age range was five months to 25 years, with a mean age of 11.8 years (Figure 3.2).

One third of the included sample had been admitted to district general hospitals with fewer than 500 beds, a third to larger district general hospitals (>500 beds) and a third to university teaching hospitals and specialist tertiary centres (Table 3.2).

Two thirds of the patients in the study sample were admitted as an emergency (including urgent) admission 337/509 (66.2%). One third (172/509; 33.8%) were elective (including planned) admissions. These admissions were generally for surgical procedures or a short procedure to

**Table 3.2 Type of hospital the patient was admitted to**

	n=	%
District general hospitals >500 beds	165	31.5
District general hospitals ≤500 beds	153	29.3
University teaching hospital	136	26.0
Specialist tertiary paediatric centre	54	10.3
Other specialty hospital	15	2.9
<b>Subtotal</b>	<b>523</b>	
Not answered	13	
<b>Total</b>	<b>536</b>	

be undertaken (Appendix 1).<sup>15</sup> The sample for this study deliberately included a proportion of children and young people undergoing a planned procedure or surgery, so the pattern of the admissions in this study was expected. The majority of patients arrived at hospital during standard working hours (08.00-17.59) with just over a third arriving ‘out of hours’ (18.00-07.59). Admissions occurred on all days of the week with a slight reduction at weekends, likely related to a lower number of patients undergoing elective/ planned surgery and procedures.

On arrival at hospital and considering the pathway of admission, the time to initial hospital assessment was reported by clinical case reviewers as delayed in 20/317 (6.3%) patients and in 17 patients a delay in management of their health condition (Table 3.3).

**Table 3.3 Delay in initial assessment on arrival in hospital**

	n=	%
Yes	20	6.3
No	297	93.7
<b>Subtotal</b>	<b>317</b>	
Unable to answer	35	
<b>Total</b>	<b>352</b>	

The majority of patients had a comprehensive set of basic physiological variables recorded with the exception of blood pressure recorded in only 77.3% of patients (367/475), and an early warning score (EWS) in only 76.8% (341/444). These data were for all admissions (elective and emergency).

For emergency admissions, delays in initiating specific treatment were also felt to be seen in very few patients and clinicians stated that this occurred very infrequently in only 8/311 (2.6%) patients.

### Analysis of routine national datasets

#### Case ascertainment

Table 3.4 shows the number (proportion) of children and young people aged 0-25 years identified as having one of

the cerebral palsies from routinely collected healthcare data within each country. (Please note that case ascertainment sources differed across all countries).

**Table 3.4 Case ascertainment**

Data Population And datasets used for ascertainment	Patients with a cerebral palsy Number (%)	Patients without a cerebral palsy Number (%)	Total population
<b>CPRD</b>			
England	6,170 (0.2)	2,726,461 (99.8)	2,732,631
England :HES Linked (HES APC, HES OPD, ONS Mortality and CPRD)	7,472 (0.4)	2,115,442 (99.6)	2,122,914
Wales	632 (0.2)	268,198 (99.8)	268,830
Northern Ireland	188 (0.2)	92,995 (99.8)	93,183
Scotland	794 (0.2)	325,612 (99.8)	326,406
<b>Data linked in each of the four countries</b>			
England NHS Digital (HES APC, Outpatients and ONS mortality)	53,409 (0.5)	10,067,341 (99.5)	10,120,750
Wales (PEDW,OPDW, WLGP, ADDE)	5,397 (0.3)	1,630,855 (99.7)	1,636,252
Northern Ireland (PAS Inpatients and Death Registration Data)	1,744 (0.3)	510,607 (99.7)	512,348
Scotland (SMR01 and Death Registration Data)	4,183 (0.6)	690,231 (99.4)	694,414

**Key to acronyms**

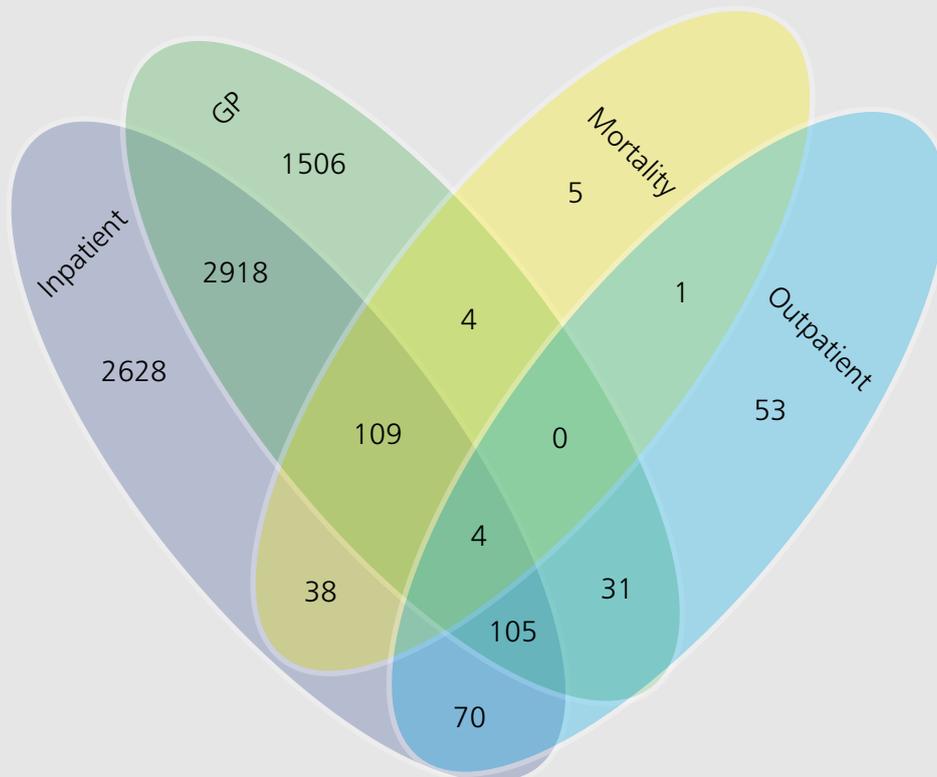
ADDE	Annual District Death Extract	PEDW	Patient Episode Database for Wales
CPRD	Clinical Practice Research Database	SMR01	Scottish Morbidity Records - General
HES APC	Hospital Episode Statistics Admitted Patient Care		Acute Inpatient and Day Case
HES OPD	Hospital Episode Statistics Outpatient Data	WLGp	Wales Primary Care GP Dataset
OPDW	Outpatients Dataset Wales	ONS	Office for National Statistics

**Prevalence of children and young people with a cerebral palsy who access the NHS**

Prevalence figures were derived from two regional datasets that linked routinely collected data from primary and secondary care

- CPRD (HES linked England ) representing 5.34% of GP practices in England
- WLGp linked to PEDW representing 70% of GP practices in Wales

Cerebral palsy is a chronic condition, yet it is not coded consistently at every contact point with NHS services. CPRD and the Welsh dataset were searched from 1st January 1979 to 31st December 2014 to ensure that the cases in the older age groups were identified within the study period. Figure 3.3 illustrates the source of case ascertainment within HES linked English CPRD dataset.



**Figure 3.3 Venn diagram illustrating the number of patients within each of the datasets where patients with a neurodisabling condition were identified within the HES Linked English CPRD dataset**

There were 7,472 patients with a neurodisabling condition identified from a total of 2,122,914 cases within the HES Linked English CPRD dataset. Of these a cerebral palsy was recorded at least once in 2,736 (36.6%) of cases in HES inpatient data only, 1,541 (20.6%) in CPRD GP data only and 3,136 (42%) were identified from both sources. A small proportion 53 (0.7%) were identified from only the outpatient datasets where the completion of diagnostic coding was poor (Figure 3.3).

The prevalence of the cerebral palsies for children and young people 0-25 years of age (2004-2014) is shown in Figure 3.4.

- 3.5 (95% CI 3.4-3.6) per 1000 for England and 2.8 (95% CI 2.7-2.9) per 1000 for Wales
- There were significantly more males 55.4% (95% CI 54.3 - 56.5) with one of the cerebral palsies in comparison to 49% (95%CI: 48.9 - 49.0) of males within the population of children and young people without one of the cerebral palsies (England HES linked dataset).

Prevalence figures for children and young people aged 10-24 years recorded to have one of the cerebral palsies remained relatively constant across the 11 years of the study, the prevalence figures for 0-9 year olds decreased

over time. This is particularly true for the 0-4 year olds and is likely to be due to the fact that 40% of cases do not have a cerebral palsy code recorded in NHS records until after their 5th birthday. The recognition of a cerebral palsy within the youngest age group may not have been confirmed or recorded in case notes. Clinical coding is undertaken by a third party of individuals who are not clinically trained and may not recognise or detect the diagnosis within clinical records. Furthermore case ascertainment was retrospective from 1979, extending back to the date of birth for those aged 20-24 years in 2004 to optimise case recognition.

The prevalence of cerebral palsies increased significantly in England across the index of multiple deprivation (IMD) quintiles from 3.1 (95% CI: 3.0-3.3) per 1000 in the least deprived to 4.0 (95% CI 3.8-4.2) per 1000 in the most deprived quintile (Figure 3.5).

The overall mortality rate in England was 26 times higher for children and young people with one of the cerebral palsies than for those without (5.3 vs 0.2 per 1000 at risk) for 0-25 year olds. The mortality rate was greatest in those younger than five years of age (Figure 3.6).

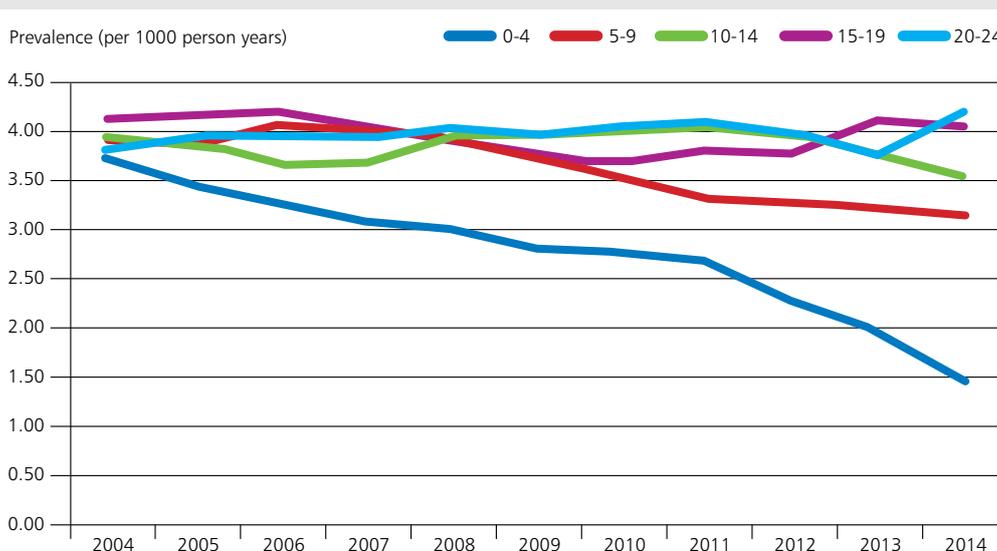
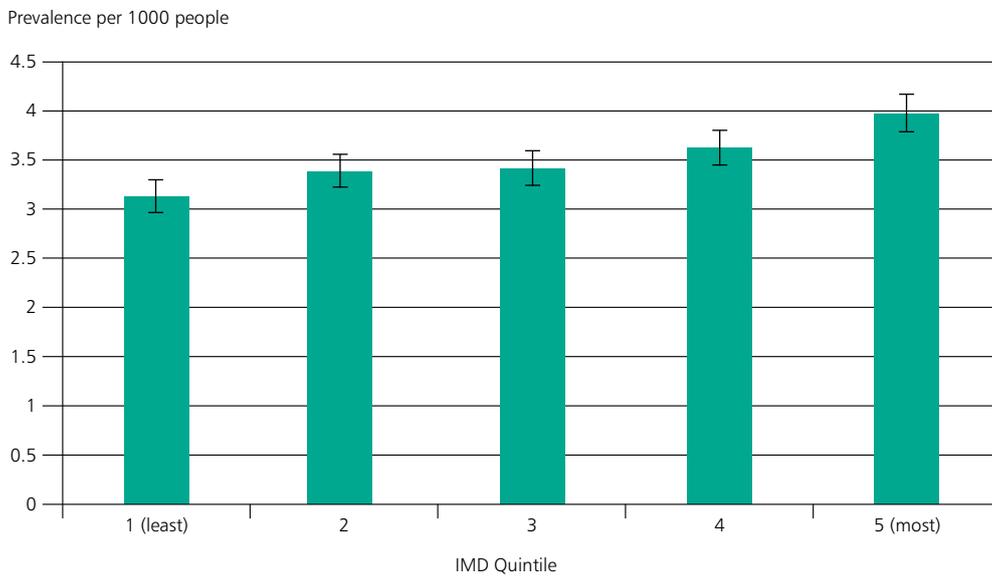
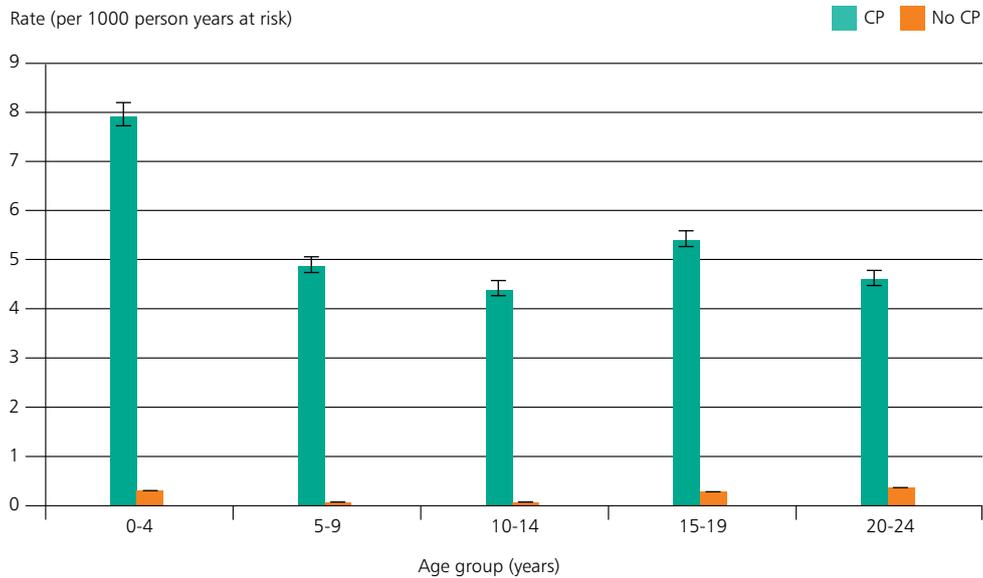


Figure 3.4 Prevalence of cerebral palsies by year and age group in CPRD (England HES Linked)



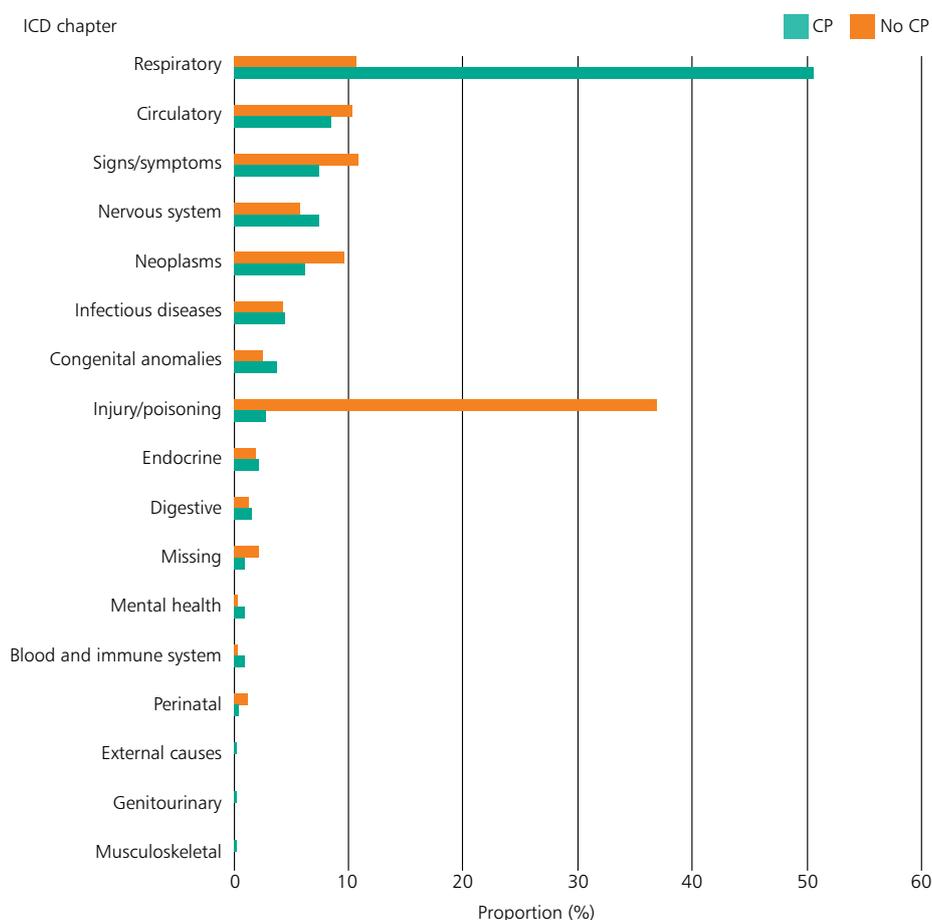
**Figure 3.5 The prevalence of cerebral palsies in children and young people within each Index of Multiple Deprivation (IMD) quintile (CPRD: England HES Linked)**



**Figure 3.6 Mortality rate (per 1000 person years at risk) among children and young people with and without a cerebral palsy between 2004 and 2014 by age group (CPRD: England HES and OPD Linked)**

Within the Wales WLGP/PEDW linked data, the mortality rate for those with one of the cerebral palsies was five per 1000 person years at risk across all age groups and 0.3 per 1000 person years at risk for those without a cerebral palsy.

The profile of recorded primary causes of death were very different between the two populations studied. By far the most commonly recorded primary causes of death for children and young people with a cerebral palsy were respiratory causes in 51% of cases (Figure 3.7). Similar results were seen across the four countries.



**Figure 3.7 Primary cause of death for children and young people with (n=174) and without a cerebral palsy (n=2,026) aged 0-24 years between 2004 and 2014 as a proportion of total deaths(CPRD: England HES Linked)**

It was not possible to determine the mortality rate according to population at risk of a cerebral palsy for Scotland or Northern Ireland. However, between 2005-2014 in Northern Ireland, 91/1,850 deaths were for children and young people with a cerebral palsy, accounting for 4.91% of all deaths in the dataset. For Scotland 2004-2014 there were 9.2% (335) of a total of 3,635 deaths for children and young people with a cerebral palsy.



## Key findings and case studies by chapter number

### CHAPTER

## 3

#### Key Findings – routine national data

- The prevalence of the cerebral palsies identified within two datasets that represent cross sections of the population (0-25 years) in England and Wales give figures of 3.5 and 2.8 per 1000 respectively. There were a greater number of males identified and an increase in the prevalence with respect to increased social deprivation. Whilst there was a significant difference between the prevalence figures between the two countries, they are consistent with the estimated population prevalence of 2-3/1000.<sup>16</sup> This suggests that the case ascertainment for this study was reasonably comprehensive
- The inconsistent and variable codes used, and the failure to record cerebral palsies at every presentation to the NHS and the delay in recording cerebral palsies within NHS datasets may have lead us to under-estimate the number of younger children with the condition in the study sample. For similar reasons some conditions that are not one of the cerebral palsies but individuals with similar motor impairment may have been included
- Respiratory conditions prevailed as the most common diagnostic group in mortality, PICU, emergency hospital admissions and primary healthcare consultations.

#### SEE RECOMMENDATIONS

**1•2**

### CHAPTER

## 4

#### Key Findings – questionnaire, case note review and organisational data

- There was variation in the support services available to young people and their carers across organisation types
- Training for care workers in aspects of management for children and young people with cerebral palsy was not provided in 27/76 organisations providing paediatric community care
- Data from the ongoing care questionnaire indicated training in aspects of self- management was provided for 73 patients, however this was reported as unknown or was not answered for 41/221 patients and not applicable for 87/221 patients.

#### SEE RECOMMENDATIONS

**11•19•20•22•28•29•30•31•32•33**

## CHAPTER

## 5

## CASE STUDY 3

## CASE STUDY 1

A teenage patient was reviewed by a new clinician in the paediatric clinic. The diagnosis recorded in the patient's medical record was 'ataxic cerebral palsy'. The clinical assessment documented a changing profile of needs over time that did not fit with this and further investigations were arranged.

*The case reviewer noted that the evidence of the investigation findings was that the diagnosis was actually one of a rare group of conditions with progressive and multi-system effects that required a completely different, proactive healthcare management plan than that for a person with ataxic cerebral palsy. They commented that it is always good practice to review the evidence for, or against, any diagnostic labels and be prepared to reinvestigate in the light of new information or new diagnostic technologies.*

## CASE STUDY 2

A teenage patient accompanied by their father was reviewed by a new clinician in the paediatric clinic. The patient's clinical signs suggested a diagnosis of unilateral cerebral palsy. An MRI scan of the patient's head revealed a significant developmental brain anomaly which fitted in with the clinical findings.

*The case reviewer noted that the clinician had documented that the patient's father walked with a stick and on enquiry into family history, this was long standing but had never been formally assessed and no diagnoses had ever been made. The father was advised to see his GP to seek neurological assessment. He was found to have the same developmental brain anomaly as his child. The reviewer noted that subsequent genetic investigations revealed the underlying cause of the unilateral cerebral palsy in both family members.*

A young child who had been born at-32 weeks, was assessed in the paediatric clinic and found to have spasticity of both lower limbs and associated clinical signs suggestive of a diagnosis of bilateral spastic cerebral palsy. An MRI head scan revealed bilateral, symmetrical signal changes that the neuroradiologist reported were NOT typical of the expected finding of periventricular leukomalacia. Further metabolic and genetic investigations were undertaken that revealed a specific diagnosis of a specific diagnosis of a rare neurodegenerative disease

*The case reviewer reflected on the important new information gleaned from the MRI scan and how this dramatically changed the management of this patient, also the implications for the family, as the parents were first cousins and planning further children, with a one in four recurrence risk. Early testing in future pregnancies could have treatment implications, as stem cell transplantation could be considered, with the chance of improved outcome.*

## CHAPTER

## 5

**Key Findings – questionnaire, case note review and organisational data**

- The patient's specific cerebral palsy diagnosis was not documented in the case notes in 110/540 (20.4%) cases reviewed
- In 150/521 (28.8%) cases reviewed, the term used to describe the diagnosis was 'cerebral palsy' with no more specific detail of tone variation. In a further 76 cases (14.6%) the term 'bilateral cerebral palsy' was used but there was no further documentation of tone variation. The diagnostic term did not include information on specific tone variation in 297/521 (57%) cases reviewed
- Where specialist expertise was in place, this was available to interpret neuroimaging on an 'ad hoc' basis in a third of organisations (paediatric outpatient care, 23/74; community paediatrics, 25/74; adult outpatient care, 12/45)
- Where undertaken, MRI neuroimaging was offered on a routine basis in 43/82 organisations providing paediatric outpatient care and 50/77 organisations providing paediatric community care. There was variation in whether organisations offered MRI under sedation or general anaesthetic. Paediatric services were less likely to offer MRI under sedation and adult services less likely to offer MRI under general anaesthetic.

**SEE RECOMMENDATIONS****1•2•3•6****Key Findings – routine national data**

- Cerebral palsies, although chronic conditions, are not coded at every contact point with NHS services. This illustrates a problem with inconsistent coding of a chronic health condition in routinely collected healthcare data
- The variation between ICD-10 and Read v2 codes recorded both within and between individual children and young people with a cerebral palsy impairs complete and accurate case ascertainment from routinely collected healthcare datasets
- The specific type of cerebral palsy was identified at some point in 79.6% of case notes (in the case notes review). The missing data and lack of consistent documentation in case notes over time would impair the ability to code cases according to type within healthcare datasets and, a 'generic' code for a cerebral palsy was used in the majority of cases
- The absence of coding by a cerebral palsy type and the absence of a system to record the level of impairment in a patient with cerebral palsy affects the ability to use routinely collected data to analyse whether healthcare utilisation is proportionate to need or disease severity. It was not possible to analyse routinely collected data by cerebral palsy subtype or by motor function
- The inaccuracy of coding of MRI within routine healthcare datasets precluded an accurate evaluation of the prevalence of MRI neuroimaging in patients with cerebral palsies. These data were more consistently recorded within designated cerebral palsy registers
- Data accuracy should be improved with a wider adoption and recording of the same classification system and SNOMED CT codes across the UK which may facilitate data comparisons from different countries and regions in the UK, highlight variations and drive up quality of care, however the introduction of SNOMED CT varies and is at different stages across the UK. The transition to SNOMED CT is likely to have a positive impact on the analysis of routine healthcare data.

**SEE RECOMMENDATIONS****1•2**

## CHAPTER

## 6

## CASE STUDY 6

## CASE STUDY 4

A young adult patient with a cerebral palsy was admitted as a day case for an investigation. The patient signed their own consent form. The procedure was without complication and they went home the same day.

*The case reviewer found documentation showing the patient had sent the questions they wanted to ask the surgeon in advance via their alphabet board. This made the discussion about consent meaningful and appropriate to their needs, as the patient did not use speech to communicate.*

All reasonable adjustments should be proactively in place to ensure that disabled people are treated no less favourably because of their disability, in line with the Equality Act 2010.

## CASE STUDY 5

A young teenager with bilateral cerebral palsy, with motor functioning at GMFCS level V, profound learning disabilities, gastrostomy tube fed and dislocated hip was admitted via the emergency department to paediatric intensive care. The patient had a stormy course, prolonged stay and, on discharge, was even more frail than before.

*The reviewer noted 28 admissions in the previous year, including five to high dependency or intensive care, but there was no evidence in the medical record of the existence of an Emergency Health Care Plan, nor of a documented discussion with the family about their wishes for their child's care or discussion about resuscitation.*

An older teenager with bilateral spastic cerebral palsy, with motor functioning at GMFCS level V, profound learning disability, relentlessly challenging epilepsy, gastrostomy tube fed due to unsafe swallow, scoliosis, and recurrent chest infections was admitted from the local hospice for a routine change of gastrostomy button without anaesthetic. The procedure was uneventful. The patient was discharged the same day back to the hospice, where they died peacefully four days later.

*The reviewer noted strong leadership of multidisciplinary care and a clear Emergency Health Care Plan in place, which had been discussed and agreed with the family, the GP and multidisciplinary care team. This documented a decision, taken in the patient's best interests, that in the event of their sudden collapse, they would be allowed a natural death, with all their symptoms promptly addressed, care for their dignity and support for the patient's family. Possible clinical scenarios that could be predicted were included in the plan, with step by step action plans. A completed Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) was also available, as per local agreed procedures. The reviewer noted that the care plan had been carefully followed and there was evidence of excellent clinical care and support for the family.*

## CHAPTER

## 6

**Key Findings – questionnaire, case note review and organisational data**

- Reviewers reported insufficient efforts to communicate with the family in 89/245 (36.3%) cases
- The preferred communication method of the patient was only ascertained for 159/275 (57.8%) patients
- Reviewers reported the patient was, wherever possible, fully included in all discussions and decision-making about them in 139/277 (50.2%) patients. Reviewers did not answer this question or were unable to answer for 72/534 (13.5%) cases reviewed
- There was room for improvement in the documentation of inclusion of the patient in the decision-making process in 179/448 (40%) cases reviewed
- There were agreed systems in place for preparing written Emergency Health Care Plans/Emergency Care Summaries in:
  - 58/81 organisations providing paediatric outpatient care;
  - 66/77 organisations providing paediatric community care;
  - 67/87 organisations providing paediatric inpatient care;
  - 24/45 organisations providing adult outpatient care;
  - 35/48 organisations providing adult inpatient care; and
  - 69/89 organisations providing emergency department care. Where they were in place, in a majority of organisations these were only partially implemented
- Reviewers found no evidence of the existence of an Emergency Health Care Plan or similar (either in the case notes or documented in the admission questionnaire) in 202/305 (66.2%) cases
- A 'Do Not Attempt Cardiopulmonary Resuscitation', or similar personal resuscitation plan, was reported to be in place by 41/271 (15.1%) reviewers. There was evidence this was validated with the patient and their family at the time of admission in 21/36 cases reviewed
- Around one third of organisational leads for paediatric inpatient (27/84), outpatient (30/77) and community services (33/77) reported that a best interests decision-making process was not embedded for young people aged 16 years or over who had been assessed as not having capacity to make a specific decision at a specific time and in a specific circumstance
- Around a quarter of organisational leads of emergency departments (16/84), one fifth of organisational leads for adult inpatient care (8/48) and four in ten leads for adult outpatient care (9/43) reported having no such best interests process embedded
- Communication with the child, young person or young adult with cerebral palsy's wider multidisciplinary team about aspects of their health and wellbeing whilst they were inpatients was reported by case reviewers to be inadequate in 137/285 (48.1%) cases
- Reviewers reported that discharge summaries about episodes of inpatient care were not copied to lead clinicians for cerebral palsy care in almost half of cases (103/223 admissions; 63/108 day cases) and were only copied to the community physiotherapist in 32% (30/92) for day case patients and 38% (70/184) for admitted patients.

**SEE RECOMMENDATIONS****11•19•20•22•25•26•28•29•30•31  
32•33**

## CHAPTER

## 7

## CASE STUDY 7

A young adult with bilateral dystonic cerebral palsy, with motor function at GMFCS level IV, was admitted for a day case procedure, for which the patient gave consent and which was uneventful with same day discharge.

*The case reviewer reported excellent coordination of care and well described health and care needs, by the neurorehabilitation consultant. This included ascertainment and recording of mental health needs and how these were being addressed. It was noted that comprehensive healthcare by specialists with the competencies to identify all unmet health needs and to draw up and implement a care plan to address these reflects good practice.*

## CASE STUDY 8

A young child with bilateral spastic cerebral palsy was admitted as a day case for botulinum toxin injections which were completed with no documented complications.

*The case reviewer found clear documentation in the acute admission notes that intensive physiotherapy was required in the community following the intervention, but there was no documentation of any communication from the acute care team to the community physiotherapist about this. Good practice would have been for there to have been advanced communication between the acute care team and community physiotherapist, giving notice of the date of intervention so that intensive physiotherapy could have been planned ahead in the therapist's busy schedule. As a minimum, there should be communication on discharge directly with the community physiotherapist, rather than leaving the communication for the patient/parent to arrange.*

## Key Findings – questionnaire, case note review and organisational data

- A lead clinician for disability care was reported to be in place in 351/403 (87.1%) hospitals
- Reviewers found documentation of a lead clinician for neurodisability care in only 31/133 (23.3%) case notes of young adults in comparison to 240/380 (63.2%) notes for children and young people
- Almost all lead clinicians responsible for providing the ongoing neurodisability care of the patient, reported that care was provided by an appropriate multidisciplinary team (205/215; 95.3%)
- Reviewers found there to be room for improvement in multidisciplinary paediatric inpatient care in 82/200 (41%) cases reviewed, in outpatient paediatric care in 62/150 (41.3%) cases, in adult inpatient care in 41/74 cases, and in adult outpatient care in 25/36 cases reviewed
- An agreed written care pathway for the assessment, diagnosis and management of children and young people with cerebral palsy was not in place in 56/82 organisations providing paediatric outpatient care; 42/81 organisations providing community paediatric care; and 42/48 organisations providing adult outpatient care. Where pathways were in place, a majority included arrangements for hip surveillance, MRI, pain identification and management, and anthropometric measurement and the monitoring of growth and nutrition.
- Evidence of adequate post-operative physiotherapy input was found in less than six out of every ten cases.

## SEE RECOMMENDATIONS

**4 • 7 • 16 • 20 • 22 • 23 • 24 • 26 • 27 • 28 • 30  
31 • 32 • 33**

## CHAPTER

## 7

## Key Findings – routine national data

- Children and young people with cerebral palsies had a similar trend of 'consultation' at primary care to those without the condition. This was true for all four countries. However, those with cerebral palsies had a higher rate of consultation and number of consultations per year compared to other children and young people in all age categories. The consultation rates were greatest in 0-4 year olds and 20-24 year olds
- Analysis of the Wales General Practice Dataset suggests that activities that include, administration, referrals and clinical activities are considerably greater for children and young people with cerebral palsies than for those without
- The rate of referrals to secondary healthcare or specialist services for children and young people with cerebral palsies was twice that for those without a cerebral palsy and decreased across the quintiles for greater social deprivation. This may represent the least deprived families requesting more referral, or the most deprived failing or lacking confidence or the ability to proactively seek referrals. Professionals need to be aware of this difference and work towards more equal access to services and thus more equal outcome opportunities. This contrasts with the information from hospital admissions which suggests no clear link between rates of hospital admissions and deprivation index
- Children and young people with cerebral palsies had a higher proportion of primary care consultations for respiratory, neurological and mental health issues and a lower proportion of consultations for infections and musculoskeletal disorders than for children without
- The rate of outpatient attendances increased for children and young people with cerebral palsies between 2004-2014. The rate of attendance was approximately ten times greater for children aged 0-4 years of age with cerebral palsies than in children without and approximately three times greater at 20-24 years
- The rate of outpatient appointments decreased significantly with age for those with cerebral palsies whilst it remained relatively constant for children and young people without a cerebral palsy, (with the exception of 20-24 year olds)
- The proportions of all outpatient attendances were greater for paediatric, therapy, nervous system, trauma and orthopaedics specialties for children and young people with cerebral palsies than those without. However there were significantly fewer attendances for dental, pregnancy, dermatology, ENT, genitourinary and gynaecological and surgical specialties
- The data suggest that children and young people with cerebral palsies attend primary and secondary healthcare settings significantly more frequently than those without a cerebral palsy. Outpatient attendance rates decrease significantly with age whilst primary care attendance increased between 15-25 years of age.

## CHAPTER

## 8

## CASE STUDY 9

A young child with bilateral cerebral palsy and multiple associated health conditions was admitted with a chest infection. The patient was prescribed antibiotics and after a short period of observation was discharged home again.

A teenager with bilateral cerebral palsy, GMFCS level IV was admitted as a day case for botulinum toxin injections. The procedure was completed and the patient discharged home.

*The case reviewers of both cases found no documentation of the patient's weight anywhere in the records. These were patients with complex disabilities at high risk of nutritional compromise. The reviewers were of the opinion that this was concerning, because accurate dose calculation depends on weight, especially in a disabled patient whose weight might not be as expected for age. Good practice would have been for the patients to have been weighed on admission using appropriate equipment for their disabilities and for this to have been clearly recorded in the medical records.*

## CASE STUDY 10

A young child with dystonic cerebral palsy was admitted for a procedure as a day case. The procedure was completed and the patient was discharged home

*The case reviewer found the admission case notes to be scanty, with no description of how the child's condition affected the patient, nor their level of functioning in any domain. Review of the community case notes also found no description of levels of functioning, other than a need for hoisting, suggesting the patient was non-mobile. The community notes documented that the patient's weight was falling, but there was no documented action plan to address this or evidence of dietician input or referral.*

## CASE STUDY 11

A teenager with bilateral cerebral palsy, with motor function at GMFCS level V, was admitted with a lower respiratory tract infection which was treated. The patient improved and was discharged next day.

*The case reviewer found excellent documentation of the patient's wider needs across domains of functioning and the associated medical conditions. The opportunity of admission was taken to review the patient's needs and further unmet needs were identified. The care plan on the ward and on discharge comprehensively addressed all identified needs and communicated clearly to the multidisciplinary team. The reviewer also found evidence in the outpatient notes of excellent, proactive healthcare.*

Identification of all needs is the first step to them being addressed as part of the comprehensive care plan. The opportunity of a hospital visit can be used to achieve this.

## CHAPTER

## 8

**Key Findings – questionnaire, case note review and organisational data**

- Reviewers could find evidence of GMFCS level documentation in the case notes in only 155/547 (28.3%) cases
- Data from the admission questionnaire indicated GMFCS level was clearly assessed and documented on admission in only 51/405 (12.6%) patients. Furthermore, where not documented on admission, GMFCS level was documented during the admission in only 21/333 (6.3%) patients
- Room for improvement in documentation in inpatient case notes about how a person's cerebral palsy affected their mobility was reported in 47.8% (144/301) of cases reviewed
- A learning disability was specifically documented in the case notes in 306/532 (57.5%) cases
- The level of learning ability was reported as assessed and documented on admission in 188/433 (43.4%) of admission questionnaires. This was unknown or not answered in 103/536 (19.2%) cases reviewed
- Reviewers identified documentation of the preferred communication method recorded in the case notes of 187/530 (35.3%), and in a clinic letter for 163/428 (38.1%) patients
- Reviewers reported that the patient's weight was recorded in the case notes of 254/333 (76.3%) admitted patients, and 104/177 (58.8%) day case patients
- Weight was reported as documented during the admission in 359/536 (67%) admission questionnaires, and in a majority of cases (285/344; 82.8%) this was the actual weight rather than an estimate
- Data from the ongoing care questionnaire indicated the patient's nutritional status had been considered and recorded in the last year in 189/208 (90.9%) of cases included
- Reviewers reported that the patient's health needs were adequately described in 278/350 (79.4%) of cases
- Data from the ongoing care questionnaire indicated adequate enquiries were made about the presence of pain in 159/184 (86.4%) patients, however reviewers found evidence in the notes in only 173/281 (61.6%) cases
- A policy of always asking about the presence of pain at each consultation with a patient with cerebral palsy was reported to be in place in only 40% of organisations.
- Reviewers reported evidence to suggest issues with the patient's eating and drinking in 144/311 (46.3%) of cases reviewed
- Case note reviewers reported that six out of ten patients with cerebral palsies whose case notes were reviewed were nutritionally vulnerable (198/333; 59.5%), more than ten percent (25/185; 13.5%) had evidence of inadequate nutritional surveillance
- Reviewers reported evidence of risk of aspiration (unsafe swallow) in 46% (144/311) patients with cerebral palsies, but no evidence that this had been assessed in the last three years in 14.4% (18/125) of these cases
- Reviewers reported that the range of health needs of more than one in ten children (58/350; 16.6%), young people and young adults with cerebral palsies were inadequately described in their case notes
- Overall symptom management was assessed by reviewers as inadequate for more than one in ten children, young people and young adults with cerebral palsies whose case notes were reviewed (34/333; 10.2% admitted patients; 22/158; 13.9% day case patients)
- Case note reviewers reported no documentation about adjustments required to meet the needs of half of the children, young people and young adults with cerebral palsies whose case notes were reviewed (128/263; 48.7% admitted patients)
- Inadequate review of personal care and activities of daily living prior to discharge from hospital, including access to equipment and appropriate support in the community, was reported by reviewers in one third of cases reviewed (81/234; 34.6% admitted patients).

**SEE RECOMMENDATIONS**

**4 • 5 • 8 • 9 • 10 • 11 • 12 • 15 • 17 • 18 • 19 • 20  
22 • 25 • 26 • 27 • 28 • 29 • 30 • 31 • 32 • 33**

## CHAPTER

## 9

**Key Findings – questionnaire, case note review and organisational data**

- Easy accessibility was not available in 38/83 organisations providing paediatric outpatient care and 16/49 organisations providing adult outpatient care
- Hoists were not available in 38/83 organisations providing paediatric outpatient care and 16/49 organisations providing adult outpatient care
- Scales was not available in 38/83 organisations providing paediatric outpatient care and 16/49 organisations providing adult outpatient care
- Changing places were not available in 38/83 organisations providing paediatric outpatient care and 16/49 organisations providing adult outpatient care
- There was variation in terms of access to wheelchairs for both inpatients and at discharge
- Wheelchair services were reported to meet the needs of the population in 31/58 organisations providing allied health professional paediatric outpatient care, and 22/32 organisations providing allied health professional adult outpatient care
- Timely access to equipment for inpatients to ensure good posture, mobility and safe transfer was stated to be adequate in 178/245 (72.7%) cases reviewed
- Assessment of equipment needs on discharge was reported to be inadequate by reviewers in 81/234 (34.6%) cases reviewed
- Two thirds of organisational lead paediatric allied health professionals reported difficulties with equipment services and waiting times (40/61).

**SEE RECOMMENDATIONS****23•27•28•34**

## CHAPTER

## 10

**CASE STUDY 12**

A young adult patient was admitted for insertion of a feeding tube under the care of a gastroenterologist and as requested by the patient's GP. As well as poor weight gain and unsafe swallow their notes clearly indicated a hip dislocation and consequent difficulty in weighing the patient due to pain.

*Reviewers agreed that this case demonstrated substandard care in several areas and of some duration. Attempts were being made to rectify the situation and the patient required careful follow-up and support from speech and language therapy, dietetics, and orthopaedics when their nutritional state allowed.*

**CASE STUDY 13**

A young child with 'spastic quadriplegia', GMFCS level V had a 2 week admission for aspiration pneumonia during which time they saw many other teams for 'catch-up'. This included a change of their feeding tube, review of their epilepsy management and a wheelchair assessment.

*Reviewers commented that this was an example of excellent care. However more often than not there was a sense that when children and young people with a cerebral palsy were admitted with an acute medical problem, their neurodisability was "peripheral" to their care needs and it is often about treating the system failure and not the whole patient.*

## CHAPTER

## 10

## CASE STUDY 14

A young child weighing just 12kg with a GMFCS level V cerebral palsy secondary to a severe hypoxic event at birth had had multiple admissions in the last 2 years with chest infections and seizures. There was no record of swallow having been assessed. However the notes from a lead in neurodisability, based in the community, mentioned that the parents were “just managing with feeding and that the child is otherwise well cared for”.

*Reviewers reflected upon the difficulties encountered by families in accepting the need to consider supplementary or gastrostomy feeds. There had been multiple opportunities for this patient’s overall care to be reviewed by the wider multidisciplinary team which had not been maximised, with consequent deterioration in patient wellbeing.*

## CASE STUDY 15

A baby with a severe cerebral palsy who had undergone several operations for ventriculoperitoneal shunt insertion and had a feeding gastrostomy was admitted with fever, uncontrolled seizures, low oxygen saturation and poor peripheral perfusion. Intravenous access was very difficult and the baby initially needed an intraosseous placement which was secured approximately 15 minutes after arrival. This was used to administer more anticonvulsant medication and a fluid bolus. The baby subsequently developed respiratory depression and was intubated by an on-site anaesthetic registrar with the assistance of a consultant paediatrician and critical care registrar. The baby was further resuscitated and stabilised with input from consultants in anaesthesia and critical care and was transferred approximately 100 miles to the nearest paediatric intensive care unit.

*Reviewers commented that babies and children with neurodisability are frequent users of emergency services. Care may be complicated by difficulties with venous access e.g. due to previous extreme prematurity, intravenous feeding and surgery as in this case. Delays in resuscitation are not uncommon and required a skilled and timely team approach to provide best outcomes.*

## CASE STUDY 16

A young adult with a long term tracheostomy was admitted for seizures under the care of a respiratory clinician with support from a neurologist in a different centre. The patient had had a similar admission three weeks earlier with no clear ongoing management plan. During this admission they were seen daily by the critical care outreach team with excellent documentation of the tracheostomy care and respiratory status. However there was no overall leadership of the patients neurodisability needs.

*The case reviewers commented that had clear leadership been in place in the community admission might have been avoided.*

## CHAPTER

## 10

## CASE STUDY 17

A young person with complex needs receiving ventilation at night was admitted to a paediatric critical care unit for surgical change of a feeding tube. There was a delay to the procedure being undertaken due to lack of elective theatre time and ultimately the patient remained in the paediatric critical care unit for 3 days as their surgery was not deemed 'urgent'.

*The reviewers agreed that patients dependent on complex technology were now more often cared for at home. However admission to ward areas other than critical care may then be impossible as staffing numbers, competence and confidence may be insufficient to permit this to safely take place.*

## CASE STUDY 18

A young person with a cerebral palsy (GMFCS level V) was initially admitted to an adult critical care unit after a severe seizure and possible aspiration. The patient was intubated and ventilated on-site and then required paediatric critical care transfer to a unit where they were known to the service and had had several previous admissions. Community notes when available gave clear evidence of a very detailed management plan including maximum levels of care/hospice care which had been agreed. However there appeared to have been no knowledge of this Emergency Health Care Plan by the local acute team in the district general hospital or discussion with the patient's family about long term plans. Similarly after admission to the paediatric critical care unit there was no evidence that discharge notes were copied to the community team, though the GP was sent a copy.

*Case reviewers felt that this was not an uncommon scenario in the highly complex patient who may be better known to specialist services than the local DGH. Therefore more comprehensive information sharing between healthcare providers, particularly for patients with complex needs is essential. A regularly updated hand held summary and Emergency Health Care Plan or patient passport is a possible solution which works for some patients and is used in some networks with success.*

## CASE STUDY 19

A young adult with a GMFCS level V cerebral palsy was admitted with a lower respiratory tract infection and poor blood gases despite already receiving ventilation at night at home. There was otherwise an excellent care plan for the patient's ongoing needs but there was limited information within it about escalation plans and DNACPR. The patient's last admission had been to paediatric critical care two years previously at which point a decision had been made with his family not to perform tracheostomy. The patient's mother now regretted this decision and demanded that all should be done.

*Reviewers commented that whilst decisions about ongoing long term care for patients with very severe disability are always difficult and need to be regularly reviewed, it is very important that information is transferred between teams and that families are fully aware of the content of any long term health care plans.*

## CHAPTER

## 10

## CASE STUDY 20

A young child with GMFCS level V bilateral spastic cerebral palsy was admitted from a hospice for change of their gastrostomy tube due to technical issues. The child was receiving full care to control seizures, treat painful spasms, and medication and regular suction for excessive oral secretions due to a very poor swallow. The patient's family, in conjunction with the neurodisability team and a consultant paediatric neurologist, had recently agreed a plan of care which was based on her comfort and palliation of symptoms.

*Reviewers commented upon a very good proforma which was completed by admitting paediatricians and which clearly outlined the patient's particular needs as well as who is to be informed and how decisions will be made in the event of sudden deterioration, and with a clear outline of what interventions should be provided along with DNACPR status in this case.*

**Key Findings – questionnaire, case note review and organisational data**

- 180/247 (72.9%) of patients with a cerebral palsy were seen within 14 hours of admission by a senior clinician. This was only the case in 116/170 (68.2%) patients admitted urgently or as an emergency and these data were poorly recorded in case notes
- 75/321 (23.4%) of patients with a cerebral palsy were seriously ill on admission. However, only 7.9% of patients reviewed had an Emergency Health Care Plan/ Emergency Care Summary present in case notes
- Discharge communication included input from the relevant members of the inpatient team in 210/391 (53.7%) patients with a cerebral palsy after admission to acute general hospitals

- Reviewers reported there was adequate review of personal care and activities of daily living prior to discharge in 153/234 (65.4%) patients with a cerebral palsy; reviewers indicated this was inadequate in 81/234 (34.6%) cases reviewed. This was unknown or unanswered in 118 cases
- 138/513 (26.9%) patients with a cerebral palsy were estimated by admitting clinicians to have been discharged with an improved level of function
- Overall inpatient care was rated as good in 161/304 (53%) patients with cerebral palsy. There was room for improvement in clinical or organisational care or both in 142/304 (46.7%) patients.

## SEE RECOMMENDATIONS

**11•14•15•19•20•22•23•26•27•28  
29•30•31•32•33**

**Key Findings – routine national data**

- The rate of hospital admissions for children and young people with one of the cerebral palsies was significantly greater than for those without cerebral palsies across all age groups. The difference decreased across the older age groups; the rate of admissions were on average 10 times greater for 0-4 year olds falling to 3 times greater for 20-24 year olds
- There was a higher proportion of elective admissions in patients with a cerebral palsy compared with those without

## Continued overleaf

## CHAPTER

## 10

## Key Findings – routine national data

- Neurological conditions accounted for the greatest proportion of elective admissions, followed by mental health and behavioural and musculoskeletal concerns for children and young people with one of the cerebral palsies
- For emergency admissions among cerebral palsy patients the three most common reasons were respiratory, neurological and injury and poisoning. The most common admissions to PICU replicated this trend as they were for neurological, respiratory and musculoskeletal reasons
- There were significantly more day case admissions for children and young people with one of the cerebral palsies than for those without, (0-4 year olds had 15 times more and 20-24 year olds 4 times more admissions) the rate of day case admissions increased between 2004 and 2014, which may indicate an increase in proactive treatment
- The mean length of hospital admissions and admissions to PICU for children and young people with one of the cerebral palsies were greater than for those without a cerebral palsy
- Respiratory conditions accounted for the greatest proportion of primary care attendances, emergency hospital admissions, admissions to PICU and deaths for children and young people with a cerebral palsy.

## CHAPTER

## 11

## CASE STUDY 21

A child with a GMFCS level III cerebral palsy had a femoral osteotomy to prevent imminent hip dislocation and was re-admitted to their local district general hospital eight days post operatively with pain and vomiting. The child's mother had initially called emergency services as she had no other contacts for the (tertiary) orthopaedic team. The surgical centre was approximately 80 miles away and the patient seemed to have been discharged with only oral morphine to give as required. After a short admission requiring intravenous fluids and regular simple analgesia the patient was discharged home but with no obvious communication with the surgical centre, the multidisciplinary team or the patient's GP.

*Reviewers commented that there was poor evidence of thorough discharge planning, including pain management. There was no record of regular simple analgesia being provided alongside opiates which might have meant that their side effects would have been minimised. The reviewers felt that this episode constituted poor evidence of a robust network of care.*

## CASE STUDY 22

A young adult underwent revision spinal surgery for scoliosis in a major orthopaedic centre. They had a cerebral palsy and this was well documented at GMFCS level III. There was evidence of a pre-operative joint multidisciplinary team discussion including management of drugs in the peri-operative period. Consent was taken from the patient and this involved consideration of the risks of blood transfusion as well as possible surgical and anaesthetic complications.

*Reviewers commented that this was the standard of care that many should expect in a "centre of excellence" and for a major procedure. However they also felt that messages were transferable for others and whether a procedure was minor or major.*

## CHAPTER

## 11

**CASE STUDY 23**

A young teenager with a GMFCS level II cerebral palsy, mild learning difficulty and no additional co-morbidity was admitted to a large district general hospital for elongation of tendon achilles which was performed by an 'adult' orthopaedic surgeon who regularly operated on children and young people with neurodisability and continued to care for them in their adult life.

*Reviewers commented on the excellent care delivered for this patient, including appropriate analgesia in a day case setting. There was also discussion of opportunities within networks of better arrangements for local care of patients, and examples of specialist surgeons from tertiary centres providing a regular contractual commitment to seeing patients and operating in the DGH, and maintaining close ongoing relationships with local paediatricians and surgeons.*

**CASE STUDY 24**

A young adult with GMFCS level II cerebral palsy and learning disabilities was admitted for routine surgery to correct a foot deformity on the same side as their hemiplegia. Records indicated that the patient was needle phobic and required considerable persuasion to have a premedication before attending the operating theatre. The patient's parent carer appeared to be the sole signatory on the consent form. There was no record in the notes of the patient's mental capacity and their own views on having this surgery.

*Reviewers agreed that this practice was unsatisfactory and that in the absence of best interest decision making having been documented and agreed this consent was against GMC and legal guidance.*

**CASE STUDY 25**

A teenager with bilateral cerebral palsy, GMFCS level III, was admitted for an elective day case orthopaedic procedure which went well and the patient was discharged home later in the day.

*The case reviewer found an excellent, detailed consent form in the medical record, including detailed explanations of the procedure, its risks and benefits, and evidence of use of Makaton to assist with communication. Whilst not 'signed' by the patient there was ample evidence that they had been properly involved and agreed to surgery. The form was also signed by their parent carer.*

**CASE STUDY 26**

A young patient with a cerebral palsy at GMFCS level V had a laparoscopic fundoplication in a large university hospital and was transferred to a paediatric high dependency unit for post-operative care. In addition the patient had a scoliosis, very difficult venous access and a vagal nerve stimulator with relatively poor seizure control. A DNACPR plan has been temporarily suspended in the peri-operative period. Analgesia was successfully provided with a combination of regular simple analgesics, local analgesia and a low dose nurse controlled morphine infusion.

*Reviewers noted that this was a case where there was very good pain assessment and management. This was carefully supervised by a paediatric pain team which included a consultant paediatric anaesthetist.*

## CHAPTER

## 11

## CHAPTER

## 12

**Key Findings – questionnaire, case note review and organisational data**

- 179/500 (35.8%) patients underwent surgery or a procedure during their admission
- 99.4% (169/170) of patients were seen by a senior surgeon or person carrying out the procedure prior to the operation or procedure
- Where the procedure was carried out under general anaesthetic or sedation, a majority of patients (125/138; 90.6%) were seen by a senior anaesthetist prior to surgery
- Where procedures were carried out under general anaesthetic, only 1 in 5 patients (29/128) signed the written consent form themselves. In 10 cases, a parent was the only person to sign the consent form for a patient aged 18 years or over
- It was reported to be routine practice to admit children and young people with severe neurodisability for surgery or procedures through the day surgery unit, in only 15/88 organisations providing paediatric inpatient care. If not, in most organisations (50/72) this was because the surgical/anaesthetic risk was felt to be too great
- Reviewers indicated pain management could have been improved for 102/203 (50.2%) children and young people with a cerebral palsy. They were unable to answer this question or did not answer this question in 93 cases. The main areas of improvement were felt to be documentation of pain enquiry and pain scoring
- Where an operation or procedure was undertaken, 100/138 (72.4%) of patients had regular pain scoring peri-operatively
- Reviewers indicated that in 132/145 cases reviewed, peri-operative pain relief was adequate, however in a third of cases they were unable to answer.

**SEE RECOMMENDATIONS**

**11•13•14•19•20•22•23•26•27•28  
29•30•31•32•33•35**

**CASE STUDY 27**

A young adult with a cerebral palsy was admitted with their first major seizure. The patient's GMFCS level was not recorded but they were able to walk unaided and most of their notes related to a complex congenital heart problem which was soon to be managed by adult cardiologists. The letter to the patient's GP stated that the patient "does have significant problems" but makes no explicit mention of a transition plan or their previous neurodisability care which has been considerable over several years.

*Reviewers comment that it seemed likely that the GP would now be leading the overall neurodisability care but that a clear management plan had not emerged even though the patient appeared to have 'graduated' from paediatric care.*

**CASE STUDY 28**

A young adult patient with complex needs including a tracheostomy, chronic respiratory disease and oxygen therapy was admitted to a large paediatric centre for eight days with acute on chronic abdominal pain. No specific diagnosis was made but the symptoms were well managed with input from a dedicated paediatric pain team. However, during admission the patient's GMFCS level was not documented, and neither was their level of learning ability. Whilst no discharge summary was evident to case reviewers there was a very well documented transition plan in place with evidence of meetings of a supportive multidisciplinary team.

*The reviewers commented that it was unusual to find such a good example of transition care in place with co-leadership, in this case, from the patient's paediatric neurodisability lead and an adult respiratory clinician but also involvement of the patient's GP and other professionals in primary care.*

## CHAPTER

## 12

## CASE STUDY 29

A young adult patient with a GMFCS level III cerebral palsy as determined by paediatricians was using a wheelchair to aid mobility at school. The patient was about to go to university 50 miles away and needed to continue their healthcare support in their new location. The last letter from the consultant paediatrician stated that she has tried to identify an adult neurodisability lead to supervise the patient's care in future but that this had proved impossible.

*The reviewers agreed that even where there were adult neurodisability leads in post their involvement in patients with a cerebral palsy may be limited to spasticity management. Generally after transition it was then up to the patient's GP, and on occasion interested surgeons, to offer care leadership. Patients and families often felt abandoned as a consequence and clinicians gave examples that physical and mental health of their patients deteriorated as a consequence.*

## CASE STUDY 30

A teenage non ambulant young person with a cerebral palsy at GMFCS level III was admitted to a general paediatric ward as an emergency from clinic with a fracture to their mid thigh bone after accidental trauma whilst being moved at school. The patient underwent surgery after a short period in traction and had excellent analgesia from an epidural anaesthetic. There were several entries in the medical and nursing notes of the patient's parent carers being concerned for their child's privacy as they were being nursed alongside a baby with bronchiolitis and a large attendant family in a (paediatric) high dependency area.

*Case reviewers commented that physical space in ward areas is often particularly limited for young people with complex needs and that privacy and dignity may be difficult to ensure in all circumstance but should be considered with high importance.*

## CASE STUDY 31

A young adult patient with a cerebral palsy at GMFCS level III who had an intrathecal baclofen pump to manage their spasticity was admitted for a minor revision to their delivery pump. The patient was noted by their consultant neurosurgeon to not be functioning as well as usual and that the patient was having issues with independence at work. The patient was often using a chair to get around. The patient's mother was at the consultation and stated that she was concerned that her child was no longer receiving any physiotherapy support despite requests to adult services to help.

*Reviewers comment that it is likely that there also needs to be a full workplace assessment for this young patient and that their regression in terms of motor ability is very common at this age and when as a young adult they are trying to get to grips with life in the workplace. This may well result in other important issues arising with both mental and physical health and wellbeing.*

## CHAPTER

## 12

**Key Findings – questionnaire, case note review and organisational data**

- Reviewers found documentation of a lead clinician for neurodisability care in only 31/133 (23.3%) case notes of young adults in comparison to 240/380 (63.2%) notes for children and young people
- Only one third (33/90) of organisations providing paediatric inpatient care had a written transition pathway
- In 50/84 inpatient organisations stated that they transferred patients to adult general medical, surgical and orthopaedic services with no specific pathways or adjustments in place for neurodisability
- There were 62 cases where there was evidence in the notes that the patient was transitioning or had transitioned from paediatric to adult services
- There was evidence in the case notes that a transition plan was in place in 17/46 of these cases
- Reviewers identified 12/21 sets of case notes where there was evidence of an identified lead worker in the records of neurodisability patients who were undergoing transition to adult care. In 7/20 cases there was evidence of multiagency involvement
- Reviewers found evidence in the case notes that if a patient was undergoing or had undergone transition to adult healthcare they had a lead GP in 39/53 cases
- There was considerable variation/inconsistency in the definitions for age that inpatient health organisations used for children and adults. 24/122 organisations defined 15-19 year olds as an “adult”, 11/315 as a “child” and 55/87 as an “adolescent/young person”
- The upper age limit for paediatric inpatient care was higher in many organisations for patients with neurodisability with 63/90 organisations using 18 or 19 years as an upper limit as compared with 28/90 in relation to general paediatric patients

- Clinical leads in acute paediatrics stated just 37/90 had a ward or ward areas for adolescent/young people and that in only a fifth (19/88) of their organisations was there an identified lead clinician or team for adolescent care. 21/89 stated that they had specific adolescent care pathways
- Responses from the adult inpatient care questionnaire indicated there was single room accommodation in 21/42 sites; en suite toilet facilities in 18/42 sites; and space for special equipment in 32/42 sites
- Leads for inpatient care of children and young people stated that young people were not routinely given an opportunity to be seen separately e.g. in medical and surgical ward rounds. In 15/101 inpatient organisations patients were not given a choice as to whether a parent was present in all discussions and as appropriate for their age
- Case note reviewers noted that mental capacity assessment was recorded in case notes where the patient was over the age of 16 years and there was a documented learning disability, in only 1 in 3 cases (42/135).

**SEE RECOMMENDATIONS**

**11•16•19•20•21•22•23•26•27•28  
29•30•31•32•33•35**

**Key Findings – routine national data**

- Transition to adult services takes significantly longer for children and young people with a cerebral palsy than for those without
- Transition from paediatric to adult services takes longer for inpatient admissions than outpatient services
- The proportion of outpatient appointments for specialties managing mental health and learning difficulties increased significantly between 10 and 24 years of age but hospital admissions for the same specialty decreased with age
- The proportion of outpatient appointments for therapies and allied professionals and neurological services increased with age and were significantly greater for children and young people with a cerebral palsy than without.

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# Appendices

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## Glossary

Term	Definition
<b>A&amp;E</b>	Accident and Emergency
<b>ADDE</b>	Annual District Death Extract
<b>AMH</b>	Adolescent Mental Health
<b>Ataxia</b>	Lack of voluntary coordination of muscle movements that includes gait abnormality
<b>BSO</b>	Business Services Organisation
<b>Cerebral palsy</b>	Cerebral palsy is the name for a group of lifelong conditions that affect movement and co-ordination, caused by a problem with the brain that occurs before, during or soon after birth.
<b>CI</b>	Confidence interval
<b>Congenital heart disease</b>	This is a general term for a range of birth defects that affect the normal workings of the heart. The term "congenital" means the condition is present at birth.
<b>Continuous Positive Airway Pressure - CPAP</b>	A therapy that increases air pressure in the throat so the airway does not collapse when someone breathes in
<b>CP</b>	Cerebral Palsies
<b>CPRD</b>	Clinical Practice Research Database
<b>CYP</b>	Children and young people
<b>Diplegia</b>	Paralysis affecting symmetrical parts of the body
<b>DNACPR</b>	Do Not Attempt Cardiopulmonary Resuscitation
<b>Dorsal rhizotomy</b>	An operation used to improve spasticity (muscle stiffness)
<b>Dyskinetic</b>	Involuntary muscle movements
<b>EDDS</b>	Emergency Department Dataset
<b>Emergency Health Care Plan/Emergency Care Summary</b>	An Emergency Health Care Plan makes communication easier in the event of a healthcare emergency.
<b>EPD</b>	Enhanced Prescribing Dataset

## APPENDICES

Term	Definition
<b>Epilepsy</b>	Epilepsy is a common condition that affects the brain and causes frequent seizures. Seizures are bursts of electrical activity in the brain that temporarily affect how it works.
<b>Fundoplication</b>	An operation used to treat gastro-oesophageal reflux. It uses the top of the stomach to strengthen the sphincter so it is less likely to allow food, drink or acid to travel back into the foodpipe.
<b>Gastrostomy</b>	A gastrostomy is a feeding tube that is inserted directly into the stomach either surgically under direct vision (open or laproscopic), endoscopically (with a camera), or radiologically (x-ray guidance). A gastrostomy tube allows the delivery of supplemental nutrition and medications directly into the stomach.
<b>GMFCS levels</b>	Gross Motor Function Classification System - <a href="https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r">https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r</a>
<b>HBS</b>	Honest Broker Service
<b>Hemiplegia</b>	A condition that affects one side of the body
<b>HES (APC)</b>	Hospital Episode Statistics (Admitted Patient Care)
<b>HQIP</b>	Healthcare Quality Improvement Partnership
<b>HSCIC</b>	Health and Social Care Information System
<b>ICD</b>	International Classification of Diseases
<b>IMD</b>	Index of Multiple Deprivation
<b>ICD-10</b>	International Classification of Diseases, version 10
<b>Intrathecal baclofen</b>	Baclofen is delivered directly into the spinal fluid to help muscle stiffness
<b>ISAC</b>	Independent Scientific Advisory Committee
<b>ISD</b>	Information Services Scotland
<b>Levels of care (adults)</b>	Level 0/1: Normal ward care in an acute hospital Level 2: High Dependency Unit for patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those 'stepping down' from ICU Level 3: For patients requiring advanced respiratory support alone or monitoring and support for two or more organ systems.
<b>MHLDD</b>	Mental Health and Learning Disabilities Dataset
<b>Monoplegia</b>	Paralysis of a single limb

Term	Definition
NECCPS	North East Collaborative Cerebral Palsy Register
NHS	National Health Services
NICPR	Northern Ireland Cerebral Palsy Register
NIHS	Northern Ireland Health Service
NIRAES	Northern Ireland Regional Accident and Emergency System (South Eastern and Southern Trusts)
NISRA	Northern Ireland Statistics and Research Agency
NPD	National Pupil Database
NRS	National Records of Scotland
NSS	National Services Scotland
ONS	Office of National Statistics
OPDW	Outpatients Dataset Wales
Paediatric critical/intensive care unit (PCCU/PICU)	A discrete area within a ward or hospital where paediatric critical care is delivered.
Paediatric levels of critical care	<p>Level 1 PCCU: A discrete area or unit where Level 1 paediatric critical care is delivered. With Paediatric Critical Care Network agreement, CPAP for bronchiolitis may be initiated or continued in a number of Level 1 Paediatric Critical Care Units.</p> <p>Level 2 PCCU: A discrete area or unit where Level 1 and Level 2 paediatric critical care are delivered.</p> <p>Other than in specialist children's hospitals, Level 2 Units should be able to provide, as a minimum, acute (and chronic) non-invasive ventilation (both CPAP and BiPAP support) and care for children with tracheostomies and children on long-term ventilation, but should not be expected to deliver specialist Level 2 interventions such as ICP monitoring or acute renal replacement therapy. Within specialist children's hospitals, Level 2 Units may provide some or all of these additional specialist interventions.</p> <p>Level 3 PCCU: A unit delivering Level 2 and Level 3 paediatric critical care (and Level 1 if required). This unit may also be called a Paediatric Intensive Care Unit (PICU).</p>
PAS	Patient Administration System
PBPPHSC	Public Benefit and Privacy Panel for Health and Social Care
PEDW	Patient Episode Database for Wales
PHA	Public Health Agency
PICANet	Paediatric Intensive Care Audit Network

## APPENDICES

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<b>Term</b>	<b>Definition</b>
<b>PYAR</b>	Person years at risk - the product of a number of people in a study times the amount of time they have spent in the study
<b>Quadriplegia/Tetraplegia</b>	Affecting all four limbs and the torso
<b>SAIL</b>	Secure Anonymised Information Linkage
<b>Scoliosis</b>	Scoliosis is where the spine twists and curves to the side
<b>Seriously ill patient</b>	A seriously ill patient is defined as a patient who requires or potentially requires critical care (level 3 care) whether their condition is medical, surgical or trauma related.
<b>SMR</b>	Scottish Morbidity Records
<b>SMR00</b>	Scottish Morbidity Records - Outpatients Attendances and Appointments
<b>SMR01</b>	Scottish Morbidity Records - General Acute Inpatient and Day Case
<b>SNOMED CT</b>	
<b>SNS</b>	Support Needs System
<b>SOSCARE</b>	Social Services Client Administration and Retrieval Environment
<b>Status epilepticus</b>	Convulsive seizures lasting more than 30 minutes
<b>Transition</b>	This describes the process of planning, preparing and moving from children's healthcare to adult healthcare. Transition should be a gradual process of change, which gives everyone time to ensure that young people and their families are prepared and feel ready to make the move.
<b>WDS</b>	Wales Demographic Service
<b>WECC</b>	Welsh Electronic Cohort of Children
<b>WLGP</b>	Wales Primary Care GP Dataset

## Appendix 1 – Resources

**NICE** National Institute for  
Health and Care Excellence

NG 62 - [Cerebral palsy in under 25s: assessment and management](#)

NG 43 - [Transition from children's to adults' services for young people using health or social care services](#)

CG 145 - [Spasticity in under 19s: management](#)



### NCEPOD Classification of Intervention

IMMEDIATE – Immediate life, limb or organ-saving intervention – resuscitation simultaneous with intervention. Normally within minutes of decision to operate.

URGENT – Intervention for acute onset or clinical deterioration of potentially life-threatening conditions, for those conditions that may threaten the survival of limb or organ, for fixation of many fractures and for relief of pain or other distressing symptoms. Normally within hours of decision to operate.

EXPEDITED – Patient requiring early treatment where the condition is not an immediate threat to life, limb or organ survival. Normally within days of decision to operate.

ELECTIVE – Intervention planned or booked in advance of routine admission to hospital. Timing to suit patient, hospital and staff.

Examples of tools covered in this report can be accessed through the links below:

**Pain scoring tools**

[Example of pain scoring tools](#)

Validated tool for the assessment and description of hand function

[The Manual Ability Classification System \(MACS\) for children with cerebral palsy](#)

Validated tool for description of eating and drinking ability

[Eating and Drinking Ability Classification System for Individuals with Cerebral Palsy \(EDACS\)](#)

**Emergency Health Care Plans**

[What is an Emergency Health Care Plan](#)

[Examples of Emergency Health Care Plans](#)

**Patient held passport**

[Example of a patient held hospital passport](#)

**Disability Matters**

[Training tools](#)

**GMFCS**

[GMFCS Scoring Tools](#)

**Surveillance of Cerebral Palsy in Europe**

[SCPE Reference & Training Manual](#)

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