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

NCEPOD

Improving the quality of healthcare

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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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Foreword

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Many more children and young people with chronic neurodisability now survive into adult life due to improvements in neonatal and general paediatric care. Importantly, some of these survivors will have additional long-term problems with day-to-day activities including mobility, hearing, vision and communication which need to be considered.

This report follows a trail of child health reviews which began in 2006/7 with the publication of 'Why Children Die' by the Confidential Enquiry into Maternal and Child Health (CEMACH).[1] This was followed by more recent reviews from the Royal College of Paediatrics and Child Health (RCPCH) highlighting deficiencies in care particularly in relation to children and young people with chronic illness.[2]

Proactive, multidisciplinary care which is underpinned by excellent communication with the patient at the centre, leads to better outcomes when compared to passive monitoring of the natural history of the disabling health condition. Recent NICE guidance has emphasised the need for improvements in care that can and should be made for patients with a cerebral palsy up to the age of 25 years.[3]

All children and young people with a neurodisability should have the right to receive the same high quality healthcare as anyone else. This should include close attention to detail to ensure their wider needs are appropriately understood and described at every opportunity, including health conditions, family reported issues, technology dependencies and need (or not) for care 24/7. When needs are adequately recognised they are more likely to be dealt with effectively as part of the overarching care plan. To achieve this goal, exceptional communication between service providers is required using robust networks to ensure that each and every need is met.

More than 40 years ago the Court report[4] recommended that each 'district' had a multidisciplinary disability team. Formal training and specialisation in neurodisability care for paediatricians followed and has been available in the UK since 2005. However, these changes and recommendations have been only partially adopted in adult health care. Although transition between child and adult healthcare was identified in 2014 by the Children and Young People's Health Outcomes forum[5] as requiring particular attention, it is woefully lacking in many areas.

Handing on the baton of the leadership of multidisciplinary team care is essential at all transitions, including to adult services. At present there are often no natural successors to lead the team and orchestrate the care in adult practice other than the patient's general practitioner who may or may not have been involved in decision making at an earlier date. The re-organisation of primary care services into larger networks offers an opportunity to bridge the gap in neurodisability services for young people with a neurodisabling condition.

This will depend on clinical champions in general practice being appointed and included in the planning and implementation of transition. Environmental issues are a major challenge for many patients, their families and services. Whilst it is rarely possible to 'fix' the disabling health condition, it should surely always be possible to

1 *Pearson, G A (Ed) Why Children Die: A Pilot Study 2006; England (South. West, North East and West Midlands), Wales and Northern Ireland. London: CEMACH. 2008*

2 *Royal College of Paediatrics and Child Health CHR-UK Programme of Work at the MRC Centre of Epidemiology for Child Health, University College London Institute of Child Health. September 2013. Overview of Child Deaths in the four UK countries.*

3 *National Institute for Health and Care Excellence (NICE) Clinical guidelines [NG62]: Cerebral palsy in under 25s: assessment and management. Published January 2017*

4 *Fit for the Future" – a report of the committee on child health services, The Court report 1976*

5 *CYPHOF Report on Long term conditions, Disability and Palliative care subgroup 2014 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216856/CYP-Long-Term-Conditions.pdfREFS).*

ensure the environment is appropriate, including adequate physical access to clinic services, and equipment to accommodate a range of different needs.

The issue of inadequate transition is not confined to neurodisability. NCEPOD is also leading on a parallel report on young people's mental health which also focuses on transition. Indeed, NICE have published guidance on the importance of it, yet this still appears to be a major failing in how healthcare services are being provided.

Identifying complex conditions and building a picture of individual needs will promote better care and enhance the value of robust datasets, mapping the utilisation of health services with greater clarity. In 2015 the routine Children and Young People's Health Services dataset in England was mandated for central flow to NHS digital for all providers of publicly funded community services. This evolved in 2017 to the all-age Community Services Dataset. This report has demonstrated the potential value of routine national data recording by clinicians at the point of care in all settings and across the UK. This will allow the scrutiny of variations in aspects of healthcare so that they can be addressed for a patient group. Using SNOMED CT as the consistent coding system across all nations will mean that like can be compared with like. Governance arrangements to allow interrogation of these data across the UK must be harmonised to make data analyses as easy as possible, since accessing the data for this part of the study was cumbersome. With the implementation of the new General Data Protection Regulations there is a risk that this will only become worse, and the benefits of using large datasets to improve care will become outweighed by the bureaucracy of the application process.

As with all NCEPOD reports I must acknowledge the enormous effort that has gone into this study. The teams at Cardiff and Swansea Universities who were committed to gathering and analysing the available national datasets, comprising hundreds of thousands of datapoints. The multidisciplinary study advisory group who helped to design the study and the case reviewers who generously gave up their time. To each clinician who took pains to complete the lengthy questionnaires. The NCEPOD Local Reporters who identified the cases for us, copied the notes and understood the need for making sure they were as complete as they could be. Further thanks are due to our NCEPOD Ambassadors who championed the topic locally, the authors for writing such a detailed report, the researchers for their analysis and guidance on interpreting the data. The whole of the NCEPOD team for running the study to schedule and to our panel of lay representatives for their invaluable insight and non-clinical interpretation of the findings. Finally I thank my fellow Trustees and our clinical co-ordinator's for all their support.

Professor Lesley Regan
NCEPOD Chair

Introduction

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In 2013 the Royal College of Paediatrics and Child Health published their *'Overview of Child Deaths in the Four UK Countries'* report.[1] 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.

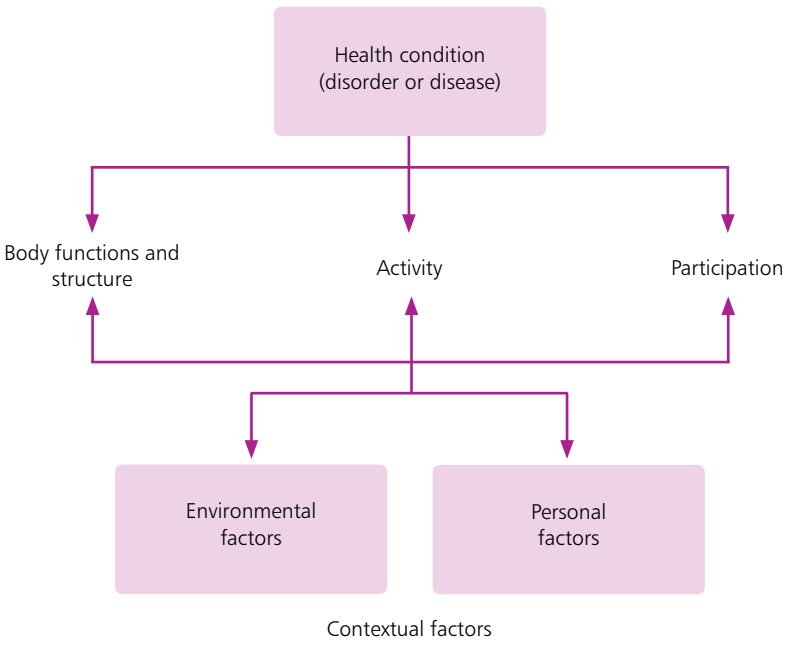

Figure 1 WHO model of disability

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.[2]

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.[2,3,4]

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'.[5,6,7,8] 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.[8] Suboptimal transition to adult services has been linked to a decrease in the utilisation of services by adolescents and deterioration in overall health.[9]

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."* **[i]**

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

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)*

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

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	*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. 5

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. 5

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. 8

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. 6

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. 7

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. 7 12

Peer reviewed data showed that a quarter of patients with a cerebral palsy, whose admission was unplanned, were seriously ill. Not all were seen in a timely fashion by senior clinicians, and recording of this event was poor. When appropriate, few patients had emergency healthcare planning in place.

Evidence from the case note reviews confirmed that clinical care was in need of improvement, including the recognition and management of aspects such as pain, learning disability, emotional and mental health and support needs. Weighing and measuring patients accurately to ensure adequate nutrition and accurate calculations for medication doses and fluids were inconsistent. Many patients in this study had unsafe swallows that were infrequently assessed. Hip and spine surveillance was variable, with hip status frequently not documented. 8

Documentation was found to be wanting in this study: the wider health needs of one in ten children, young people and young adults with cerebral palsies were inadequately described in their case notes, including their preferred communication method and level of learning ability. Documentation about adjustments required to meet needs was missing in the case notes of half of the study sample. Often it was reported that basic equipment needed to meet simple needs were absent, such as hoists, wheelchairs, weighing scales and changing places. These issues were reported by the parent carers as well as clinicians in the hospitals who responded. 8 9

Documentation of consent to procedures was found to be inadequate or inappropriate in a substantial number of cases reviewed where the patient was admitted for a procedure or surgery under general anaesthesia.

This study highlights considerable uncertainty about how and when transition to adult care occurred. NICE published guidance in 2016,[10] the same year that NHS Scotland set generic "gold standards" for leadership and planning of transition in healthcare.[11] However, translation into practice does depend on there being equivalent services for young adults "on the other side of the divide", to those available in paediatric services. Since this is hardly ever the case for patients with cerebral palsies or other neurodisabling conditions, the gap that opens up poses enormous challenges for patients and their families as well as health and social care providers, with a large burden of complex healthcare falling on to GPs. Peer review and the routine data highlighted that transition can take longer for children and young people with cerebral palsies than for those without. Also, the interface with different specialties involved throughout the transition period varied with the proportion of outpatient appointments for specialties managing mental health and learning disabilities increasing significantly between 10 and 25 years of age, but hospital admissions for the same specialties decreased with age.

1

1 – 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.[12] 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 ≥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).

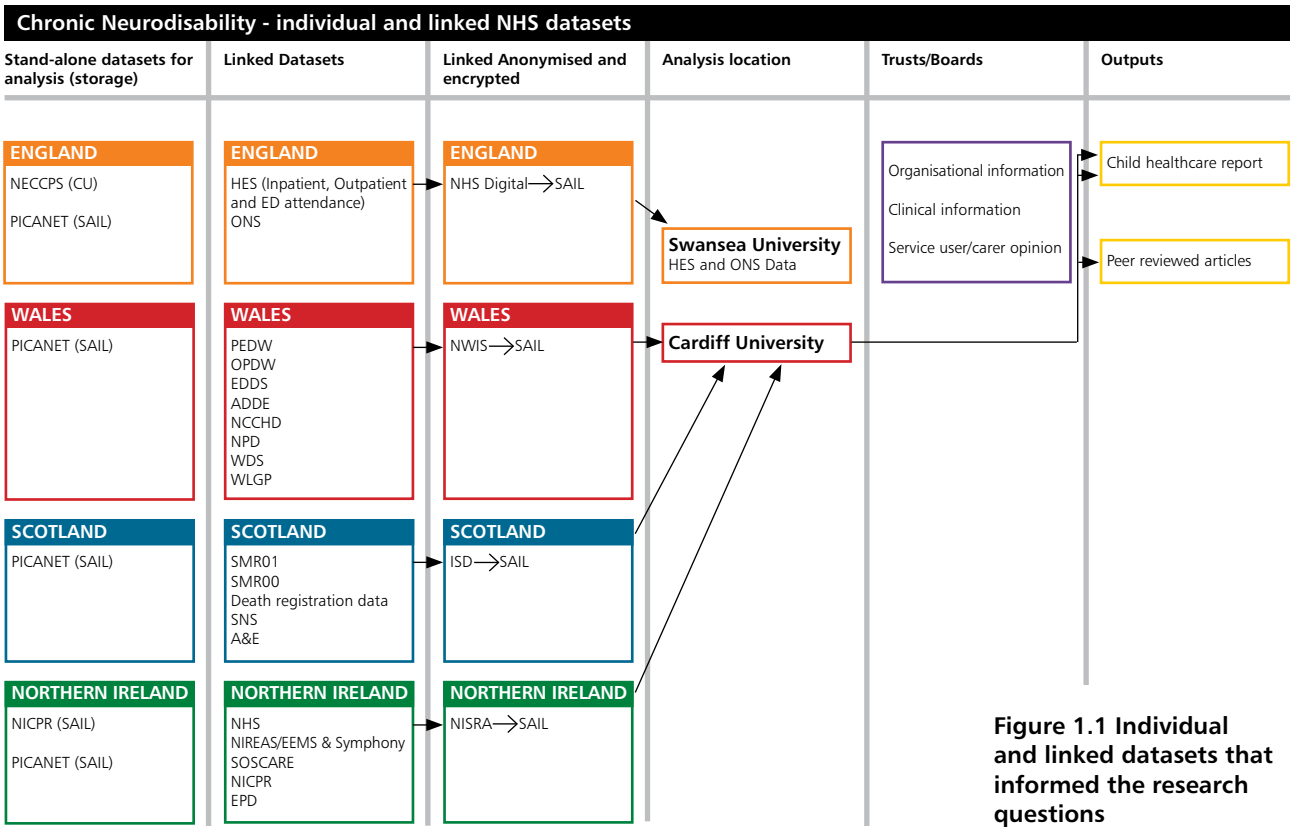

Figure 1.1 Individual and linked datasets that informed the research questions

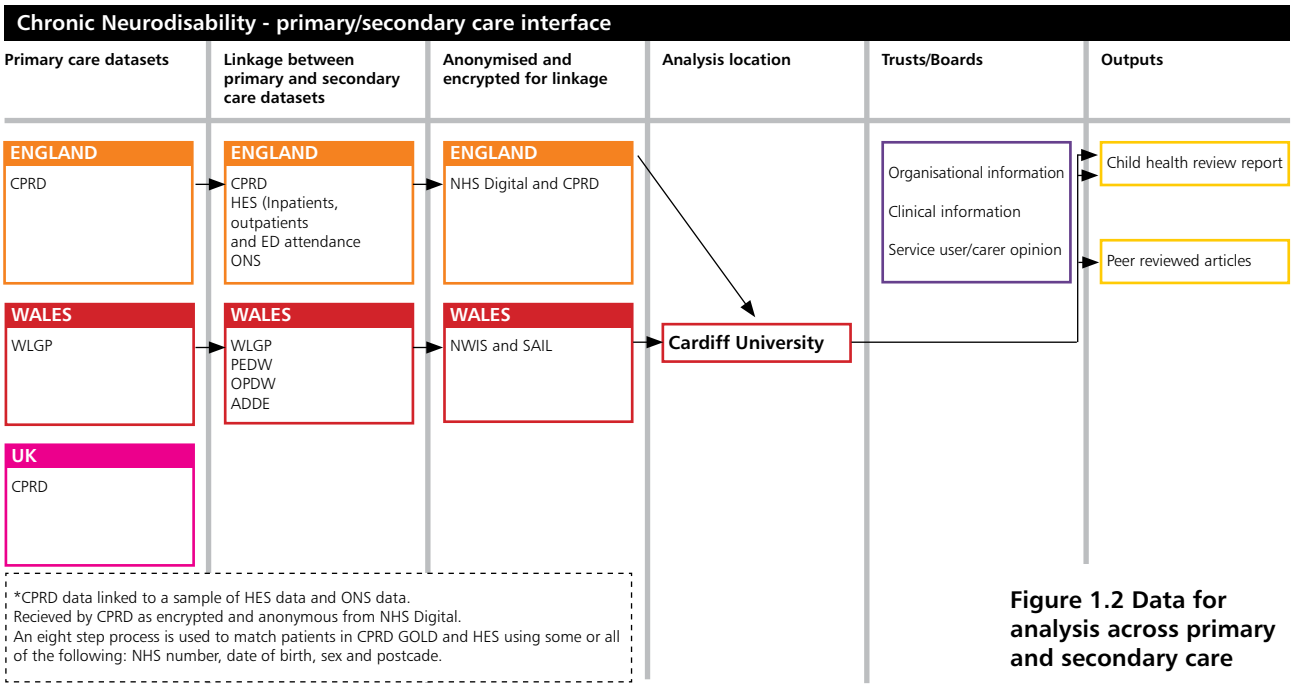

Figure 1.2 Data for analysis across primary and secondary care

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.

- 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
Inpatients					
Name	*HES APC	SMR01	PEDW	PAS	
Source	NHS Digital	ISD	SAIL	HBS	
Data timescale	2004-2014	2004-2014	1979-2014	2004-2014	
Coverage	Total population	Total population	Total population	Total population	
Outpatients					
Name	*HES Outpatients	SMR00	OPDW	Outpatients Dataset	
Source	NHS Digital	ISD	SAIL	HBS	
Data timescale	2004-2014	2004-2014	1979-2014	2004-2014	
Coverage	Total population	Total population	Total population	Total population	
Primary care					
Name			WLGP	EPD	*CPRD
Source			SAIL	BSO	CPRD
Data timescale			1979-2014	2010-2014	1979-2014
Coverage			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
Emergency department					
Name	HES Accident and Emergency	A&E Datamart	EDDS	Symphony-Belfast, Northern & Western Trusts	
Source	NHS Digital	ISD	SAIL	HBS	
Data timescale	2007-2014	2007-2014	2009-2014	2011-2014	
Coverage	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	
Intensive care					
Name					PICANet
Source					PICANet
Data timescale					2008-2014
Coverage					Total UK population
Mortality					
Name	*ONS Mortality	Death Registration Data	ADDE	Death Registration Data	
Source	ONS	ISD	SAIL	Northern Ireland Statistics and Research Agency	
Data timescale	2004-2014	2004-2014	2004-2014	2004-2014	
Coverage	Population linked to HES	Population registered with a GP	Total population	Population in the GP Patients Registration Index	
Cerebral Palsy or Special Needs Registers					
Name	NECCPS	SNS		NICPR	
Source	Regional Maternity Survey Office	ISD		Queens University, Belfast	
Time Scale	Those born 2004-2014	2004-2014		Those born 1981-2011	
Coverage	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

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

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).[13] A description of data linkage process within SAIL for the Wales datasets can be found in Appendix 3.

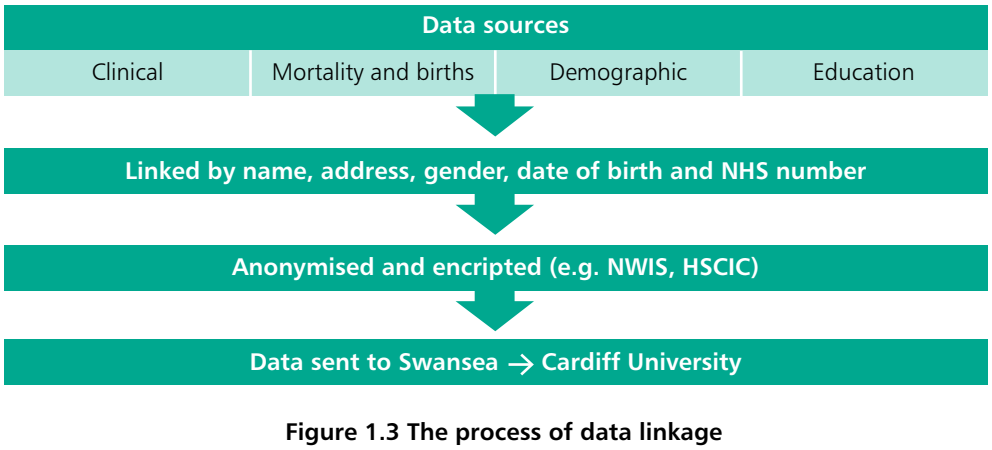

Figure 1.3 The process of data linkage

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, PICANet 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.[14]

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 PICANet. 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[14]
- medications prescribed (e.g. anticonvulsants, laxatives, neuromuscular relaxants) adapted from Meeraus et al.[14]

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.

Information governance

All data received and handled by NCEPOD and Cardiff University complied with all relevant national requirements, including the Information Commissioners Office (NCEPOD Z5442652), the NHS Act 2006 (15/CAG/0210), the NHS Code of Practice and Public Benefit and Privacy Panel for Health and Social Care (for NHS Scotland). As anonymous data were requested ethical approvals were not required, but approvals from the data providers for each country was. 'Approved researcher status' for each member of the data linkage team was sought and granted in order to access data from the Office for National Statistics (ONS). Each member of the team completed Medical Research Council (MRC) Research Data and Confidentiality e-module training.

The findings of the report were reviewed by the Study Advisory Group, Reviewers, NCEPOD Steering Group including Clinical Co-ordinators, Trustees and Lay Representatives on four occasions prior to publication.

2 – 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 though 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

- 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.

3 – Data returns and study populations

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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 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.

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

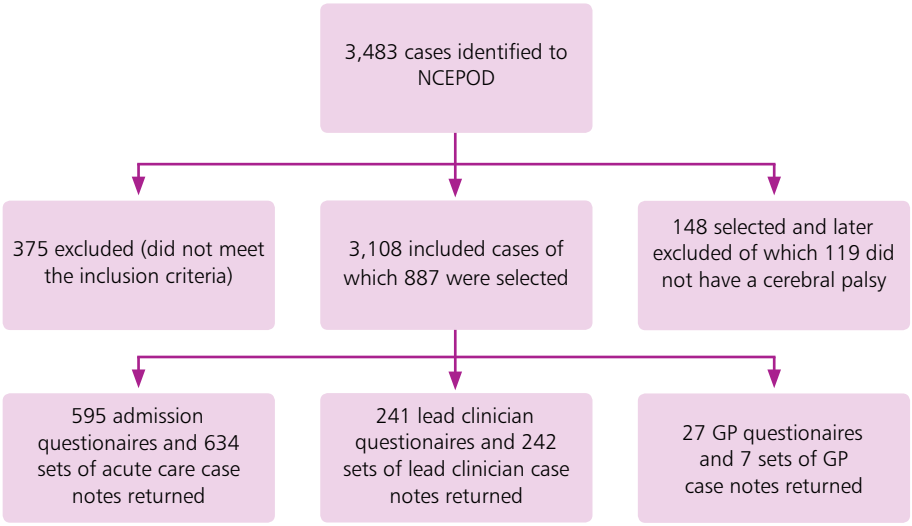

Figure 3.1 Data returns

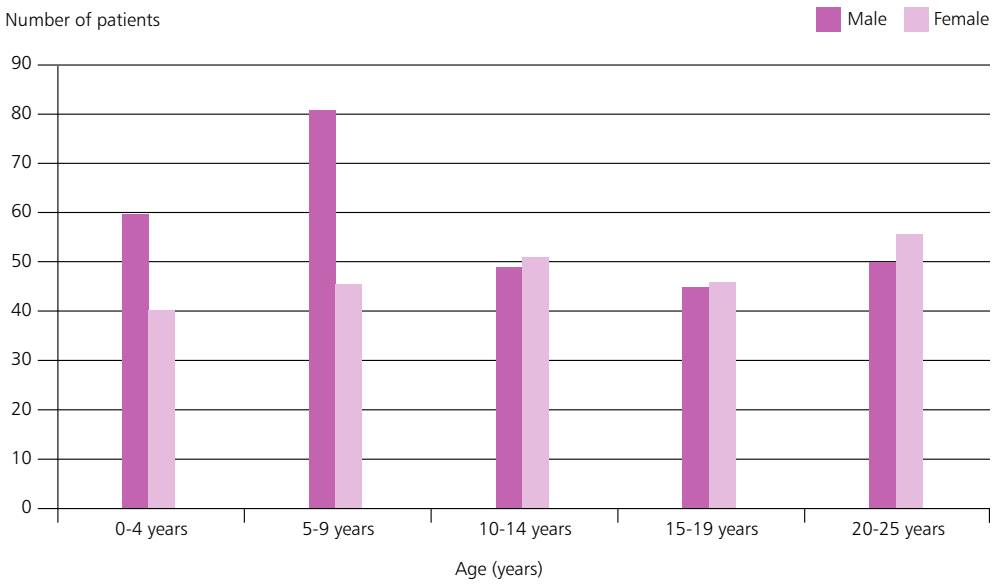

Figure 3.2 Age and gender of the study population

Please note that the denominators throughout the report will reflect the number of different data sources that have 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 be undertaken (Appendix 1).[15] 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. 11

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
Subtotal	**523**	
Not answered	13	
Total	**536**	

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
Subtotal	**317**	
Unable to answer	35	
Total	**352**	

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
CPRD			
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
Data linked in each of the four countries			
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 Acute Inpatient and Day Case*
HES APC	*Hospital Episode Statistics Admitted Patient Care*		
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.

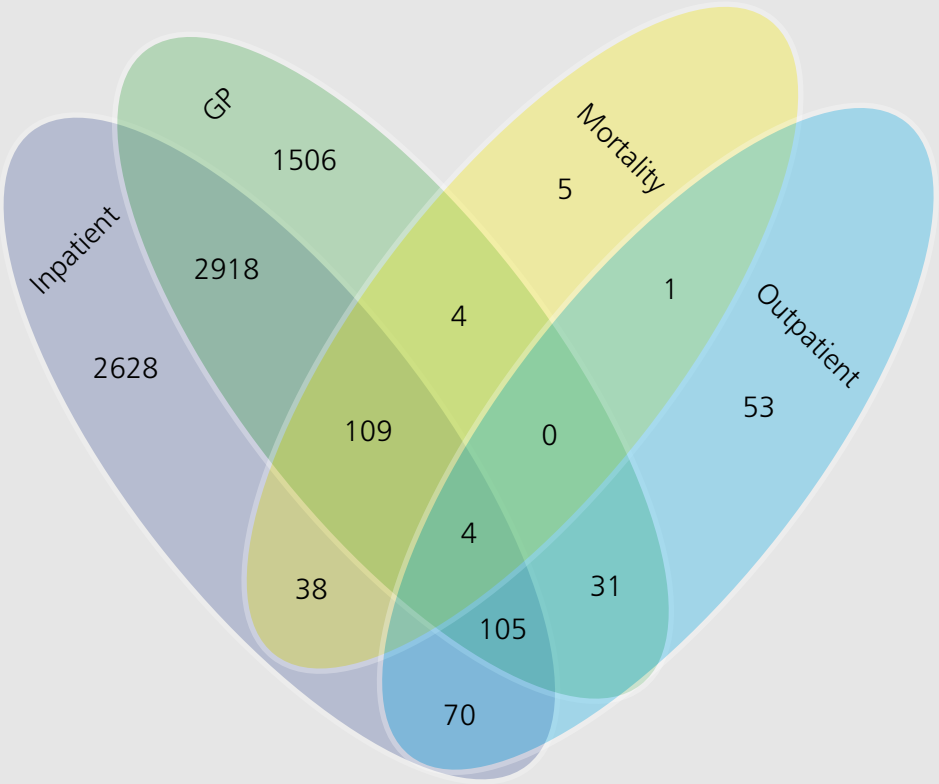

Figure 3.3 Venn diagram illustrating the number of patients within each of the datasets where patients with a neurodisabling condition were identified within the HES Linked English CPRD dataset

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. [5]

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).

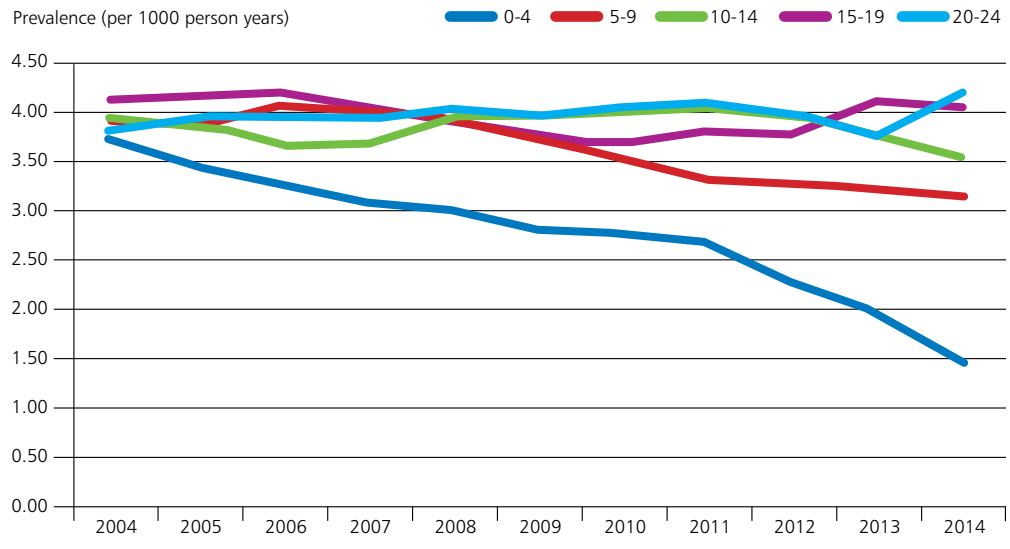

Figure 3.4 Prevalence of cerebral palsies by year and age group in CPRD (England HES Linked)

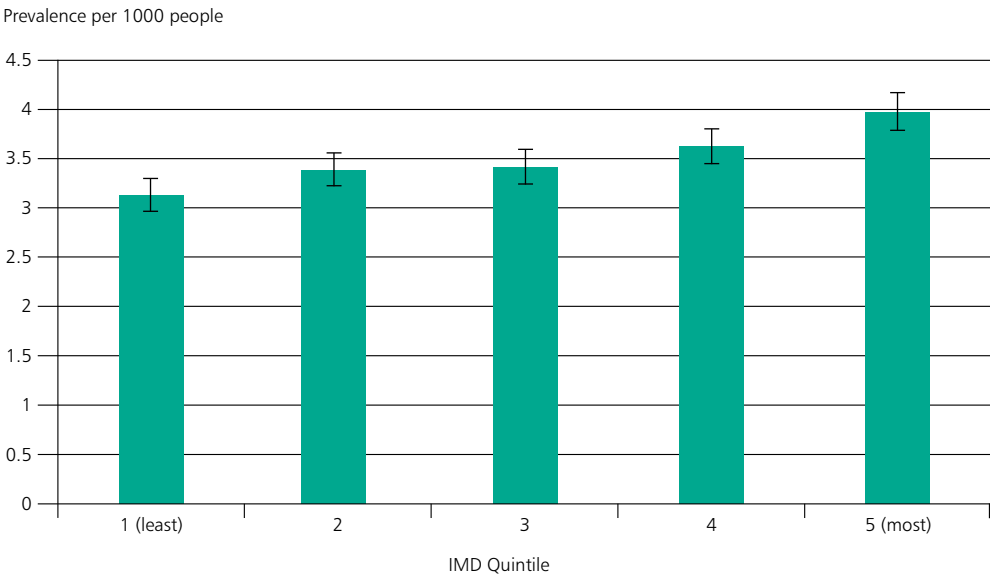

Figure 3.5 The prevalence of cerebral palsies in children and young people within each Index of Multiple Deprivation (IMD) quintile (CPRD: England HES Linked)

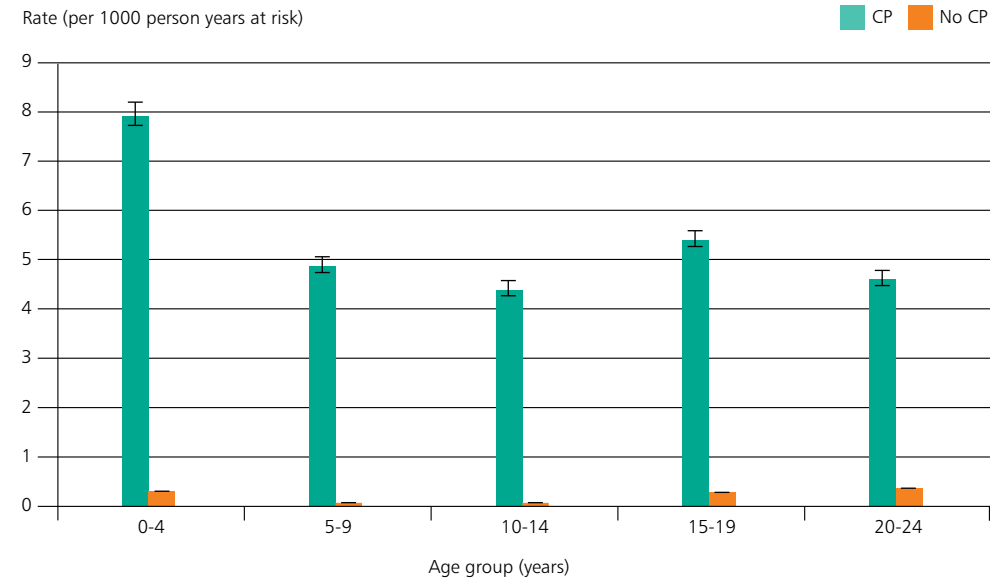

Figure 3.6 Mortality rate (per 1000 person years at risk) among children and young people with and without a cerebral palsy between 2004 and 2014 by age group (CPRD: England HES and OPD Linked)

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.

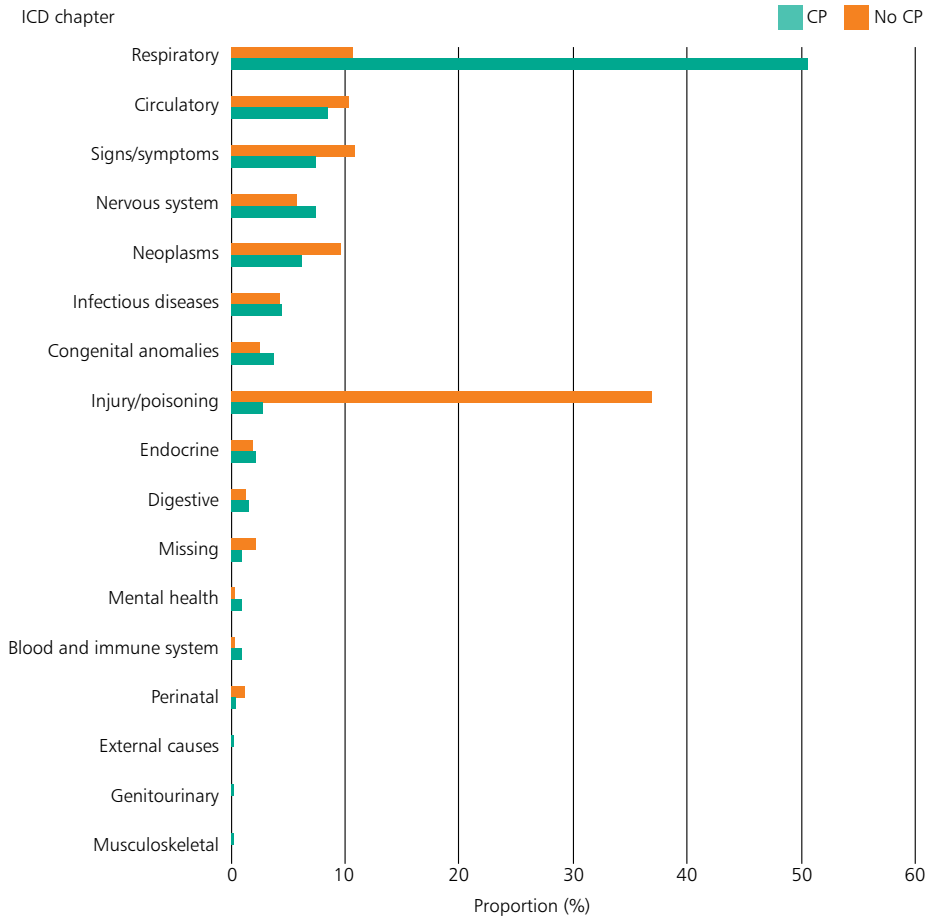

Figure 3.7 Primary cause of death for children and young people with (n=174) and without a cerebral palsy (n=2,026) aged 0-24 years between 2004 and 2014 as a proportion of total deaths(CPRD: England HES Linked)

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 – 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.[16] 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 4
- Respiratory conditions prevailed as the most common diagnostic group in mortality, PICU, emergency hospital admissions and primary healthcare consultations.

SEE RECOMMENDATIONS 1•2

4 – Support for patients, carers and families

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Study Advisory Group question: *Is the emotional health and wellbeing of children and young people being met with appropriate support and referral.*

Why is this important? *The care and support given to families can be just as important as the clinical service provided. A network of support is essential of patients, parents and carers so that they know who they can turn to for advice, preventing isolation.*

Data from the organisational questionnaires showed access to support systems for families for different aspects of care varied between different organisations and between paediatric and adult services (Figures 4.1 and 4.2).

Where a children's social care team was reported to be available by leads of different aspects of service, there was variation in which groups of children the team would support, as shown in Table 4.1.

Variation was reported between organisations in the definition of the threshold for involvement of children's social care teams. Paediatric outpatient care organisational questionnaire respondents did not know what these thresholds were, or reported them to be unclear. The threshold was in some cases at a level where there were safeguarding concerns, others reported that they were 'high' or 'very high'. Other organisations reported working

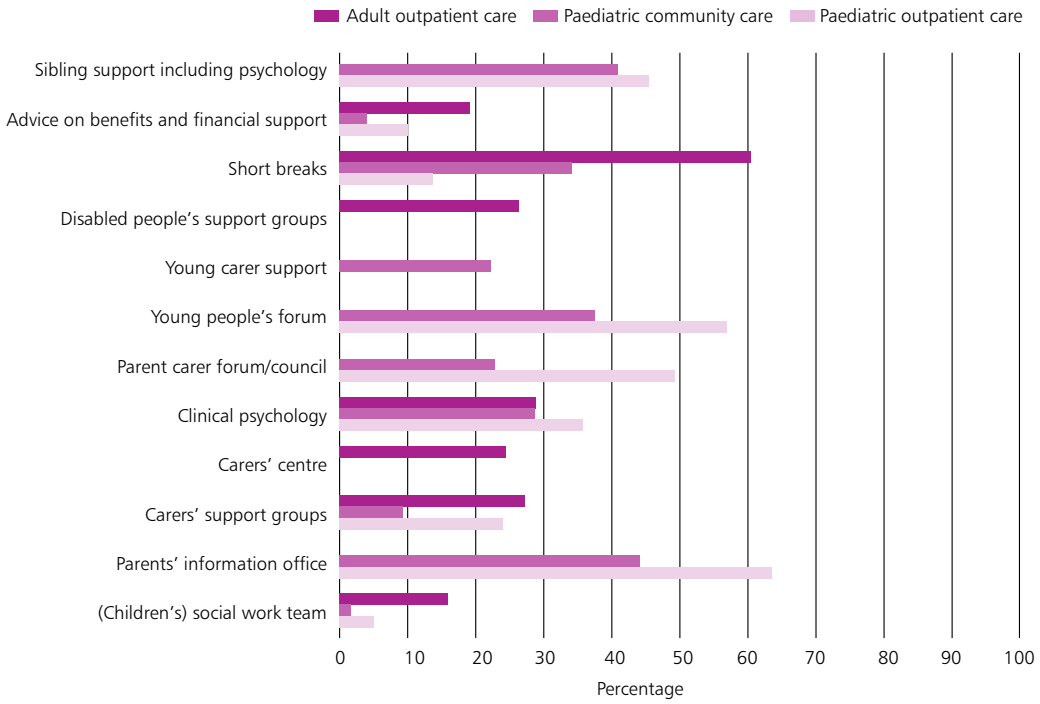

Figure 4.1 Outpatient care – percentage of family support services not in place

with different teams in different areas, each with different thresholds. The most specific threshold definition given was: "Under 18, unable to participate in community activities because of lifelong impairment, essential care or medical or emotional needs cannot otherwise be met".

It was reported in the community paediatric care questionnaire that there was access to a family liaison officer, support worker or carer's centre team for disabled children and young people in 32/76 organisations but not in 44/76. This question was not answered for 5/81 organisations.

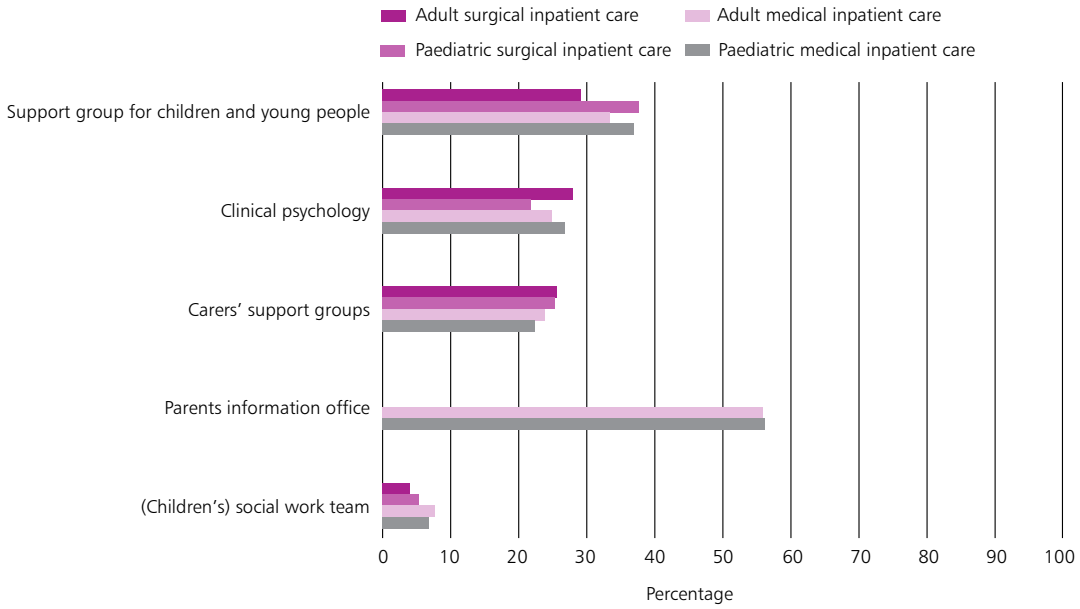

Figure 4.2 Inpatient care – percentage of family support services not in place

Table 4.1 Groups supported by social care teams

	Paediatric outpatient care	Community paediatric care
All families with disabled children and young people routinely	25	41
Only involved if there are safeguarding issues	17	23
Other	12	1
Subtotal	**54**	**65**
Not answered	24	14
Total	**78**	**79**

Support systems available for children and young people with cerebral palsies in schools were reported in the community paediatric care questionnaire to include:

- Specialist teachers for children and young people with physical and medical needs (61/78)
- Specialist teachers for children and young people with vision impairments (75/78)
- Specialist teachers for children and young people with hearing impairments (74/78)
- Specialist teachers for children and young people with autism spectrum conditions (70/78)
- Educational psychology (71/78) and
- Other (12/78).

Organisational data for community paediatrics and for adult outpatient care explored whether they were able to recommend local, accessible leisure opportunities as shown in Table 4.2.

Table 4.2 Local, accessible leisure opportunities could be recommended

	Community paediatric care	Adult outpatient care
Yes	68	26
No	11	13
Subtotal	**79**	**39**
Not answered	2	14
Total	**81**	**53**

Clinical leads for patient disability care and GPs were asked whether their patient's psychological and emotional needs were fully addressed (Tables 4.3 and 4.4). In 90 patients the lead clinician did not know and in 14 patients the GP did not know.

Table 4.3 The patient's psychological and emotional needs were fully addressed – lead clinician

	n=	%
Yes	93	71.0
No	38	29.0
Subtotal	**131**	
Unknown	90	
Total	**221**	

Table 4.4 The patient's psychological and emotional needs were fully addressed – GP

	n=
Yes	8
No	1
Subtotal	**9**
Unknown	14
Total	**23**

Where they believed the needs were believed not to be met, this was reported to be because of lack of available specialist clinical expertise by 26/36 clinical leads for disability care.

Training

NHS England's Five Year Forward View and Next Steps on the NHS Five Year Forward View emphasise the importance of supporting patients in aspects of self-management.[17,18]

Training for patients themselves in aspects of self-management was reported to be provided, for specific procedures or broad areas of management to a variable extent, by leads for different aspects of care (Table 4.5)

Clinical leads for patient disability care reported that training in aspects of self-management was not provided for 20/93 of their patients where it was applicable. This was unknown for 41 patients. In the opinion of the lead for disability care, this training was adequate for 57/59 patients where it could be identified. This training was regularly reviewed for 42/48 patients, and was unknown for 25/73 patients.

Training for parent carers in aspects of management, including technology dependencies e.g. ventilator or gastrostomy tube, was reported to be provided to a variable extent, by leads for different aspects of care (Table 4.6).

Table 4.7 shows where clear care pathways were reported to be in place for parent carers to be provided with training in the specific competences required to deliver care for their child.

Table 4.5 Training for patients to aid self-management was provided

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Adult outpatient care	Adult inpatient care
Yes	53	50	60	23	30
No	29	26	26	24	18
Subtotal	**82**	**76**	**86**	**47**	**48**
Not answered	2	5	4	6	18
Total	**84**	**81**	**90**	**53**	**66**

Table 4.6 Training for parent carers included technology support

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Adult outpatient care	Adult inpatient care
Yes	65	71	78	26	37
No	18	6	9	19	11
Subtotal	**83**	**77**	**87**	**45**	**48**
Not answered	1	4	3	8	18
Total	**84**	**81**	**90**	**53**	**66**

Table 4.7 Pathways in place for training of parent carers

	Yes	No	Subtotal	Unknown	Total
Moving, handling and postural management	135	16	**151**	70	**221**
Technology support	134	13	**147**	74	**221**
Support for safe eating and drinking	135	12	**147**	74	**221**

It was notable that in a third of responses for each pathway this was not known.

Training for **care workers** in aspects of management for children and young people with cerebral palsies was reported not to be provided in the community paediatric care questionnaire in 27/76 organisations.

Training for **other professionals** providing services for **disabled children, young people and their families** (e.g. doctors, therapists, teachers, social workers, health visitors, school staff, leisure providers etc.) was reported in the community paediatric care questionnaire to be provided in only 53/78 organisations. Disabled children, young people and their families were reported to be involved in delivering this training in only 7/53 organisations.

Training for **other professionals** providing services for **disabled young adults** and their families (e.g. doctors, nurses, allied health professionals, social workers, education staff, leisure providers, support workers etc.), was reported to be provided in the adult outpatient care questionnaire in only 13/47 organisations. Disabled young adults and their families were reported to be involved in delivering this training in only 2/13 organisations.

The data highlighted that the provision of such training was much less in adult services compared with paediatric services.

Involving families in the design of services

Systems were reported to be in place for the views of children and young people to inform service design and delivery to a variable extent from different lead's perspectives, as shown in Table 4.8.

Systems were reported to be in place for the views of parent carers and families to inform service design and delivery to a variable extent from different perspectives, as shown in Table 4.9.

Patient and parent carer survey

Forty three parent carers who had children aged 2-25 years, and 11 young people aged 12-16 gave their views. The majority of participants lived in England but responses also came from those living in Wales and Scotland.

In relation to the health services they had experienced, the survey asked for three things that could be improved and three things that had gone well.

Things that could be improved

The most common themes were:

- Problems with access to services, particularly physiotherapy and occupational therapy
- Provision of information, waiting times for appointments and wheelchair services
- Poor communication from and between healthcare professionals
- Provision of equipment and orthotics
- Suitable access and equipment in healthcare settings, such as hoists and appropriate beds.

Table 4.8 Children and young people were involved in the service design

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Paediatric surgical inpatient care	Adult outpatient care	Adult inpatient care	Emergency department care
Yes	49	38	62	56	18	24	49
No	30	40	22	25	24	22	39
Subtotal	**79**	**78**	**84**	**81**	**42**	**46**	**88**
Not answered	5	3	6	9	11	20	4
Total	**84**	**81**	**90**	**90**	**53**	**66**	**92**

Table 4.9 The views of parent carers and families to inform service design were considered

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Paediatric surgical inpatient care	Adult inpatient care	Emergency department care
Yes	53	47	68	60	25	39
No	27	32	15	19	21	50
Subtotal	**80**	**79**	**83**	**79**	**46**	**89**
Not answered	4	2	7	11	20	3
Total	**84**	**81**	**90**	**90**	**66**	**92**

Things that went well

For both patients and parent carers, physiotherapy, occupational therapy and speech and language therapy were all mentioned positively. The relationship and support of particular healthcare professionals and services was noted frequently. Orthotics and provision of equipment was felt to be good.

When asked about whether the professionals working with their child/young person listen to them and and take account of their views in decision-making, 22 parents said that most professionals listened to the child/young person and 27 stated that they listened to the parent carer. However, 14 felt that most professionals do not listen to the child/young person and 10 stated that most professionals did not listen to the parent carer. From the children responding five felt that most health professionals working with them listened to them and took account of their views in decision-making; three felt that most did not listen to them.

In relation to **transition** five parents indicated that the child/young person had moved from children's to adults' services, four of whom felt that it had not worked well and one felt that it had gone quite well. Seven people responded to the question about the care in adult services compared to children's services. Of these, four thought that it was not as good as in children's services and three thought it was non-existent.

In relation to **other services outside of healthcare** they had experienced, such as education, social care, voluntary organisations and independent services, the survey asked for three things that could be improved and three things that had gone well.

Things that went well

Outside of a healthcare setting, school, sports clubs and youth clubs were popular. Technology, such as laptops, and equipment, including wheelchairs, extra time in exams and orthotics were also noted as positive actions. Parents most commonly mentioned education and access to youth clubs, sports and day centres were important.

Things that could be improved

Access to equipment was felt to be a problem, both everyday and equipment for participating in sport. More support and access in education was mentioned and this covered support whilst in school but, for some, access to a school instead of home schooling.

Parents felt support was needed at school, such as adjustments, equipment, extra time in exams and better understanding. Closer working between health and education and access – to buildings, transport, changing facilities, education, activities, short breaks, places of interest, social activities, employment, equipment, funding.

Care and kindness always

Case note reviewer reported documentation of family upset at their child repeatedly being handled "like a lump of meat" and another reported documentation of family upset when their child was described as a "bed blocker" on the intensive care unit.

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.

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5 – Diagnosis

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Study Advisory Group questions: *Are there delays in diagnosis? Is there variation in how the cerebral palsies are described?*

Why is this important? *Timely diagnosis of a cerebral palsy matters so that early interventions can be accessed and all reasonable adjustments put in place to facilitate the best possible participation in everyday activities.*

The diagnosis of a cerebral palsy is clinical, based on specific findings on medical, developmental and family history and on clinical examination. A cerebral palsy is not the same as 'any physical disability of any cause', but is a very precise and specific diagnosis. It is important to distinguish the cerebral palsies from other conditions that may masquerade as such, but which have very different clinical courses and implications for management. These include, progressive, neurodegenerative conditions, hereditary spastic paraplegias and situations where a child's development arrested at a stage before motor skills were acquired and has stopped progressing further, leading to postural changes and contractures due to disuse. The Surveillance of Cerebral Palsy in Europe's Reference and Training Manual provides clear guidance on the diagnostic assessment process to be undertaken.[16] In addition, red flags for other neurological conditions and risk factors for the cerebral palsies are detailed in the NICE Guideline NG62.[19]

Timely diagnosis

A timely diagnosis is one that is made as early as possible in the child's life. The majority of children with a cerebral palsy will receive their diagnosis by three years of age,[20] although this will vary in individual circumstances and will depend on the severity of motor impairment, with those with the most severe motor impairment being identified earliest. For some infants, for example those born prematurely, the clinician may use the term 'probable emerging cerebral palsy' during the period in the early months when neurological signs can fluctuate, to avoid over-diagnosis in those whose neurological signs subside over time, but also to facilitate early interventions.

Whilst routinely collected population datasets do not record the time of diagnosis, 60% of cases of a cerebral palsy first appeared within CPRD (England HES linked) dataset before the age of five years, 38.5% before the age of two years. The North of England Collaborative Cerebral Palsy Survey data, showed that the diagnosis of a cerebral palsy was made before the age of two years in 73% (293/398) of cases. There is therefore an apparent delay between the diagnosis of a cerebral palsy recorded in routine national datasets and within the cerebral palsy registers (the latter is influenced by the rules of the register i.e. the data capture points, which can vary between registers.)

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.

A delay in diagnosis was reported by the case reviewers in 19/193 (9.8%) of the case notes reviewed. Where the diagnosis was made in the last three years (n=46), lead clinicians who returned a questionnaire indicated there had been a delay in diagnosis in five patients.

Description of tone variation and pattern of motor impairment

Precision of description of tone variation and pattern of motor impairment are well described in the Surveillance of Cerebral Palsy in Europe Reference and Training Manual[16] and are very important in informing accurate management across settings and ensuring the best outcomes.

Documentation of the patient's specific cerebral palsy diagnosis was recorded by the case reviewers in 430/540 (79.6%) cases, no such documentation in 110/540 cases (20.4%), unable to answer was recorded in 15/554 cases. 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, whilst in a further 76/521(14.6%) only the term 'bilateral cerebral palsy' was used, but the tone variation was not described. The diagnostic term did not include information about the specific tone variation in 297/521(57%) cases. Table 5.1 shows whether a diagnosis was documented, by age of the patient as reported by the case reviewers.

Table 5.1 Documentation of the patient's specific cerebral palsy diagnosis by age

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	79	116	84	84	68	**431**
No	18	5	20	21	36	**100**
Subtotal	**97**	**121**	**104**	**105**	**104**	**531**
Not answered	1	6	3	2	1	**13**
Total	**98**	**127**	**107**	**107**	**105**	**554**

Routinely collected data about a cerebral palsy diagnosis

Challenges in identifying those with cerebral palsies from routinely collected population data included:

1. Lack of specificity of ICD-10 and Read version v2 codes used. The most common code used for the cerebral palsies was G80.9 (cerebral palsy unspecified) in CPRD (England HES linked data); analysis by a cerebral palsy type was therefore not possible. G80.9 was used for:
   - 41% of all inpatient episodes
   - 71% of outpatient attendances (for the few cases where disease coding for a cerebral palsy was available)
   - 87% of patients who died
2. For some children and young people, multiple codes were used
3. Cerebral palsies were rarely coded at every point of contact with NHS services
4. Different codes were used on different occasions for the same child or young person.

To enable a summary of the variation in coding used, READ v2 codes used were mapped on to ICD-10 'group' codes for the GP data (Appendix 3). For the 8,965 patients with cerebral palsies identified within CPRD GP dataset,

- 77% (6,884) were coded from one group code (G80-G83 or equivalent Read code), across all contacts, the majority (94%) of which (6,472) included a G80-G83 code, of those, 68.9% (4,463) were coded exclusively with a G80 code.
- In 22% a combination of two group codes were used over time and three or more different codes were used for 1% of cases.

Of all children and young people with cerebral palsies identified in CPRD dataset, cerebral palsies were only coded at one time point in all of the person's contacts with NHS in 36.4% (3,265/8,965) (G80-83.3 or equivalent Read v2) of cases at any time during the study period, most of these cases appeared in CPRD GP data (2080 (63.7%) and 1185 (36.3%) from England HES data).

Availability and use of magnetic resonance imaging

MRI neuroimaging is an important tool for understanding the causal pathway of a cerebral palsy and it can highlight some important conditions with different management implications that may be missed, such as developmental brain anomalies and neurometabolic conditions. Guidelines for the use of MRI have been issued by the American Academy of Paediatrics[21] who recommend neuroimaging for all children where a diagnosis of a cerebral palsy is being considered and NICE guidance NG62[19] recommends neuroimaging only when it is not clear how the cerebral palsy came about.

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.

CASE STUDY 3

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.

Within the population-based North of England Collaborative Cerebral Palsy Survey (NECCPS) 56% (239/429) of patients (<12 years of age and born between 1995 and 2002) with cerebral palsies had MRI neuroimaging. These data were recorded inconsistently in the Northern Ireland Cerebral Palsy Register. A review of the prevalence of MRI neuroimaging was attempted within CPRD GP and HES linked data, however a generic code for MRI was most frequently used which may have included MRI neuroimaging. The data were imprecisely coded and thus unlikely to give a true representation of the situation.

Variation in MRI scan reporting matters when considering neuroimaging in children and young people with cerebral palsies. If accurate information is to be gleaned from the imaging about likely causation of the cerebral palsy, correct identification of any clues to timing of the disruption to the developing brain as well as an accurate description of the pattern of brain disruption are essential.[22] MRI neuroimaging was reported in the organisational surveys to be offered as either routinely of selectively depending on clinical assessment (Table 5.2). There was also wide variation in access to neuroradiological expertise for neuroimaging reporting, where it existed, with a split between routine provision and ad hoc provision with 133/193 (68.9%) providing routine provision.

Table 5.2 Provision of MRI for patients suspected of having a cerebral palsy

	Paediatric outpatients	Paediatric community
Routinely	43	50
Selectively depending on clinical assessment	37	27
Subtotal	**80**	**77**
Not answered	3	1
Total	**83**	**78**

Figure 5.1 shows access and lack of access to Magnetic Resonance Imaging without sedation, with sedation and under general anaesthetic as reported by organisational leads for different pathways of care. Often the default position was to use general anaesthetic.

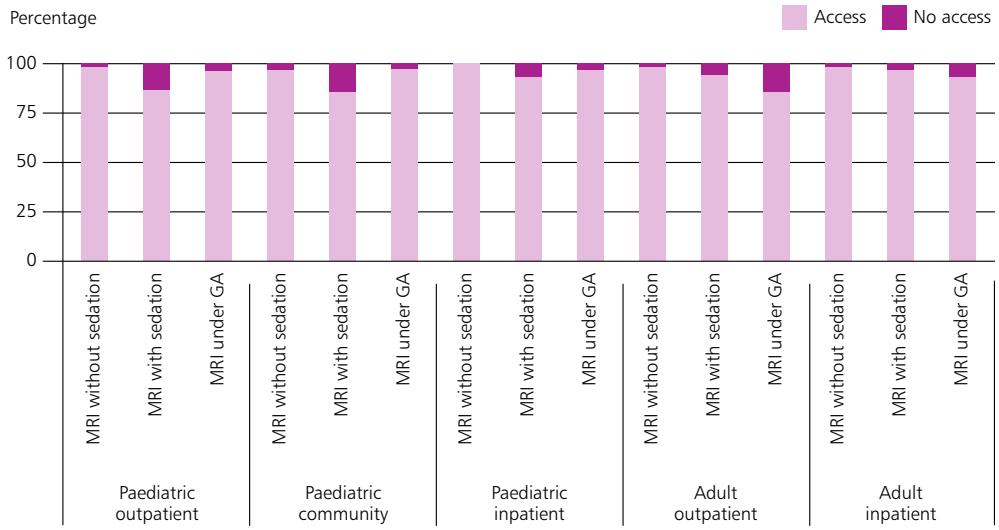

Figure 5.1 Availability of MRI neuroimaging by use of sedation or general anaesthesia

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.

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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.

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6 – Communication

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Study Advisory Group question: *How well are care plans communicated to patients and their families?*

Why is this important? *Good communication underpins all clinical practice and is encouraged by the:*

- *General Medical Council's 2015 Duties of a Doctor guidance "You must listen to patients, take account of their views and respond honestly to their questions"*[23]
- *UK National Health Service's constitution: "Staff should aim to be open with patients, their families, carers or representatives, including if anything goes wrong; welcoming and listening to feedback and addressing concerns promptly and in a spirit of co-operation"*[24]
- *Good doctor-patient communication correlates positively with increased patient satisfaction.*[25]

Communication about diagnosis

Communication between families and professionals at the start of the clinical journey sets the scene and is remembered. NICE Guideline NG62[19] makes recommendations about the information and support that professionals should share with families on an ongoing basis. SCOPE (previously known as the Spastics Society) produced guidance on 'sharing the news' of a child's disability, known as 'Right from the Start'.[3] Data from the paediatric inpatient and community care questionnaires reported that 'Right from the Start' or equivalent guidance was embedded in general paediatric practice in only 27/80 organisations and in community paediatric practice in only 46/75 organisations. Specific training in 'Right from the Start' or equivalent guidance for those communicating disability diagnoses had been delivered for general paediatric teams in only 25/82 organisations and for disability or community paediatric teams in only 19/75 organisations. Parents were reported to be given written information about the diagnosis by general paediatric teams in only 51/81 organisations in only 57/73 organisations completing the community paediatric care questionnaire.

Data from the community paediatric care organisational questionnaire indicated that parents were provided with sources of support and information locally in 66/74 organisations and nationally in 60/74 organisations.

Leads for the disability care for individual patients reported that the patient and family had been given written information about their cerebral palsy and associated health conditions in 115/154 cases, but not in 39/154. This was unknown for 67/221. Of GPs who responded, 7/9 reported their patients had been given adequate written information about their cerebral palsy and associated conditions and 15/23 patients this was unknown.

Communication with the patient and family

In their opinion, case reviewers reported that sufficient effort had been made to communicate directly with 156/245 (63.7%) patients. The patient's preferred communication method had been ascertained for 159/275 (57.8%) patients, which varied with age as shown in Table 6.1.

Reviewers reported evidence that the patient was, where possible, included in all discussions and decision-making about them, including where appropriate in the consent process for 91/180 admitted patients and 48/97 day case patients. Documentation of inclusion of the patient in discussions and decision-making in the opinion of the case reviewers is shown in Table 6.2. 11

Table 6.1 Preferred communication method ascertained, by age - reviewers' opinion

	1-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	25	50	33	26	25	**159**
No	17	31	26	26	16	**116**
Subtotal	**42**	**81**	**59**	**52**	**41**	**275**
Unable to answer	0	6	5	9	4	**24**
Not applicable	21	10	7	9	4	**51**
Total	**63**	**97**	**71**	**70**	**49**	**350**

Table 6.2 Documentation of inclusion of patient in discussions and decision-making - reviewers' opinion

	Admitted patients		Day case patients	
	n=	%	n=	%
Yes	120	40.0	59	39.9
No	180	60.0	89	60.1
Subtotal	**300**		**148**	
Unable to answer	52		34	
Total	**352**		**182**	

There was room for improvement in the documentation of inclusion of the parent carers in discussions and decision-making in the opinion of the case reviewers for only 50/206 (24.3%) patients.

Documentation of decision-making for the patient could have been better, in the opinion of case reviewers, for 106/236 (44.9%) patients. Reviewers were unable to answer in 116/352 cases reviewed. Table 6.3 shows whether documentation of decision-making for the patient could have been better by age group.

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.

Table 6.3 Clarity of documentation of decision-making by patient's age - reviewers' opinion

	1-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	5	20	17	22	42	**106**
No	31	30	27	19	23	**130**
Subtotal	**36**	**50**	**44**	**41**	**65**	**236**
Not answered	21	35	21	28	11	**116**
Total	**57**	**85**	**65**	**69**	**76**	**352**

Communication in an emergency – Emergency Health Care Plans/Emergency Care Summary (Scotland)

There is evidence that parents and families have a strong preference not to keep having to tell their child or young person's story endlessly to new people and this is most frustrating of all in an emergency.

Paediatricians worked with the Council for Disabled Children to produce training materials about Emergency Health Care Planning, including video exemplars of the communication required to underpin such plans.[26] Training resources to underpin advance care planning can also be found in the 'Disability Matters' resources.[27]

Variations were reported in whether (or not) systems were in place for the preparation of such emergency plans for patients with the most complex medical/surgical needs (Table 6.4).

Table 6.4 An agreed system in place for preparing written Emergency Health Care Plans

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Adult outpatient care	Adult inpatient care	Emergency department care
Yes	58	66	67	24	35	69
No	23	11	20	21	13	20
Subtotal	**81**	**77**	**87**	**45**	**48**	**89**
Not answered	3	4	3	8	18	3
Total	**84**	**81**	**90**	**53**	**66**	**92**

Table 6.5 Emergency Health Care Plans were available in different formats

	Paediatric outpatient care	Community paediatric care	Adult outpatient care	Adult inpatient care
Yes	34	26	17	26
No	45	50	24	18
Subtotal	**79**	**76**	**41**	**44**
Not answered	5	5	12	22
Total	**84**	**81**	**53**	**66**

Table 6.5 shows whether Emergency Health Care Plans and other communications were available in other languages or formats. For both the existence of, and the availability of format, it can be seen that they were not as frequent in the adult services as paediatric services.

Systems in place for recording Emergency Health Care Plans were not well embedded. In 5/69 organisations written advice about care on presentation to the emergency department was not present. Senior emergency department clinicians were not involved in setting up systems for

emergency health care planning in 27/69 organisations and Emergency Health Care Plans were reported to be fully accessible for disabled people and their families in only 47/87 organisations.

Table 6.6 shows where there was evidence in the notes and/or admission questionnaire that the team treating the patient on admission had access to an Emergency Health Care Plan or similar document that recorded what had been previously discussed about appropriate levels of intervention, variation from advanced life support guidance, treatment limitations.

Table 6.6 Access to an Emergency Health Care Plan or similar - reviewers' opinion

	n=	%
Yes – Emergency Health Care Plan present in the clinical case notes for the recent admission	24	7.9
Yes – Emergency Health Care Plan recorded as available in the admission questionnaire	20	6.6
No evidence of the existence of an Emergency Health Care Plan or similar	202	66.2
NA – Emergency Health Care Plan not appropriate in this patient	59	19.3
Subtotal	**305**	
Not answered	47	
Total	**352**	

Case note reviewers found evidence of an Emergency Health Care Plan or similar document in just 7.9% of records and data from the clinical questionnaire that this would have been available in 12.7% based on information provided by admitting responsible clinicians. Whilst Emergency Health Care Plans are not appropriate in all admission scenarios, the majority of patients in this study, where GMFCS level was documented, were felt to have motor function at GMFCS level V i.e. those most likely to have the most complex needs, where such a plan may be particularly important and useful.

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.

Resuscitation status

Admitting clinicians were asked whether, where appropriate, the resuscitation status of the patient was recorded at the point of admission. In 169/232 (72.8%) patients this was recorded but in a further 96 patients it was unknown (Table 6.7).

Table 6.7 Resuscitation status (where appropriate) was recorded on admission

	n=	%
Yes	169	72.8
No	63	27.2
Subtotal	**232**	
Unknown	96	
Not applicable	177	
Not answered	31	
Total	**536**	

Table 6.8 Resuscitation status at the point of admission was clear, by urgency of admission

	Yes	No	Subtotal	Unknown	Not applicable	Not answered	Total
Emergency (including urgent)	124	52	**176**	53	94	14	**337**
Elective (including planned)	38	8	**46**	39	74	13	**172**
Subtotal	**162**	**60**	**222**	**92**	**168**	**27**	**509**
Not answered	7	3	**10**	4	9	4	**27**
Total	**169**	**63**	**232**	**96**	**177**	**31**	**536**

Documentation of resuscitation status was reported to be less well done in patients with a cerebral palsy admitted as an emergency. This was clear on emergency admission in 124/176 (70%) patients, compared to 38/46 patients admitted electively (Table 6.8).

The number of elective admissions was relatively small but this finding might be explained by there being more time for consideration of resuscitation status when an admission is planned, and possibly the risk of deterioration being more routinely considered when a patient is admitted for particularly major surgery. Lack of clarity on the part of the admitting team about escalation of care in the face of an acute and severe deterioration in health may cause real problems in an emergency setting for patients with ongoing major complex needs. The admitting clinicians will usually be less familiar with the patient's underlying condition.

A 'Do Not Attempt Cardiopulmonary Resuscitation' or similar Personal Resuscitation Plan was reported to be in place by 41/271 (15.1%) case reviewers, with evidence that this was validated with the patient and their family at the time of admission for only 21/36 patients.

CASE STUDY 6

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.

Lead clinicians for disability care reported documented discussions with the patient and their family or primary carers about appropriate levels of intervention for only 85/183 patients, and this was unknown for 38/221. The outcome of this discussion was no limitation to interventions, with full resuscitation and intensive care as required for 56/84 patients, limitation to treatment, with no intubation or intensive care for 17/84 and 'other' for 11/84.

Emergency Health Care Plans should be proactively drawn up with the family and in discussion with the MDT who knows the person best. This should include a statement as to what had been discussed and agreed about levels of intervention, including a resuscitation decision, either within the plan itself or on a separate template, as per local policy. This can facilitate communication with changing junior doctors and saves families from telling their stories again on each occasion. This also encourages families to share their views on appropriate levels of intervention in the circumstances.

Capacity assessment for young people aged 16 years and over

The Mental Capacity Act 2005 in England and Wales states that when there are concerns that a young person aged 16 years or older who may have an impairment of their brain or mind, which may affect decision-making at a particular time and in a particular context, then an assessment should be made of their capacity in relation to that decision. Similar legislation exists in Scotland and Northern Ireland. The extent to which mental capacity was routinely assessed according to this legislation was variable (Table 6.9).

Evidence that an assessment of mental capacity was made was reported by reviewers for only 42/135 patients. Variation in whether documentation of decision-making could have been better varied with the age of the patient, as shown in Table 6.10.

Table 6.9 Mental capacity was routinely assessed

	Emergency department care	Paediatric inpatient care	Adult inpatient care	Adult outpatient care
Yes	69	50	39	30
No	17	38	4	12
Subtotal	**86**	**88**	**43**	**42**
Other	NA	NA	4	NA
Not answered	6	2	19	11
Total	**92**	**90**	**66**	**53**

Table 6.10 Assessment of whether documentation of decision-making could have been better, by age - reviewers' opinion

	1-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	5	20	17	22	42	**106**
No	31	30	27	19	23	**130**
Subtotal	**36**	**50**	**44**	**41**	**65**	**236**
Not answered	21	35	21	28	11	**116**
Total	**57**	**85**	**65**	**69**	**76**	**352**

Best-interests decision-making

Leads for different aspects of service reported variation in whether (or not) a best interests decision-making process was embedded in practice for those patients assessed as not having capacity to make a specific decision at a specific time and in a specific circumstance, as shown in Table 6.11. 12

Children, young people and competent young adults were reported to be routinely included in the decision-making and consent process. They were assisted to complete written consent where possible, as appropriate to their level of understanding prior to surgery or invasive procedures in 75/84 organisations providing paediatric inpatient care and in 43 organisations providing adult inpatient care.

Table 6.11 A best interests decision-making process was embedded for young people aged 16 years or older

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Adult outpatient care	Adult inpatient care	Emergency department care
Yes	47	44	57	34	40	68
No	30	33	27	9	8	16
Subtotal	**77**	**77**	**84**	**43**	**48**	**84**
Not answered	7	4	6	10	18	8
Total	**84**	**81**	**90**	**53**	**66**	**92**

Communication between professionals

Leads for the patient's inpatient care reported that the admitting team did not have ready access to the patient's community records and clinic letters regarding their cerebral palsy at the time of admission for 122/414 (29.5%) patients and this was unknown for 122/536 patients Access to these community/disability notes varied with age, as shown in Table 6.12.

Data from the emergency department (ED) organisational questionnaire indicated that ED summaries were routinely copied to the GP in 88/89 organisations, to the usual lead clinician in only 12/89 organisations, to the usual therapists in even fewer: 7/89 organisations and to the family or disabled person in just 15/89 organisations.

Table 6.12 Access to community records by age

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Subtotal	Not answered	Total
	n=	n=	n=	n=	n=	n=	n=	n=
Yes	65	87	73	34	31	290	2	**292**
No	17	20	13	28	42	120	2	**122**
Subtotal	**82**	**107**	**86**	**62**	**73**	**410**	**4**	**414**
Unknown	18	18	13	26	32	107	4	**111**
Not answered	0	3	1	3	2	9	2	**11**
Total	**100**	**128**	**100**	**91**	**107**	**526**	**10**	**536**

Communication with the patient's wider multidisciplinary team about aspects of their health and wellbeing whilst they were inpatients was reported by case reviewers to be inadequate for 137/285 (48.1%) patients. This also varied by age, as shown in Table 6.13.

Organisational data from the paediatric and adult inpatient care questionnaires indicated that discharge planning meetings were held that included the patient's usual healthcare team as shown in Table 6.14.

There was evidence of multidisciplinary discharge planning as reported by case reviewers for only 50/144 (34.7%) patients. Reviewers could not answer for 25/169 patients. It is important to note that multidisciplinary discharge planning will only be needed for complex patients. 10

Variation in the reported adequacy of communication on discharge by case reviewers is shown in Tables 6.15 and 6.16. The data highlighted that communication was relatively good with patients and their GP, but lacking for the wider multidisciplinary team. This is particularly important for day case patients as they will need timely intervention with physiotherapy, but if the physiotherapists, for example, are not alerted to the patient's needs, they will not know to make contact.

Where discharge was to a community setting, Table 6.17 shows where written communication was directed.

Table 6.13 Communication with the patients' wider multidisciplinary team, by age - reviewers' opinion

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	33	37	33	28	17	**148**
No	18	32	21	20	46	**137**
Subtotal	**51**	**69**	**54**	**48**	**63**	**285**
Unable to answer	6	16	11	21	13	**67**
Total	**57**	**85**	**65**	**69**	**76**	**352**

Table 6.14 Discharge planning included the patient's usual healthcare team

	Paediatric inpatient care	Adult inpatient care
For all paediatric/surgical inpatient episodes lasting a specified number of weeks	8	10
For all inpatient episodes where the young adult's needs have changed significantly since admission	23	25
On an ad hoc basis	57	24
Rarely	1	2
Never	1	0
Subtotal	**88**	**50**
Not answered	2	16
Total	**90**	**66**

**Answers may be multiple*

Table 6.15 Adequate communication on discharge to the community from inpatient care for admitted patients - reviewers' opinion

Admitted patients	Patient and their family		General practitioner to the community		The lead clinician for cerebral palsy management		The patient's usual MDT		Community physiotherapy services	
	n=	%	n=	%	n=	%	n=	%	n=	
Yes	244	93.1	242	86.7	120	53.8	84	42.9	70	38.0
No	18	6.9	37	13.3	103	46.2	112	57.1	114	62.0
Subtotal	**262**		**279**		**223**		**196**		**184**	
Unable to answer	43		34		57		75		84	
Not applicable	44		36		21		27		30	
Not answered	3		3		51		54		54	
Total	**352**		**352**		**352**		**352**		**352**	

Table 6.16 Adequate communication on discharge to the community for day case patients - reviewers' opinion

Day case patients	Patient and their family		General practitioner to the community		The lead clinician for cerebral palsy management		The patient's usual MDT	Community physiotherapy services
	n=	%	n=	%	n=	%	n=	n=
Yes	130	92.9	127	84.1	45	41.7	27	30
No	10	7.1	24	15.9	63	58.3	66	62
Subtotal	**140**		**151**		**108**		**93**	**92**
Unable to answer	40		24		49		53	46
Not applicable	0		2		14		23	30
Not answered	2		5		11		13	14
Total	**182**		**182**		**182**		**182**	**182**

Table 6.17 Groups provided with written discharge information

	n=	%
General practitioner	422	94.2
Lead clinician for cerebral palsy care	87	19.4
Community allied health professionals	69	15.4
Community care medical and nursing staff	56	12.5
No discharge summary in the notes	22	4.9
Social care	12	2.7
Palliative care team	7	1.6
Subtotal	**448**	
Not answered	34	
Total	**482**	

The written communication was reported by lead clinicians for inpatient care to include a clear discharge plan for 448/478 (93.7%) patients. This was not answered for 58/536. The patient and family were copied in to the discharge plan for 327/384 (96.2%) patients. This was unknown for 64/448. The written communication included input from all relevant members of the multidisciplinary team providing care during admission for only 210/391 (53.7%) patients, and was unknown for 145/536. The written communication included information to all relevant members of the multidisciplinary team providing care to follow admission for just 190/368 (51.6%) patients, and was not known for 168/536. 10

Lead clinicians for disability care reported that they were made aware of the acute admission for just 108/197 (54.8%) patients, this was unknown for 24/221.

Lead clinicians for disability care reported being made aware of or copied in to discharge summaries and further planning for only 112/200 (56%) patients. This was unknown for 21/221.

Lead clinicians for disability care reported there to have been ongoing communication between different healthcare providers e.g. acute, community, specialist, including in regional or national centres, therapies etc. for 186/207 (89.9%) patients, but not for 21/207. This was unknown for 14/221.

Data from the inpatient allied health professional paediatric inpatient care questionnaire indicated that communication between allied health professionals providing inpatient care for disabled children and young people and allied health professionals who provide usual outpatient or community care routinely occurred by telephone or email in 45/62 organisations, by a written report on discharge in 11/62 and on an ad hoc basis in 12/62. Data from the adult allied health professional inpatient care questionnaire indicated such communication to occur routinely by telephone or email in 27/51 organisations, with a written report on discharge for 23/51 organisations and on an ad hoc basis for 5/51.

Data from the adult outpatient care questionnaire indicated that organisations had clear policies in place to ensure continuity of patient care, including close handover between professionals and familiarisation with case histories, at all interfaces and points of transition of care in only 17/43 organisations.

Case note reviewers assessed the overall adequacy of communication regarding the patient's healthcare during the admission as shown in Figure 6.1.

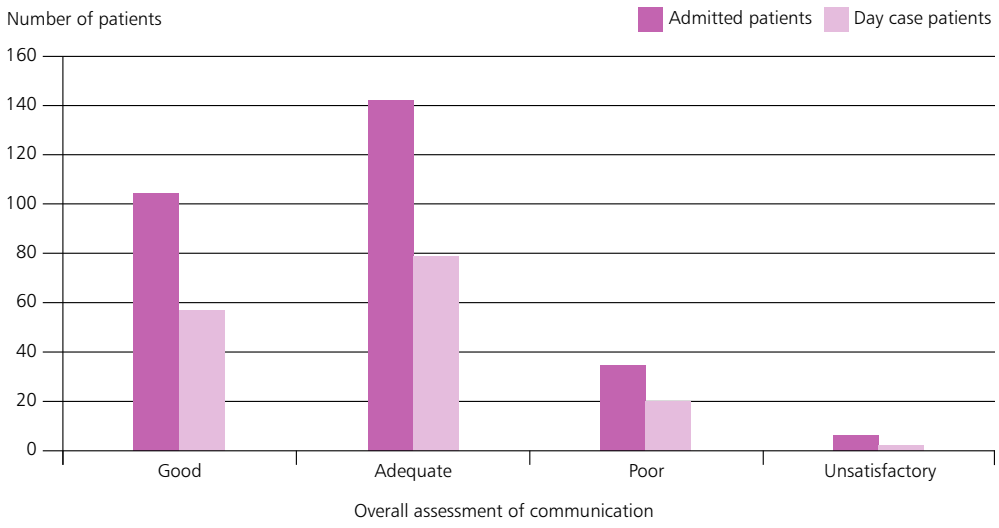

Figure 6.1 Overall quality of communication about patient healthcare during the inpatient admission - reviewers' opinion

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.

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7 – Multidisciplinary care

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Study Advisory Group question: *Are robust frameworks of multidisciplinary care always available within the service provision?*

Why is this important? *Patients with a cerebral palsy have complex needs, requiring input from different specialties at different points in their care. Underpinning this there should be a defined care pathway to ensure that all team members are aware of their needs. This requires good leadership that overlaps with primary care and social care whilst ensuring proper safeguarding.*

Leadership of multidisciplinary care

Every multidisciplinary team needs clear leadership to ensure excellent communication and effective co-ordination of care and this will depend on the age and level of disability. A lead clinician for disability care was reported to be in place by 351/403 (87.1%) leads for paediatric inpatient care, but was found to be documented in the case notes in only 240/380 (63.2%) of the cases reviewed for children and young people with cerebral palsies. Leads for care of adults with cerebral palsies reported a lead clinician for disability care to be in place in even fewer cases: 31/133 (23.3%) (Tables 7.1 and 7.2). 12

Table 7.1 Details of the patient's usual lead clinician for their cerebral palsy management was documented in the case notes – children (under 18 years of age) - reviewers' opinion

	Admitted patients		Day case patients	
	n=	%	n=	%
Yes - details recorded	162	66.1	78	57.8
No details recorded - no obvious usual lead clinician	56	22.9	36	26.7
Details not recorded	27	11.0	21	15.6
Subtotal	**245**		**135**	
Unable to answer	9		9	
Total	**254**		**144**	

Table 7.2 Details of the patient's usual lead clinician for their cerebral palsy management was documented in the case notes – adults (18 years of age or older) - reviewers' opinion

	Admitted patients	Day case patients
	n=	n=
Yes - details recorded	21	10
No details recorded - no obvious usual lead clinician	64	24
Details not recorded	10	4
Subtotal	**95**	**38**
Unable to answer	3	0
Total	**98**	**38**

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.

Table7.3 Access to a key worker by healthcare service

	Paediatric outpatient care	Community paediatric care	Allied health professional paediatric inpatient care	Adult outpatient care	Allied health professional adult inpatient care
	n=	n=	n=	n=	n=
Routinely available for disabled children/ young people and families	11	16	25	5	19
Only available for those with the most complex disabilities	46	44	21	20	13
Only available for pre-school children	4	11	NA	NA	NA
Not available	6	NA	15	16	15
Subtotal	**61**	**71**	**46**	**25**	**32**
Not answered	17	10	2	12	5
Total	**84**	**81**	**63**	**53**	**52**

The NICE guideline on cerebral palsy (NG62)[19] recommends timely, expert multidisciplinary care for everyone with a cerebral palsy. Access to a key worker or lead professional was reported to be variable in different care settings, as shown by the different organisational questionnaires in Table 7.3.

Care pathways underpinning multidisciplinary care

An agreed, written care pathway for assessment, diagnosis and management of children and young people with cerebral palsies was reported not to be in place by 56/82 organisations for paediatric outpatient care, by 42/81 leads in the organisational questionnaire for community paediatric care, and by 42/48 respondents of the adult outpatient care questionnaire.

Where pathways were in place, variation was reported in where care pathways for children and young people with cerebral palsies were published. This did not offer ease of access to referrers and parents (Table 7.4).

Table 7.4 Availability of care pathways

	Paediatric outpatient care	Community care
	n=	n=
Local Offer (England)	4	6
Organisation website	7	10
Written referral guidance for GPs, health visitors etc.	6	8
Not published	7	19
Other (please specify)	12	18
Subtotal	**23**	**39**
Not answered	3	0
Total	**26**	**39**

**Answers may be multiple*

Table 7.5 Content of care pathways

	General paediatric outpatient care	Community paediatric care	Adult outpatient care
	n=25	n=39	n=44
Hip surveillance	23	38	NA
Magnetic resonance imaging of the head +/- spine	19	25	NA
Anthropometric measurement and monitoring of growth and nutrition	23	25	NA
Spine monitoring and when to refer to spinal orthopaedic surgeon	23	25	NA
Pain identification and management	20	24	18

8 11

Table 7.6 Responsible clinician for hip and /or spine surveillance

	Hip surveillance		Spine surveillance	
	Paediatric outpatient care	Community care	Paediatric outpatient care	Community care
	n=	n=	n=	n=
Physiotherapist	50	49	49	51
General practitioner	3	2	1	2
Community paediatrician	59	59	53	55
General paediatrician	20	19	15	15
Disability paediatrician	24	36	27	37
Orthopaedic surgeon	46	45	43	40
Ad hoc hip surveillance	5	5	8	6
No standardised hip surveillance in place	7	6	8	2
Subtotal	**83**	**79**	**82**	**79**
Not answered	1	2	2	2
Total	**84**	**81**	**84**	**81**

**Answers may be multiple*

The details of what was reported to be written in the care pathway for children and young people with cerebral palsies is shown in Table 7.5.

Hospitals were asked to indicate which professionals in their hospital were responsible for **hip surveillance and spine surveillance for those patients at GMFCS level III-V**, the responses are shown in Table 7.6.

The term 'hip surveillance' covers a spectrum of practice, including unstructured, variable reviews to high quality, standardised, structured surveillance programmes such as that embedded across much of Scandinavia and also now across Scotland: the Cerebral Palsy Integrated Programme Scotland (CPIPS).[28] In Sweden where this was first developed and adopted, hip dislocation rates have fallen from 11% to 0.4% through earlier detection and proactive surgical intervention where necessary. Orthopaedic surgery for contractures has also reduced from 40% to 15% since the programme started. The programme encourages collaborative working between the child or young person, their family and clinical team. CPIPS is a national programme across all of Scotland, started in 2013, based around a centrally stored website accessible from NHS terminals all over Scotland. Structured assessments and measurements are undertaken by paediatric physiotherapists who have all undergone the same training programme, x-rays ordered and assessed, then a standard dataset is recorded in the CPIPS database. To date 1963 children and young people with cerebral palsies in Scotland are registered on the CPIPS, believed to be more than 95% of the population of children and young people with cerebral palsies in Scotland. More than 6000 assessments have been documented and more than 5000 x-rays reported on. A similar structured surveillance programme is being adopted in Northern Ireland. NHS England is leading a working group aiming to seek funding to adopt the same database as in Scotland, for use across England.

Lead clinicians for disability care reported that the patient's hip status was not documented in the case notes for 55/207 (26.6%) patients. Where hip status was documented, both hips were reported to be in joint for 69/136 (50.7%) patients, one or more hips were migrating out of joint for 38/136 (27.9%) patients, one or both hips were completely dislocated in 29/136 (21.3%) patients and hip status was unknown in 8/152 patients. For those patients at GMFCS level III-V, before skeletal maturity was reached, lead clinicians for disability care reported hip status was not documented at least annually in 26/113 (23%) patients, it was unknown for 47/174 patients and the question was recorded as not applicable for 14/174 patients.

The NICE guideline on cerebral palsy (NG62) is clear about the care pathways that should be accessible for all children diagnosed with cerebral palsies, with emphasis on early referral to an expert team for urgent multidisciplinary assessment (Recommendation 1.5.1), the requirement for care to be delivered by multidisciplinary and integrated local teams (Recommendation 1.5.3) that can network other specialist services easily as required (Recommendation 1.5.4).

Spine surveillance

If a scoliosis was identified, a referral was made to the spinal orthopaedic surgeon as reported in 81/83 organisational questionnaires for general paediatric outpatient care, in 74/78 organisational questionnaires for disability or community care and in 34/43 organisational questionnaires for adult outpatient care.

Lead clinicians for disability care reported the patient's current spine status to be straight in 88/156 (56.4%) patients, curved in 68/156 (43.6%) patients and unknown in 65/221 patients. Where a curve was present, there was evidence of regular input from a spinal orthopaedic surgeon for only 36/61 patients. For patients with cerebral palsies at GMFCS level III-V there was evidence of documentation of the status of the spine at least annually in 55/88 patients, but not in 33 patients and unknown in 75 patients.

Clinical delivery models

There was variation in care pathways reported in the organisational questionnaires for paediatric outpatient care, community paediatric care and adult outpatient care as shown in Table 7.7.

Table 7.7 Care pathways for children and young people with a cerebral palsy

	Paediatric outpatient care	Paediatric community care	Adult outpatient care
	n=	n=	n=
Non-specialist - seen as part of general clinical caseload	48	54	41
Specialist uni-disciplinary, i.e. each specialist sees the child or young people separately	51	61	17
Multidisciplinary for postural management	46	45	14
Multidisciplinary for feeding management	38	47	5
Outreach clinics in special schools	56	69	11
Other	41	32	15
Subtotal	**83**	**81**	**53**
Not answered	1	0	0
Total	**84**	**81**	**53**

**Answers may be multiple*

Quality of multidisciplinary care

The organisational data showed that whilst most organisations had access to physiotherapists and occupational therapists, some had no access at all to key multidisciplinary team members, including psychologists, continence practitioners, learning disability mental health teams and psychological support for patients and their families. NICE guideline NG62 is clear as to which practitioners should be involved in the expert multidisciplinary team for everyone with a diagnosis of a cerebral palsy.

Lead clinicians for disability care reported that the care of the patient was delivered by an appropriate multidisciplinary team in 205/215 (95.3%) patients. Where it was reported to not have been delivered appropriately, the specialty input that was reported to have been missing was learning disability in four patients, general medicine in three patients, trauma and orthopaedics in two patients, paediatric neurology in two patients, rehabilitation in two patients, general surgery pain management, child and adolescent psychiatry and respiratory medicine all one case.

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.

Table 7.8 shows the variation by age in person-centred, developmentally appropriate goal setting which considered body structure and function as well as activity and participation, as reported by clinical leads for disability care.

Table 7.8 Evidence of person-centred, age and developmentally appropriate goal setting

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Subtotal	Not answered	Total
	n=	n=	n=	n=	n=	n=	n=	n=
Yes	29	44	32	17	6	**128**	5	**133**
No	7	19	12	4	4	**46**	5	**51**
Subtotal	**36**	**63**	**44**	**21**	**10**	**174**	**10**	**184**
Unknown	8	13	6	5	3	**35**	2	**37**
Total	**44**	**76**	**50**	**26**	**13**	**209**	**12**	**221**

Access to physical therapies

Clinical leads for disability care considered that there was not timely and adequate adjunctive physical therapy after treatments involving botulinum toxin type A, continuous pump-administered intrathecal baclofen, orthopaedic surgery or selective dorsal rhizotomy (as per recommendation 1.2.15 of NICE Clinical Guideline 145: Spasticity in under 19's[29] in 13/113 (11.5%) patients. This question was not answered for 17/221 patients and not applicable in 91/221 patients. For those 13 patients, two children were 0-4 years old, three were 5-9 years old, four were 10-14 years old, one was 15-19 years old, and two were 20-25 years old. The therapist case reviewers noted the high number of patients who were reported to have received timely therapies and reflected that this may have been differently reported by the therapy leads than by the doctors. Case note reviewers reported evidence of adequate post-operative physiotherapy in only 194/342 (56.7%) cases reviewed. 6

Case note reviewers reported evidence of regular physiotherapy to support and build function and prevent impairment in only 221/309 (71.5%) patients. This varied with age as evidenced in Table 7.9.

Table 7.9 Regular physiotherapy by age - reviewers' opinion

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=	n=	n=
Yes	47	72	48	43	11	**221**
No	10	17	16	20	25	**88**
Subtotal	**57**	**89**	**64**	**63**	**36**	**309**
Unable to answer	6	8	7	7	10	**38**
Not answered	0	0	0	0	3	**3**
Total	**63**	**97**	**71**	**70**	**49**	**350**

Clinical management strategy

A clear, overall multidisciplinary clinical management strategy was reported to be in place by 179/215 (83.3%) lead clinicians and this was reported to have involved discussion with the patient and their family in all cases. For the 36/215 (16.7%) patients where the lead clinician reported no such strategy, six children were 0-4 years old, fourteen were 5-9 years old, five were 10-14 years old, two was 15-19 years old and seven were 20-25 years old. The age was not stated for two patients.

Leads for clinical inpatient care reported other teams to be involved in the daily care and management of the patient in 320/493 (64.9%) of cases. MDT meetings were reported to have occurred during the admission for only 77/453 (17%) patients. The results of these meetings were clearly documented in the shared notes during the admission in 62/73 patients and the patient and/or carer were made aware of the outcome of the discussions in 63 cases. This was not known for 14/77 patients.

The case reviewers assessed the quality of multidisciplinary care across four settings, and found room for improvement in all, with a marked increase in adult services (Figure 7.1). The overall quality of care of community and outpatient care is shown in Figure 7.2. 12

Data on primary care was not forthcoming from the organisational data and case review so the routine national data was used to build on the overall picture of care.

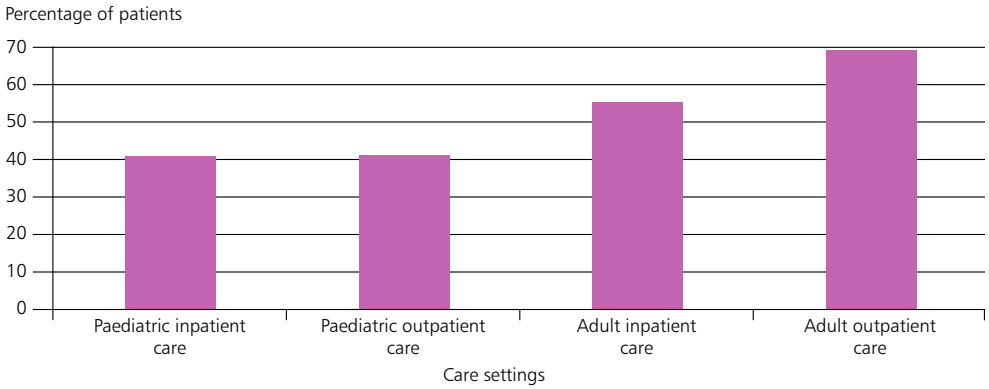


Figure 7.1 Room for improvement in multidisciplinary care - reviewers' opinion

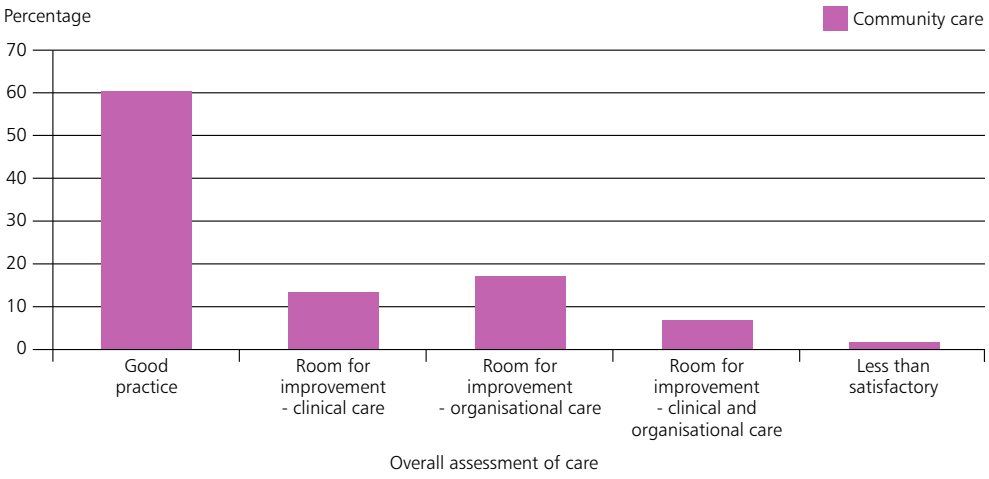


Figure 7.2 Overall assessment of care - community care - reviewers' opinion

General practice

Data to explore the interface between primary and secondary care for children and young people with cerebral palsies were available from CPRD for a sample of 6.9% of UK general practices, where data were linked to HES for an estimated 5.34% of GP practices in England. Overall consultation rates were calculated for all four countries within CPRD, with a more detailed analysis for England where the dataset was largest. In Wales, GP data were available from 70% of GP practices from WLGP linked to PEDW.

The rate of General Practice consultations followed the same trend for each country across the age groups. The highest referral rates were in the 0-4 and 20-24 year age groups. There were significant differences between the countries within each age group but there was no overall consistent trend seen for one country over another (Figure 7.3).

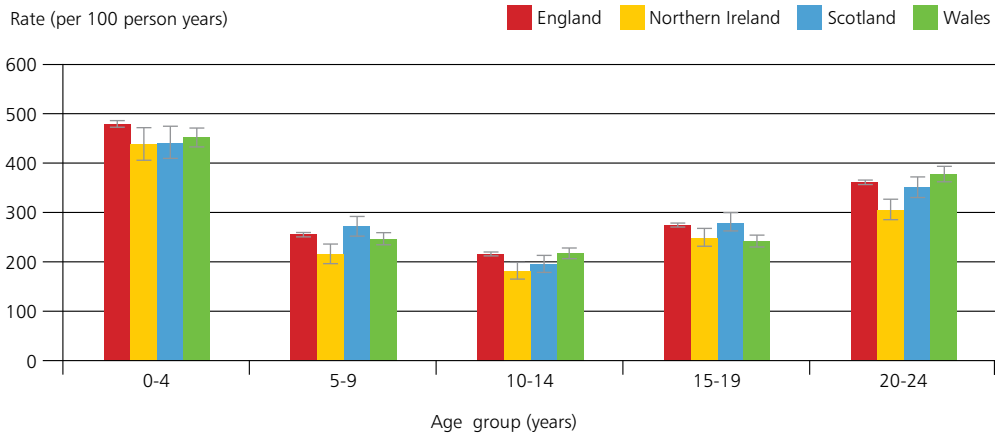


Figure 7.3 Rate of GP consultations (per 100 person years at risk) for patients with a cerebral palsy identified in CPRD GP data by age group

The annual rate of GP consultations for children and young people with a cerebral palsy (Figure 7.4) was greater than for those without a cerebral palsy (Figure 7.5). The trend of consultations was similar across the age groups for the two populations with the greatest rates for those of 0-4 and 20-25 years of age. The GP consultation rates remained relatively constant between 2004-2014 for both populations.

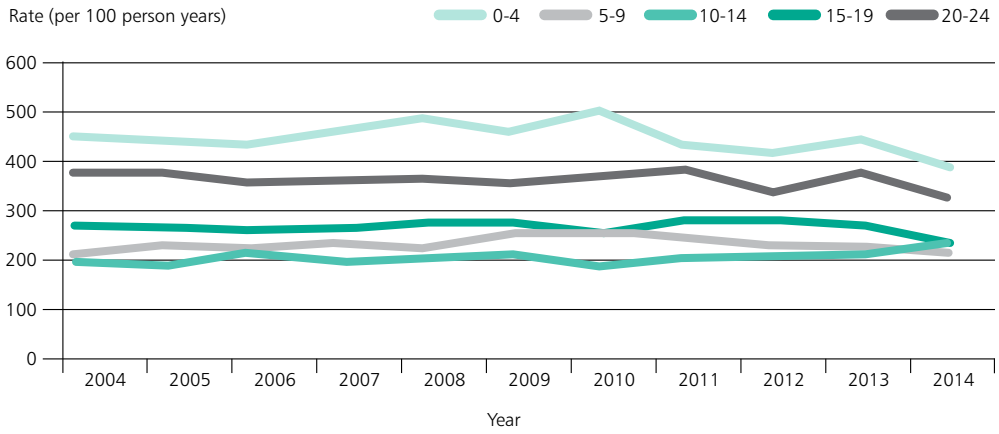
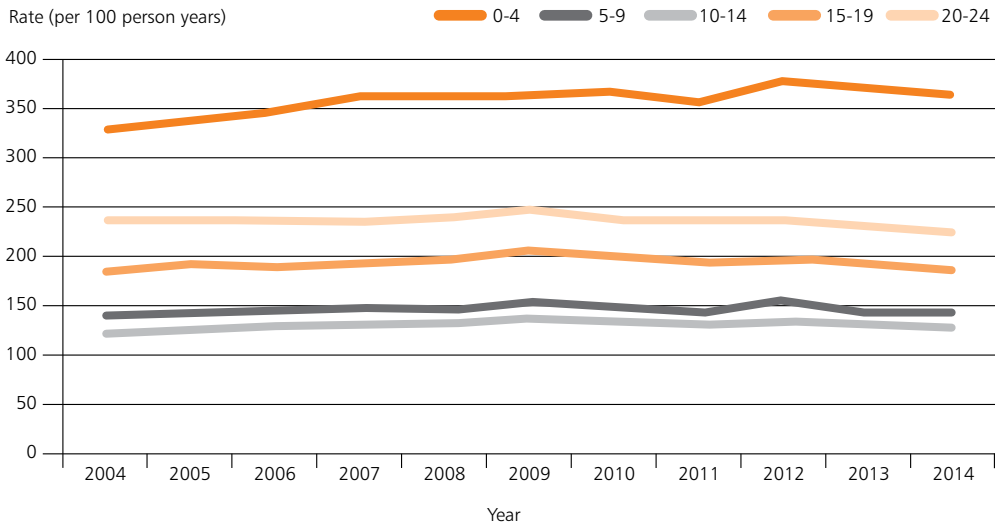


Figure 7.4 Rate (per 100 person years at risk) of GP consultations for children and young people with a cerebral palsy by year and age group (CPRD: England HES Linked)



Figures 7.5 Rate (per 100 person years at risk) of GP consultations for children and young people without a cerebral palsy by year and age group (CPRD: England HES Linked)

There was a small but steady increase in the consultation rate from the least to the most deprived quintile for children and young people without a cerebral palsy. This trend was not repeated for those with a cerebral palsy where there was no significant difference between the least deprived quintile and the two most deprived quintiles, the consultation rate dipped for the 2nd and 3rd quintile (Figure 7.6).

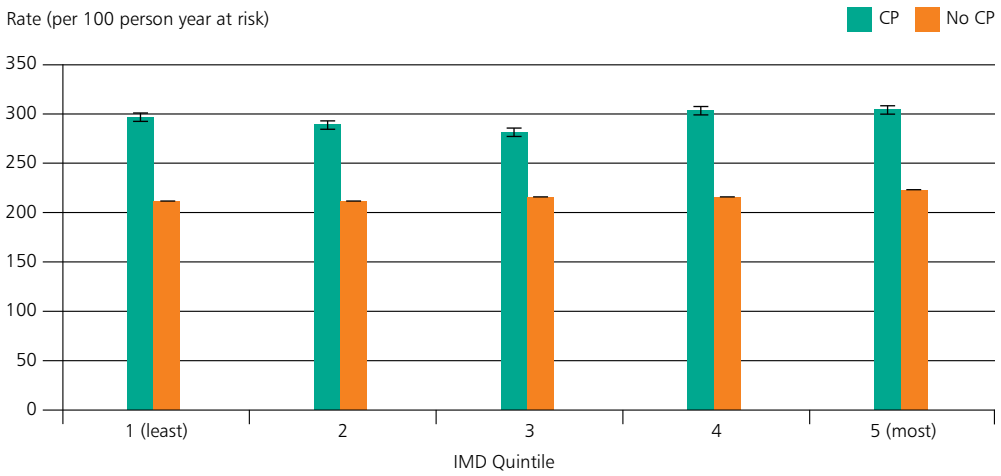


Figure 7.6 Rate of GP consultations (per 100 person years at risk) for children and young people with and without a cerebral palsy within each Index of Multiple Deprivation (IMD) quintile (CPRD: England HES Linked)

The median number and interquartile ranges of GP consultations per year are shown in Figure 7.7. Those with a cerebral palsy in all age groups having more consultations per year than those without (Figure 7.8) the highest numbers of consultations per years were seen in those of 0-4 years of age (Figure 7.9).

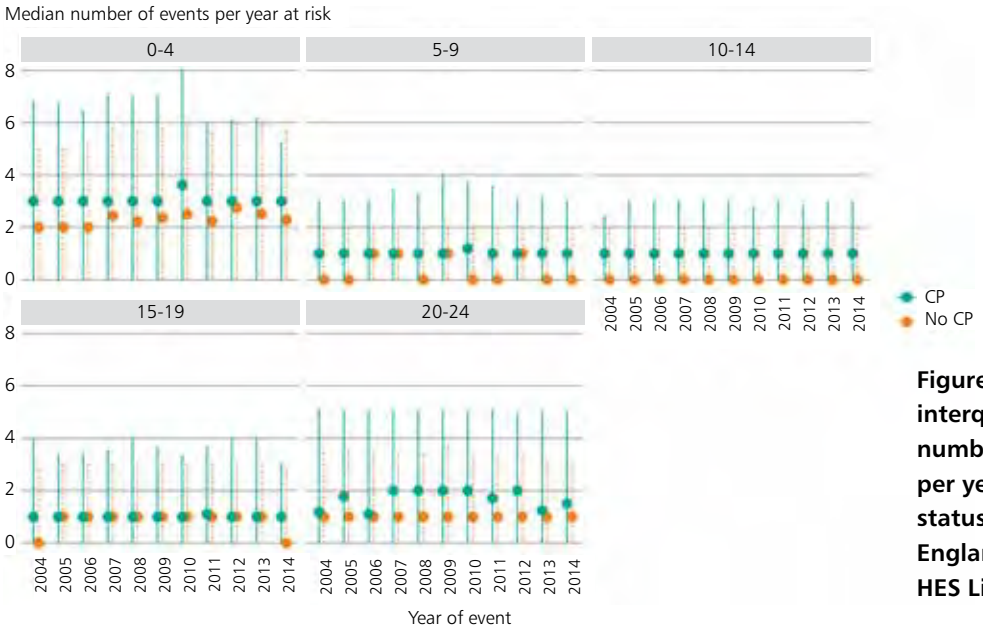


Figure 7.7 Median and interquartile ranges for the number of GP consultations per year by cerebral palsy status and age group for England (CPRD: England HES Linked)

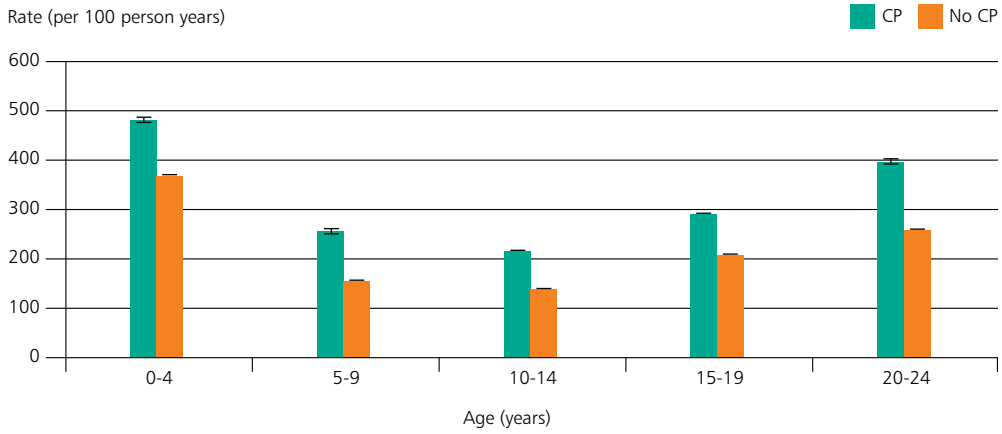


Figure 7.8 Rate of GP consultations per 100 person years at risk for children and young people aged 0-24 years with and without one of the cerebral palsies between 2004 and 2014 (CPRD UK)

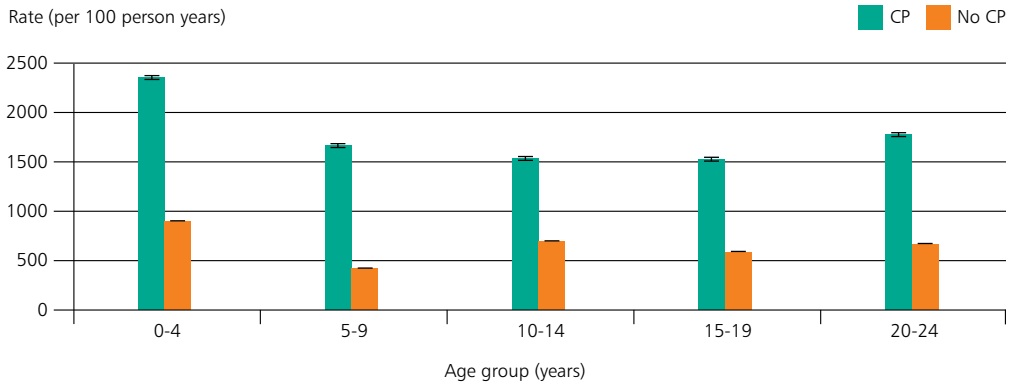


Figure 7.9 Rate of GP contacts per 100 person years at risk for children and young people aged 0-24 years with and without one of the cerebral palsies between 2004 and 2014 (WLGP Wales)

For the CPRD analysis 'consultations' were limited to 'GP consultation – surgery/clinic', 'home visit' and 'telephone consultation' whereas the WLGP data included patient administration, referrals and clinical intervention as well as GP contact. These data suggest that the activity within primary care over and above direct GP contact was considerable and significantly greater for children and young people with one of the cerebral palsies than for those without.

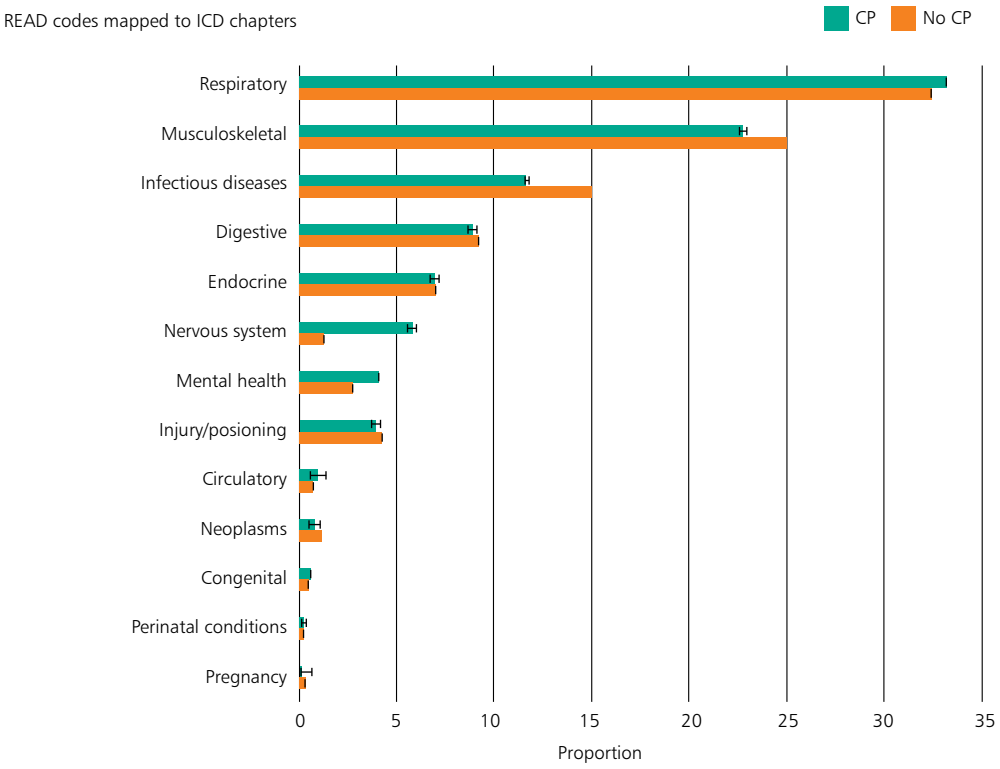


Figure 7.10 Reasons for consultation: Proportion of total GP consultations between 2004-2014 for children and young people aged 0-24 years with and without a cerebral palsy by Read codes mapped to ICD-10-CM Chapters (CPRD England)

The most common reasons for GP consultations among children and young people with and without cerebral palsies were respiratory conditions. Children and young people with cerebral palsies had a higher proportion of consultations for respiratory, neurological and mental health issues and a lower proportion of consultations for infections and musculoskeletal disorders than those without a cerebral palsy (Figure 7.10). The same analysis of WLGP data gave similar results with the exception of mental health where there was no clear difference between the two groups.

Rate of referrals from General Practice

The pattern of primary care referrals to external care centres (e.g. secondary care for inpatient or outpatient care) followed a similar age related trend for children and young people with (Figure 7.11) and without a cerebral palsy (Figure 7.12). The rate of referrals for children and young people with one of the cerebral palsies was appoximately twice that of those without one of the cerebral palsies across all age groups.

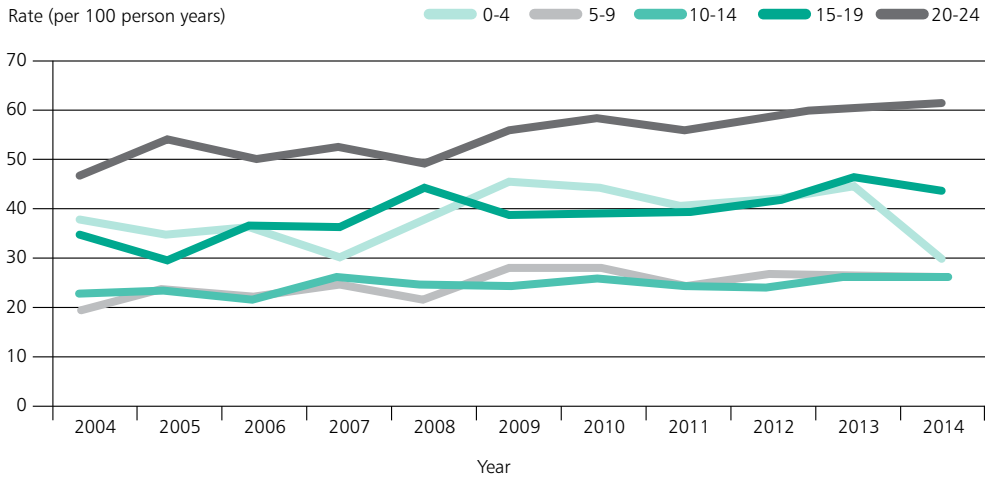


Figure 7.11 Rate of referrals from primary care to external care centres between 2004 and 2014 for children and young people with cerebral palsies by year and age group (CPRD: England HES Linked)

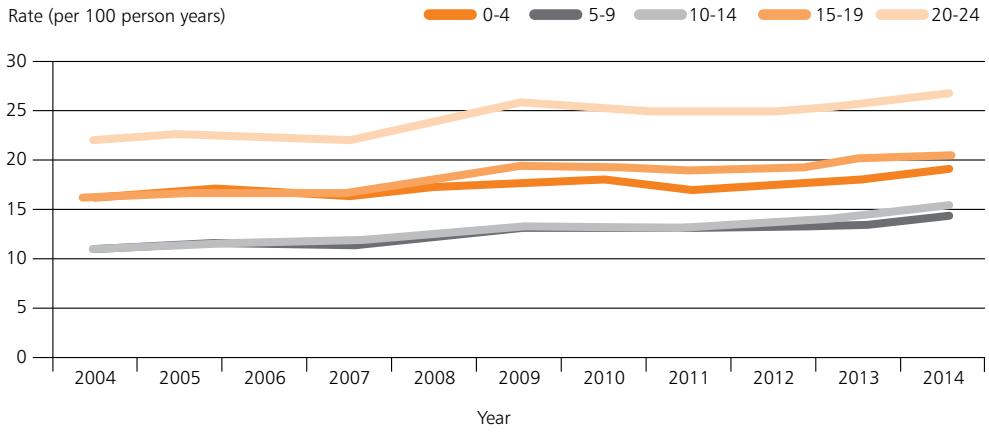


Figure 7.12 Rate of referrals from primary care to external care centres between 2004 and 2014 for children and young people without cerebral palsies by year and age group (CPRD: England HES Linked)

The rate of referrals for children and young people with one of cerebral palsies decreased with respect to increasing IMD quintiles of social deprivation. There was no significant difference between the rate of referrals for children and young people without one of cerebral palsies between IMD quintiles (Figure 7.13).

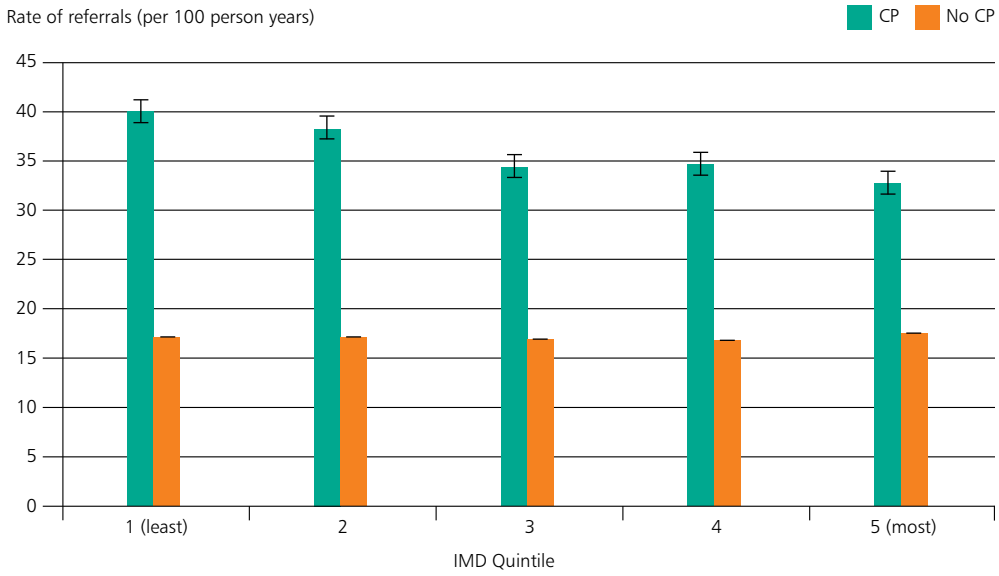


Figure 7.13 Rate of referrals between 2004-2014 for children and young people with and without one of the cerebral palsies by patient Index of Multiple Deprivation (IMD) quintile (CPRD: England HES Linked)

Outpatient appointments for children and young people with a cerebral palsy

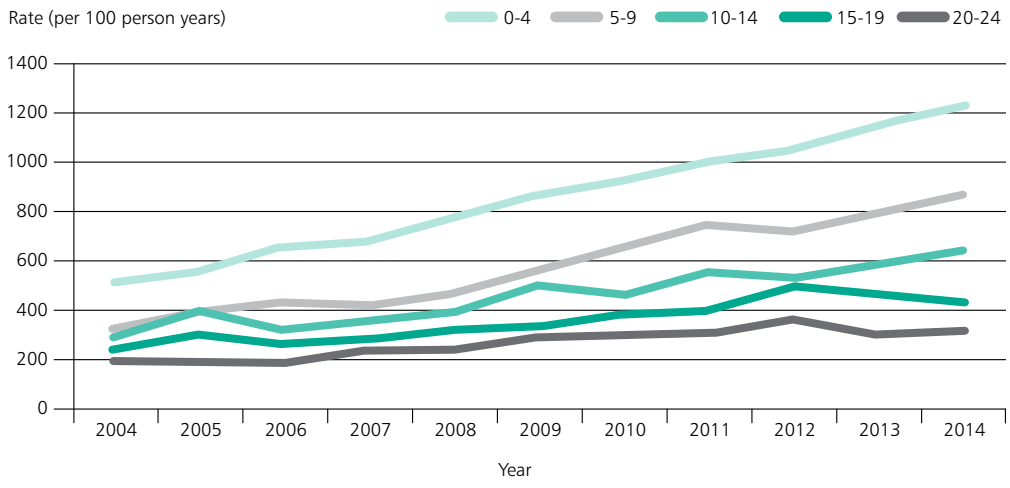


Figure 7.14 Rate per 100 person years at risk of outpatient appointments between 2004 and 2014 for children and young people with a cerebral palsy by year and age group (CPRD: England HES Linked)

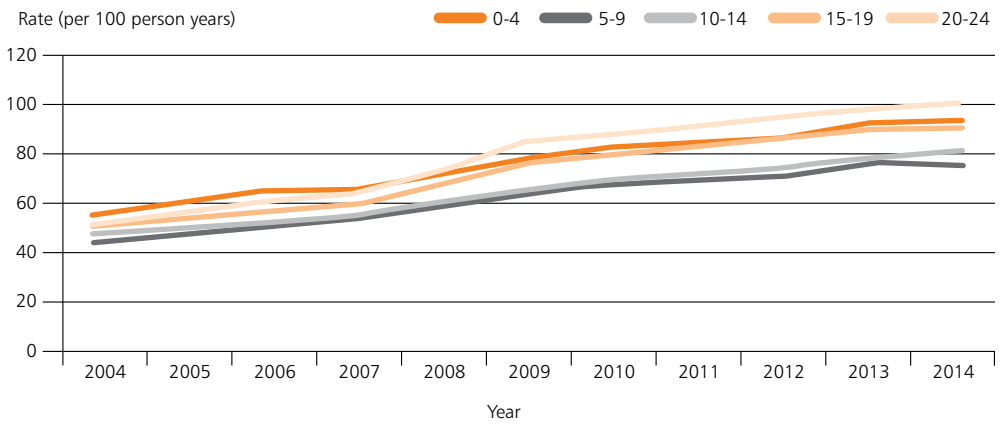


Figure 7.15 Rate per 100 person years at risk of outpatient appointments between 2004 and 2014 for children and young people without a cerebral palsy by year and age group (CPRD: England HES Linked)

Children and young people with one of the cerebral palsies (Figure 7.14) had significantly more outpatient appointments than children and young people without (Figure 7.15). The rate for 0-4 year olds and 20-24 year olds with a cerebral palsy was approximately 10 times and 3 times greater respectively than for those without a cerebral palsy.

The rate of outpatient appointments decreased across the older age groups with the lowest appointment rate for those aged 20-24 years of age.

The rate of outpatient appointments increased between 2004 and 2014 for both populations, and approximately doubled for those with a cerebral palsy in all age groups.

The rate of outpatient appointments was greatest in the least deprived (quintiles 1 and 2) and the most deprived quintiles for children and young people with a cerebral palsy. There was no significant variation in the rate of outpatient appointments across the deprivation quintiles for those without a cerebral palsy (Figure 7.16).

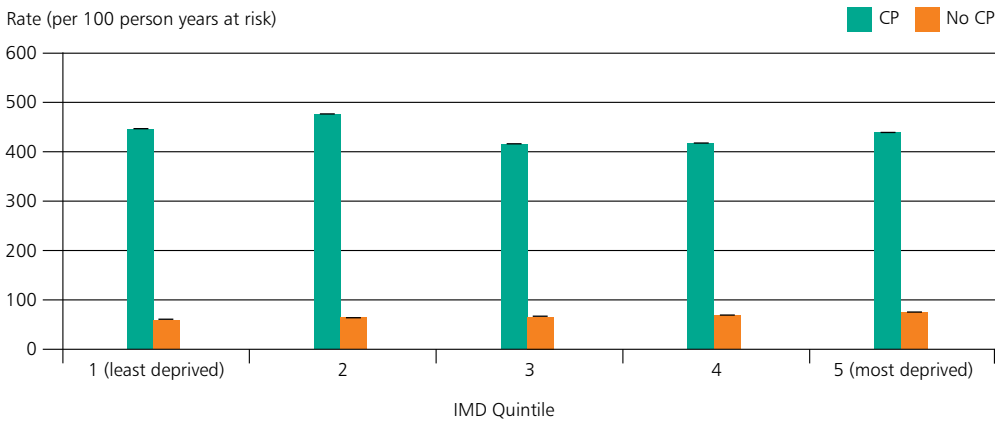


Figure 7.16 Rate of outpatient appointments per 100 person years at risk for children and young people with and without a cerebral palsy aged 0-24 years between 2004 and 2014 by Index of Multiple Deprivation (IMD) quintile

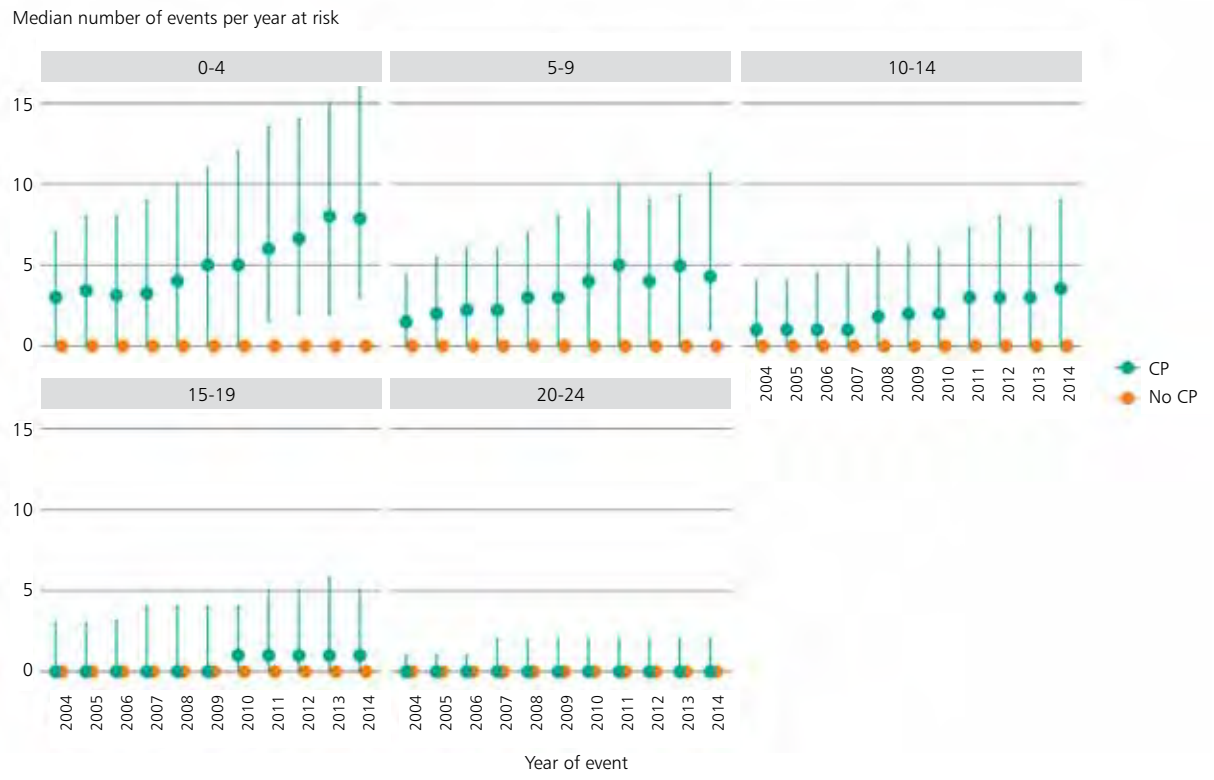


Figure 7.17 Median and interquartile range of outpatient appointments between 2004 and 2014 for children and young people with and without a cerebral palsy by age group (CPRD: England HES Linked)

The median number of outpatient appointments per year decreased with age for children and young people with cerebral palsies but remained unchanged for those without.

The median number of outpatient appointments per year per child or young person with a cerebral palsy increased between 2004 and 2014 for those younger than 15 years. There was a small increase for those 15-20 years of age but none was evident for those between 20 and 24 years of age) (Figure 7.17).

Reasons for outpatient appointments were seldom coded with an ICD-10 diagnostic code, but could be grouped according to specialty attended (available on request). Data are presented for 2010-2014 when the specialty groups included in HES datasets were most recently revised.

Overall 43% of outpatient attendances for children and young people with cerebral palsies were recorded as surgical specialties, 42% medical, 11% therapies and allied health professionals and 3.5% mental health specialties (NHS main specialty codes). The greatest proportion for both groups of children and young people was recorded as paediatric attendances followed by therapies (Figure 7.18).

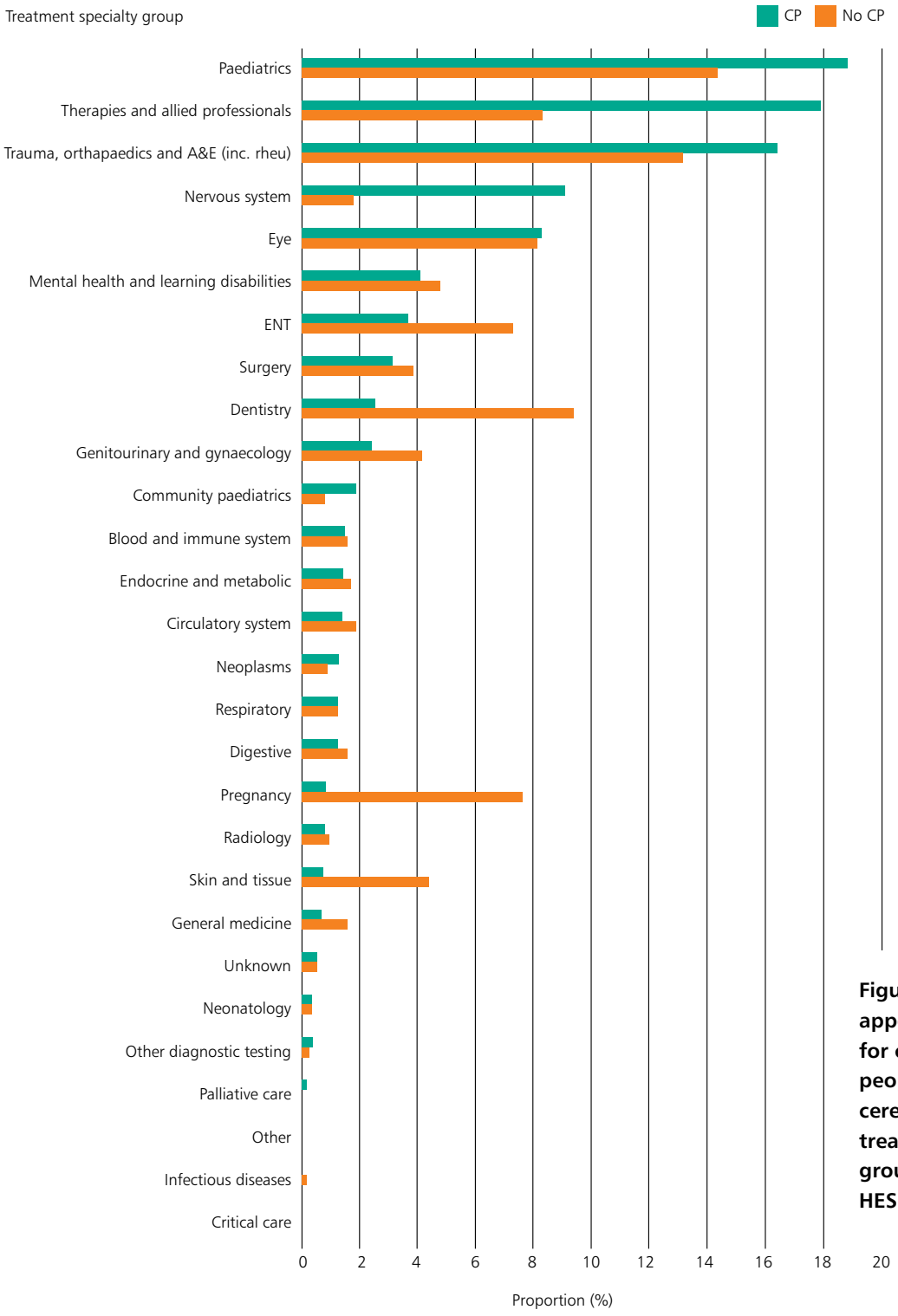


Figure 7.18 Outpatient appointment specialties for children and young people with and without cerebral palsies by treatment specialty group (CPRD: England HES Linked; 2004 2014).

Community paediatric outpatient attendances were greater for children and young people with the cerebral palsies. However, community based services were seldom recorded in the HES outpatient datasets, as activity occurring in community settings was not subject to routine data collection at the time of the study.

For children and young people with cerebral palsies, the proportion of all attendances for paediatric, therapy, nervous system, trauma and orthopaedics outpatient appointments was greater than that for children and young people without cerebral palsies. However, there were significantly fewer outpatient appointments for dental, pregnancy, dermatology, ENT, genitourinary and gynaecological and surgical attendances.

There were few OPD attendances for respiratory conditions considering that this was the greatest cause of primary care attendance, emergency hospital admissions and mortality. However, these may have been recorded as paediatric attendances.

Figure 7.19 summarises the rate of outpatient involvement in children and young people with cerebral palsies which decreases with age. The rate of outpatient attendance drops dramatically for 20-24 year olds, where the rate of primary care consultations increased from the age of 15 onwards.

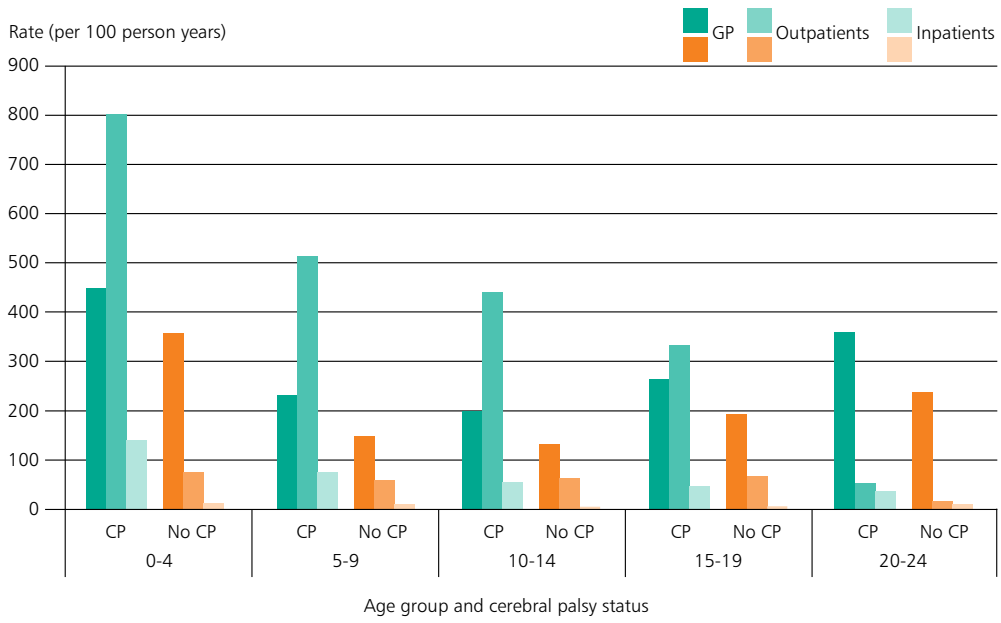


Figure 7.19 Rate of GP, Outpatient and Inpatient attendances for children and young people with and without a cerebral palsy between 2004 and 2014 by age group (CPRD: England HES Linked)

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

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.

8 – Description of needs and ongoing symptom management

Back to contents

Study Advisory Group question: *Do children and young people with a cerebral palsy have their comorbidites and associated conditions proactively managed, or does the absence of this lead to more hospital admissions and attendances than other children?*

Study Advisory Group question: *Are service pathways designed to enhance user experience, and to enable access to specialised services where appropriate.*

Why is this important? *If the many needs of children and young people with cerebral palsies are to be appropriately met and reasonable adjustments made to allow participation in everyday activities and access to services, needs must first be accurately identified and described.*

Gross Motor Function

The cerebral palsies are, by definition, primarily conditions with effects on posture and movement, albeit with a wide range of possible associated impairments across domains of functioning as well as associated medical conditions, each with their own implications for management.

The Gross Motor Function Classification System (GMFCS) is a well-established, simple, straight-forward five-level classification that differentiates children and young people with cerebral palsies based on their current gross motor function and need (or not) for assistive technology and wheeled mobility. Description of GMFCS levels informs realistic goal setting, appropriate surveillance and intervention planning.[30]

Case note reviewers reported great variation in documentation of GMFCS level in case notes. The GMFCS level was documented somewhere in the case notes in 155/547 (28.3%) of cases reviewed, was not documented anywhere in the case notes in 392/547 (71.7%), reviewers were unable to answer in 7/554 (1.3%) cases (Table 8.1).

Table 8.1 Documentation anywhere in the case notes of a GMFCS level - reviewers' opinion

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Total
Yes	24	56	47	23	5	**155**
No	72	80	56	84	100	**392**
Subtotal	**96**	**136**	**103**	**107**	**105**	**547**
Unable to answer	2	1	4	0	0	**7**
Total	**98**	**137**	**107**	**107**	**105**	**554**

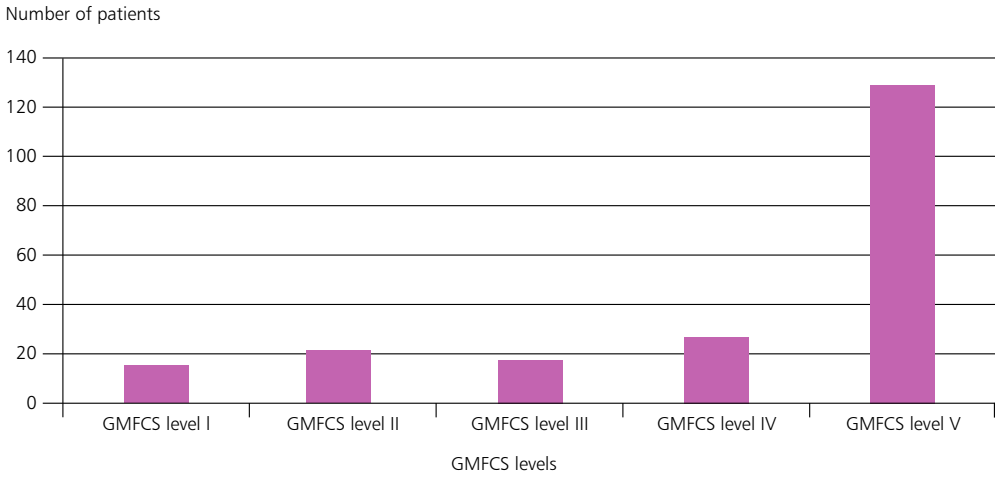


Figure 8.1 GMFCS level reported by the lead clinician

Figure 8.1 shows the GMFCS levels for each patient as reported by their lead clinician. This was marked as not recorded in 10/221 (4.5%) patients.

NCEPOD identified a sample population for this study from hospital admissions. The least independently mobile patients, especially those with motor function at GMFCS level V, are known to be more likely to be admitted to hospital.[31]

Descriptors of functioning

Lead clinicians for acute inpatient care reported having access to community case notes at the point of admission in only 292/414 (70.5%) cases and this was reported to include documentation of GMFCS level in only 105/197 (53.3%) cases and to be unknown in 95/292 (32.5%) cases. Lead clinicians for inpatient care reported that GMFCS level was clearly assessed and documented on admission for 51/405 (12.6%) patients and not known in 131/536 (24.4%) patients (Figure 8.2). Where GMFCS

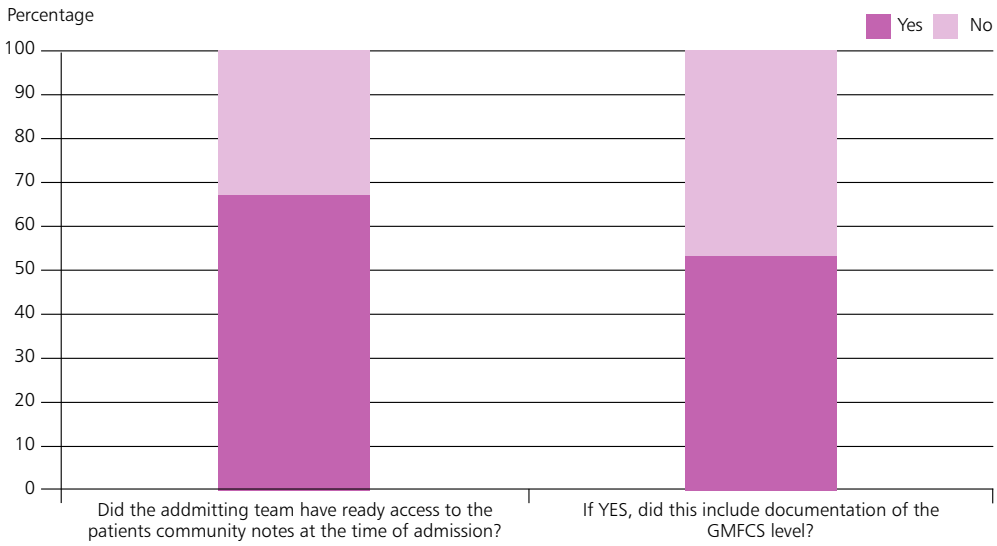


Figure 8.2 Access to community notes and was GMFCS level documented in them

level was not assessed or recorded on admission, it was documented during the admission in only 21/333 (6.3%) cases reviewed (Figure 8.3).

Case note reviewers reported that it was clear from the admission notes how the patient's cerebral palsy affected their mobility in 232/333 (69.7%) admitted patients and 92/173 (53.2%) day case patients. The case reviewers were unable to answer for 19/352 (5.4%) admitted patients and 9/173 (5.2%) day case patients (Figure 8.4).

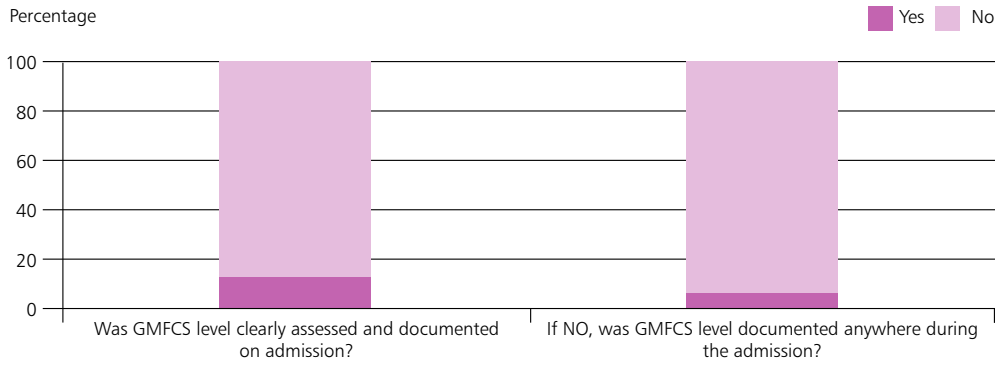


Figure 8.3 GMFCS level was documented on or during the admission

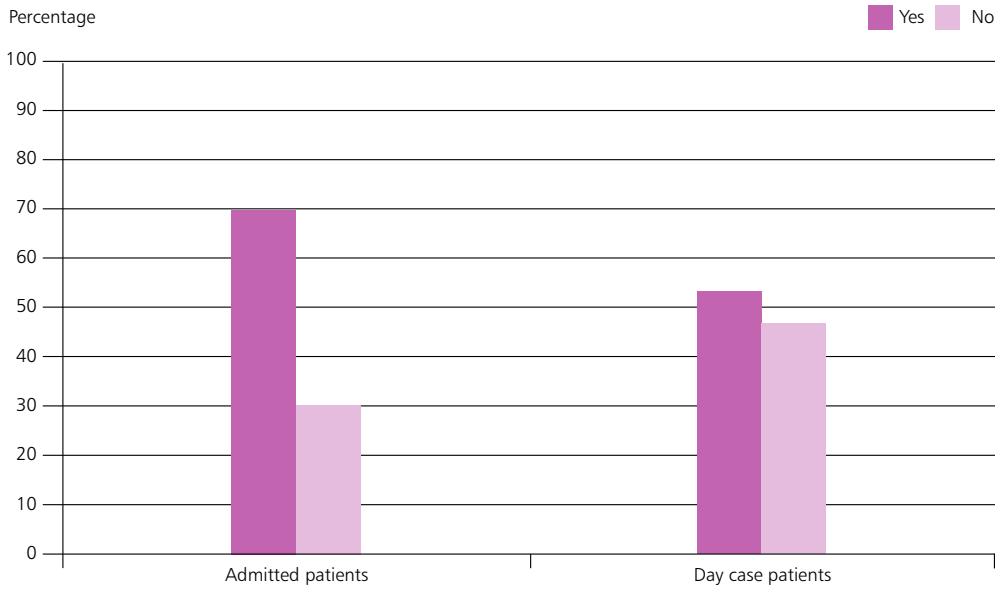


Figure 8.4 Documentation of how patient's cerebral palsy affected their mobility- reviewers' opinion

A proactive approach to symptom and postural management was reported not to have been taken by 18/207 (8.7%) lead clinicians for disability care and 1/18 GP, reportedly because of lack of available specialist clinical expertise according to 8/18 lead clinicians and 1/1 GP; because of lack of engagement with the family (3/18 lead clinicians) and lack of engagement with the patient (1/18 lead clinicians). Adequate symptom control on admission to hospital was reported by case reviewers to be absent for 23/285 (8.1%) patients. Adequate attention to posture, mobility and safe transfers, with timely access to appropriate equipment as required on the ward was reported by reviewers to be lacking in 67/245 (27.3%) cases.

The range of symptoms reported by lead clinicians for disability care at the time of the most recent assessment is shown in Table 8.2.

Table 8.2 Range of symptoms present

	Symptom present				If present, current status		
	Yes	No	**Subtotal**	Not documented	Active/ Symptomatic	Quiet on treatment	Not answered
	n=	n=	**n=**	n=	n=	n=	n=
Constipation	92	94	**186**	35	16	74	2
Feeding/ swallowing issues	140	66	**206**	15	42	91	7
Gastro-oesophageal reflux	100	94	**194**	27	21	77	2
Drooling	101	91	**192**	29	34	63	4
Sleep issues	78	98	**176**	45	39	36	3
Airway issues	57	139	**196**	25	30	24	3
Respiratory issues	84	118	**202**	19	40	42	2
Medication administration issues	33	168	**201**	20	13	18	2
Nutritional issues	91	115	**206**	15	39	45	7
Behavioural emotional issues	50	143	**193**	28	36	12	2
Continence issues	120	66	**186**	35	43	73	4
Postural/ transfer issues	135	62	**197**	24	62	65	8

National Routine Data

Within the routinely collected NHS datasets most cases were recorded as G80.9 (non-specific cerebral palsy) and thus the specific type of cerebral palsy was rarely recorded. There are no clinical codes for functional severity of the condition. Other than data reported to the Northern Ireland Cerebral Palsy Survey, the only routinely collected population data about GMFCS levels at this time in the UK is that collected by paediatric physiotherapists and reported to the Cerebral Palsy Integrated Programme Scotland (CPIPS).

At the start of this study the aim was to identify cohorts of children and young people with one of the cerebral palsies from two regional cerebral palsy registers and the Support Needs System (SNS) in Scotland and link these to routinely collected datasets. However, during the study the North of England Collaborative Cerebral Palsy Survey (NECCPS) was no longer supported as a standalone dataset and the data linkage was not possible. Problems identifying NHS numbers for those within the Northern Ireland Cerebral Palsy Register (NICPR) could not be resolved for data linkage within the timescale of the project. The SNS is not routinely or consistently used across the twelve NHS Health Boards and data were not considered representative of the population. Therefore, analysis of data within the NECCPS and NICPR, as standalone datasets, was undertaken to give a description of the potential healthcare needs of two representative populations of children and young people with a cerebral palsy according to levels of functional impairment and related morbidity.

The NICPR is a confidential record of every child with one of the cerebral palsies born in Northern Ireland since 1977 or living in the area since 1992. The dataset received from the NICPR included those born between 1981 and 2011. There were 1,802 children with cerebral palsies aged up to 33 years by 2014 (but within the age range 0-24 within the study time period).

The dataset received from NECCPS included 429 children born between 2004 and 2014 with one of the cerebral palsies living in the North of England. The patients within the cohort were aged 0-12 years old by the end of the study period (2014) and data were collected prospectively. These data are summarised in Table 8.3.

Table 8.3 Data recorded within NECCPS and NICPR about the demographics, cerebral palsy type, GMFCS level and mortality of children and young people with one of the cerebral palsies.

Variable		NECCPS (n=429) Date of birth 2004-2014		NICPR (n=1,802) Date of birth 1981-2011	
		Frequency	Proportion (95% CI)	Frequency	Proportion (95% CI)
Gender	Male	260	60.6 (55.9-65.1)	1,037	57.5 (55.3-59.8)
	Female	168	39.2 (34.7-43.9)	763	42.3 (40.1-44.6)
	Missing	1	0.2 (0.0-1.3)	2	0.1 (0.0-0.4)
Deprivation	1 (least)	NA	NA	105	5.8 (4.8-7.0)
	2	NA	NA	93	5.2 (4.2-6.3)
	3	NA	NA	148	8.2 (7.0-9.6)
	4	NA	NA	306	17.0 (15.3-18.8)
	5 (most)	NA	NA	861	47.8 (45.5-50.1)
	Missing	NA	NA	289	16.0 (14.4-17.8)

Table 8.3 Data recorded within NECCPS and NICPR about the demographics, cerebral palsy type, GMFCS level and mortality of children and young people with one of the cerebral palsies (Continued).

Variable		NECCPS (n=429) Date of birth 2004-2014		NICPR (n=1,802) Date of birth 1981-2011	
		Frequency	**Proportion (95% CI)**	**Frequency**	**Proportion (95% CI)**
Cerebral palsy type	Spastic bilateral	218	50.8 (46.1-55.5)	913	50.7 (48.4-53.0)
	Spastic unilateral	177	41.3 (36.7-46.0)	717	39.8 (37.6-42.1)
	Dyskinetic	9	2.1 (1.1-3.9)	88	5 (4.0-6.0)
	Dyskinetic choreoathetoid	3	0.7 (0.0-1.3)	NA	NA
	Dyskinetic dystonic	10	2.3 (1.3-4.2)	NA	NA
	Ataxic	NA	NA	48	3 (2.0-3.5)
	Unclassifiable	NA	NA	9	0 (0.3-0.9)
	Missing	12	2.8 (1.6-4.8)	27	1 (1.0-2.2)
GMFCS level	I	65	32.3 (26.3-39.1)*	300	16.6 (15.0-18.4)
	II	54	26.9 (21.2-33.4)*	683	37.9 (35.7-40.2)
	III	20	9.9(6.5-14.9)*	283	15.7 (14.1-17.5)
	IV	26	12.9 (9.0-18.9)*	114	6.3 (5.3-7.5)
	V	36	17.9(13.2-23.8)*	393	21.8 (20.0-23.8)
	Unknown	1		NA	NA
	Missing	227		29	1.6 (1.1-2.3)
DIED	Yes	17	4.0 (2.5-6.3)	83	4.6 (3.7-5.7)
	No	412	96.0 (93.7-97.5)	1,719	95.4 (94.3-96.3)

** Proportion calculated for the population where GMFCS level was recorded in NECCPS (as these data were only recorded in less than half of the cases they should be interpreted with caution)*

There was a greater proportion of males amongst children and young people with one of the cerebral palsies and NICPR confirmed a strong relationship between social deprivation and the cerebral palsies.

The proportion of cerebral palsy types was similar in both populations with an estimated 50% of the population having bilateral spastic cerebral palsy and 40% unilateral spastic cerebral palsy.

The distribution of GMFCS levels differed between the NICPR and the NECCPS populations. In both populations an estimated 1 in five children and young people had a GMFCS level V score. The proportion of GMFCS level V in these population samples was lower than in the case note review that identified children and young people from hospital admission case notes and is likely to represent the more seriously affected group.

Pain management

Pain is known to be a significant determinant of levels of participation and quality of life for children and young people with cerebral palsies and has been prioritised by parent carers as well as health professionals as an area requiring optimisation in routine management. [32-36,19]

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 the paediatric outpatient care questionnaire in 29/80 organisations and in the community or disability paediatric care questionnaire in only 33/80 organisations.

Respondents from 60% of organisations reported that they did not have a policy in place to promote routine enquiries about the presence of pain at each consultation where the patient had a cerebral palsy.

Chronic pain was reported by lead clinicians for disability care to be adequately assessed for 159/184 (86.4%) patients, but not for 25/184 (13.6%) patients (Table 8.4). There was evidence of a management plan for pain in just 98/126 (77.8%) patients and frequently this was not known (Table 8.5).

Table 8.4 Adequacy of enquiries made about the presence of pain

	Lead clinician for disability care		Case note reviewer	
	n=	%	n=	%
Adequate	159	86.4	173	61.6
Inadequate	25	13.6	108	38.4
Subtotal	**184**		**281**	
Unknown	37		69	
Total	**221**		**350**	

Table 8.5 Presence and adequacy of a pain management plan - reviewers' opinion

	If pain was present:			
	Was a clear management plan made to address this?		Is there evidence in the notes that pain was adequately controlled?	
	n=	%	n=	%
Yes	98	77.8	78	64.5
No	28	22.2	43	35.5
Subtotal	**126**		**121**	
Unable to answer	59		61	
Not applicable	71		60	
Not answered	94		108	
Total	**350**		**350**	

Reviewers were of the opinion that pain management could have been improved for 102/203 (50.2%) patients. They were unable to answer for 50/350 (16.9%) patients, found the question not applicable for 43/350 (12.3%) patients and did not answer for 54/350 (15.4%) patients. Reviewers reported that pain management could have been improved as in Table 8.6.

Table 8.6 Improvement that could have been made to the pain management plan - reviewers' opinion

	n=
Documentation of pain enquiry	85
Use of an appropriate scoring system	65
Evidence of a pain management plan	51
Referral to a specialist pain team	11
Total	**102**

**Answers may be multiple*

Hand function

A clear description of the patient's level of hand function is important, to know what they may be able to manage independently by way of self-care and everyday activities and where support may be needed across settings. Lead clinicians reported information about patients' level of hand function for 212/221 (96%) patients.

Learning ability or learning disability

A clear understanding of the patient's level of learning or intellectual ability is important as this determines what support the patient will need to be involved in decision-making about their care and the level of language and communication style required to receive and convey information. People with learning disabilities are known to have worse outcomes overall than people without learning disabilities; men and women with learning disabilities are likely to die 13 and 20 years younger than men and women without learning disabilities respectively.[37] Contributing to premature mortality amongst people with learning disabilities is **diagnostic overshadowing**, when the condition or disability is blamed for a symptom or sign and is a barrier to the thorough, systematic evaluation of symptoms and signs that anyone without disabilities would expect. These oversights can lead to poor nutrition, postural deformities, pain, and premature death, as illustrated by the 'six lives' described in Mencap's report 'Death by indifference'.[38]

Case note reviewers reported documentation in the case notes of the patient's learning **ability** for the admission and in clinic letters/summaries (Table 8.7).

A learning disability was specifically documented in the case notes, as reported by the case reviewers, in 306/532 (57.5%) patients.

The patient's level of learning ability was clearly assessed and documented on admission to hospital, as reported by the lead paediatrician for acute care, in only 188/433 (43.4%) patients. This item was documented as 'unknown' in 58/536 (10.8%) patients and was not answered in 45.

Table 8.7 Documentation in the case notes of learning ability - reviewers' opinion

		In a clinic letter				
		Yes	**No**	**Subtotal**	**Not answered**	**Total**
In the case notes	Yes	144	38	**182**	45	**227**
	No	83	166	**249**	63	**312**
	Subtotal	**227**	**204**	**431**	**108**	**539**
	Not answered	6	4	**10**	5	**15**
	Total	**233**	**208**	**441**	**113**	**554**

Intellectual impairment was recorded in 791/1760, 44.9% (95% CI (42.6 - 47.3)) of the NICPR population. Data on intellectual ability with respect to GMFCS levels were available for 1,708 children and young people (Table 8.8).

Of 1,629 children where place of education was recorded, 46% attended special schools, 40% attended main stream, the remainder were home tutored, had left education or had alternative provision.

Similar data were available for 196 children and young people on the NECCPS where an estimated 40%+ were recorded to have IQ< 80.The trends in intellectual impairment across GMFCS levels were similar to that found in the NICPR data (Table 8.9).

This figure was slightly higher than the overall figure within the NICPR and NECCPS but consistent with the fact that hospital admissions represent children and young people with more serious levels of impairment.

Table 8.8 Intellectual ability as recorded for 1,708 children and young people on the NICPR according to GMFCS level (frequency and %)

	GMFCS level					
	I	**II**	**III**	**IV**	**V**	**Total**
No impairment IQ>70	238 (79.3)	467 (68.4)	166 (58.7)	31 (27.2)	26 (6.6)	**928**
Moderate IQ 50-69	28 (52.8)	94 (50.8)	57 (52.8)	27 (36.0)	32 (8.9)	**238 (30.5)**
Severe IQ<50	16 (30.2)	84 (45.5)	45 (41.7)	43 (57.3)	312 (86.9)	**500 (64.1)**
Unknown	9 (17.0)	7 (13.2)	6 (5.6)	5 (6.7)	15 (4.2)	**42 (5.4)**
Total	**291**	**652**	**274**	**106**	**385**	**1708**

Table 8.9 Intellectual ability as recorded for 196 children and young people in the NECCPS, according to GMFCS level (frequency and %)

	GMFCS level					
IQ	**I**	**II**	**III**	**IV**	**V**	**Total**
>80	51 (79.7)	39 (75.0)	13 (68.4)	6 (25.0)	* (< 1%)	**109+**
50-80	10 (15.6)	11 (21.2)	6 (31.6)	12 (50.0)	8 (22.2)	**47**
<50	* (< 5%)	2 (3.8)	0 (0)	5 (20.8)	26 (72.2)	**33+**
Total	**61+**	**52**	**19**	**23**	**34**	**189**

**Figures were <5 and report small numbers cannot be reported (total figures are therefore more than recorded in the total columns)*

Communication

Communication is more than just talking and can also involve facial expressions, gestures, eye gaze, behaviours, signs, symbols and/or low or high level technological aids.[27] Establishing how a patient communicates is vital to be able to glean information from them, share information with them and involve them in decision-making about their care. Table 8.10 shows the variation reported in documentation of the patient's preferred communication method.
The lead clinicians for inpatient care indicated that 143/287 (49.8%) patients had special communication needs.

Table 8.10 Documentation in the case notes of preferred communication method - reviewers' opinion

		In a clinic letter				
		Yes	**No**	**Subtotal**	**Not answered**	**Total**
In the case notes	Yes	99	47	**146**	41	**187**
	No	58	211	**269**	74	**343**
	Subtotal	**157**	**258**	**415**	**115**	**530**
	Not answered	6	7	**13**	11	**24**
	Total	**163**	**265**	**428**	**126**	**554**

Of the 1,756 children and young people in the NICPR, where communication skills were recorded, 795 (45.27% (42.93-47.63%) had a communication difficulty. The figure for children and young people in the NECCPS cohort was similar at 96/208 (46.15% (39.27-53.17%) (Table 8.11).

Table 8.11 Means of communication as recorded for 1,756 children and young people in the NICPR and for 208 children and young people from the NECCPS dataset

		NICPR		NECCPS
Communication method	**Freq.**	**Percent**	**Freq.**	**Percent**
Age appropriate communication skills	961	54.72 (52.39-57.04)	111	53.37 (46.59-60.02)
Speech	286	16.29 (14.63-18.09)	53	25.48 (20.04-31.81)
Formal methods *Speech and formal method* *Formal methods only*	130 *88* *42*	7.40 (6.27-8.72) *5.11 (4.09-6.13)* *2.39 (1.77-3.22)*	22	10.58 (7.09-15.49)
No verbal communication or formal method used	332	18.91 (17.14-20.81)	21	10.10 (6.7-14.94)
Missing	47	2.68 (2.02-3.54)		
Total	**1756**	**100**	**208**	

Table 8.12 Communication impairment as recorded for 1,742 children and young people with one of the cerebral palsies according to GMFCS level in the NICPR (frequency and %)

	GMFCS level					
	I	**II**	**III**	**IV**	**V**	**Total**
Impaired level of communication	47 (15.8)	185 (27.4)	107 (38.5)	75 (66.4)	374 (95.9)	**788 (44.9)**
Total	**296**	**669**	**278**	**113**	**386**	**1,742**

Vision

The case reviewers reported that an enquiry had been made on admission about the patient's level of vision/vision impairment in 139/252 (55.2%) cases reviewed, but were unable to answer in 60 cases. The question was marked as not applicable in 17 and was not answered in 23 cases. The lead clinicians for acute care reported 110/214 (51.4%) patients to have vision impairment.

From NICPR data, it was possible to analyse means of communication by GMFCS level for 788 children and young people where both factors were recorded (Table 8.12).

The proportion of children and young people with visual impairment were similar in the two populations at 29.7% (95% CI: 27.7-31.9) in the NICPR and 36% (95%CI: 29.7-43.1) in the NECCPS (Table 8.13).

Table 8.13 Visual impairment recorded according to GMFCS in the NICPR and NECCPS cohorts where both factors were recorded (frequency % and 95% CI)

	GMFCS level					
Visual impairment	**I**	**II**	**III**	**IV**	**V**	**Total**
NICPR	39/300 (13.0 (9.7-17.3))	185 (27.4) (21.5 (18.6-24.8))	91 /283 (32.2 (27.0-37.8))	46 /114 (40.4 (31.8-49.5))	207 /393 (52.7 (47.7-57.6))	536 /1802 (29.7 (27.7-31.9))
NECCPS	11/64 (17.2 (9.9-28.2))	15/51 (28.8 (18.7-43.0))	6 /18 (31.6 (16.3-56.3))	11/55 (42.3 (11.6-32.4))	27/35 (77.1 (61.0-87.9))	70/194 (36.1 (29.7-43.1))

Hearing

Case note reviewers reported that an enquiry had been made about the presence of hearing impairment in just 53/119 (44.5%) cases reviewed. They were unable to answer from the information available in 36 cases and the question was not applicable in 14/169 (48.3%) cases. The lead clinician for inpatient care reported documentation of hearing impairment in 39/287 (13.6%) patients.

Table 8.14 Hearing impairment recorded according to GMFCS level in the NICPR cohort where both factors were recorded (frequency % and 95% CI)

	NICPR	GMFCS level						
		I	II	III	IV	V	Missing	Total
NICPR	Hearing impairment	10/287 (3.5 (1.9-6.3))	48/670 (7.2 (4.4-8.0))	9/277 (3.3 (1.7-6.1))	8/108 (7.4 (3.8-13.9))	57/386 (14.8 (11.6-18.7))	3/13 (23.1 (8.2-50.3))	**135/1746 (7.7 (6.6-9.1))**
	Uncertain		8 (1.2 (0.6-2.3))			51 (13.2 (10.2-17.0))		**74 (4.2 (3.4-5.3))**

Table 8.14 shows that there was no significant difference between the overall proportion of children and young people recorded with hearing impairment within the NICPR (7.7%: 95% CI: 6.6-9.1) (Table 8.14) and the NECCPS dataset (5.05%. (95% CI: 2.77-9.05) (10/198) (The numbers in the NECCPS were too small within each GMFCS level to report).

Eating and drinking ability and nutritional status

Inadequate food intake leads to poor nutrition and growth, which is common among children with cerebral palsies.[39,40,41] Multiple challenges can occur from difficulties in how the mouth handles food and drink to swallowing and digestion.

Lead clinicians for disability care reported 33/217 (15.2%) patients to have feeding difficulties but could eat orally with some adjustment. A further 22/217 (10.1%) required a feeding tube to augment oral feeding and 98/217 (45.2%) required a feeding tube for total nutrition as unable to eat or drink safely.

Case note reviewers reported that the patient's weight had been recorded in the medical record during the admission for only 254/333 (76.3%) admitted patients and 104/177 (58.8%) day case patients.

Lead clinicians reported their patient's nutritional status had been considered and recorded in the last year for 189/208 (90.9%) patients and was unknown for 13 patients.

Lead clinicians for acute admissions reported that weight was documented during the admission in only 359/536 (67%) patients, of which 285 were based on actual weights, 59 estimated weights and for 13 this was unknown. The reasons given for not weighing inpatients were lack of availability of suitable equipment in seven patients, the patient was too sick to be moved in 22 patients and no reason was given in 25 patients.

Accurate fluid and drug calculations depend on accurate weight measurement. Wider availability of weighing equipment in inpatient settings suitable for people of all ages with a range of disabilities is essential if disabled people are to receive high quality healthcare. 9

Lead clinicians for acute admissions reported that height was documented during the admission in only 63/536 (11.8%) patients, of which 55 were based on actual height measurement the remaining were estimated heights.

There were reported to be clinical concerns about the weight, growth or nutritional status of the patient in 62/213 (29.1%) patients, yet lead clinicians for disability care were able to report the most recent weight of only 195/221 (88.2%) patients and height or length of 79/142 (55.6%) patients. Where the weight or height/length was not available, this was reported to be because of lack of suitable equipment to assess weight in five patients and to assess height/length in 34 patients, lack of an available hoist in four for weight and seven for height/length. Postural deformities were reported to prevent accurate measurement of height/length of 56/133 (42.1%) patients, and the patient was in pain and could not be moved was the reason given in 2/113 (1.8%) patients. Only 21/221 (9.5%) leads for disability care reported using other anthropometric measures (triceps skin fold thickness, mid arm circumference). Where clinical leads reported there

to be suboptimal nutritional status, input was not sought from a dietician in 13/114 (11.4%) patients nor from a gastroenterologist in 50/84 patients.

Case note reviewers were of the opinion that 59.5% (198/333) of patients were nutritionally vulnerable, affecting all age groups. There was evidence of adequate, regular assessment of the patient's nutritional status in 160/185 (86.5%) cases reviewed, but not in 25/185 (13.5%). Reviewers reported 170/315 (54%) patients to be tube fed and that there were specific problems with tube feeding for 69 patients. Reviewers reported evidence to suggest issues with the safety of the patient's eating and drinking (i.e. aspiration risk) for 144/311 (46.3%) patients and that there was evidence that this had been formally assessed in the last three years for 107/125 (85.6%) patients, but not for 18/125 (14.4%) patients. Table 8.15 shows data from the routine data where this was recorded.

Table 8.15 Frequency table showing feeding problems recorded among those in the NICPR (n=1,802)

Feeding problems	Freq.	Percent
No problem	1,248	69.26
Feeds via nasogastric tube	34	1.89
Gastrostomy in situ	85	4.72
Unknown method	134	7.44
Feeding orally with difficulty	134	7.44
Gastroesophageal reflux	26	1.44
Missing	141	7.82
Total	**1,802**	**100**

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.

Spasticity

The NICE Clinical Guideline 145: 'Spasticity in under 19's:[29] management' recommendations 1.1.1 and 1.1.2 state that *"children and young people with spasticity should have access to a network of care that uses agreed care pathways supported by effective communication and integrated team working and that this network should include a team of healthcare professionals experienced in the care of children and young people with spasticity."*

It was seen in chapter 5 that reviewers noted the diagnostic term used to describe the patient's cerebral palsy did not include information about the specific tone variation (i.e. spasticity, dyskinesia, dystonia, choreoathetosis, ataxia) in 297/521 (57%) cases reviewed. Spasticity was reported to be present by 186/218 (85.3%) lead clinicians for disability care, who reported routine access to a network of care that uses agreed care pathways supported by effective communication and integrated team working for 162/179 (90.5%) patients. The patients views about the effectiveness of treatments and interventions were reported to be recorded, as appropriate for age and cognitive ability, by 58/85 lead clinicians, but not for 27/85 patients. Lead clinicians reported 78/173 (45.1%) of their patients to have fixed contractures. 5

There was sufficient information to assess the quality of spasticity management for patients with spastic cerebral palsy over the last three years for 207/271 (76.4%) patients. In the reviewers opinions, spasticity management was supervised by a team with specialist expertise in spasticity for 176/196 (89.8%) patients, but not for 20/196 (10.2%) patients.

Associated conditions

A wide range of conditions are known to be regularly associated with the cerebral palsies and need to be addressed in the overall care plan if the patient is to experience the least possible symptoms and enjoy maximum participation and the best quality of life.

Lead clinicians for inpatient care reported 396/491 (80.7%) patients to have associated conditions. This was unknown for 45/491 (9.2%) patients. As an example, Table 8.16 shows the prevalence of seizures in this group of patients.

Table 8.16 Prevalence of seizures in children and young people with one of the cerebral palsies

Condition	Frequency	Proportion
Seizures	NECCPS 60/201	NICPR 450/1802
	28.6 (22.7-35.3)	25.0 (23.0-27.0)

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.

Seizures were recorded in the case notes of one in four children and young people with a cerebral palsy.

Reviewers reported that the patient's health needs were not adequately described in 58/350 (24.3%).

Reviewers were asked if there was room for improvement in the admission documentation about how the patient's cerebral palsy affected their health, mobility and social functioning. The findings are shown in Table 8.17.

Table 8.17 Room for improvement in the admission documentation about how the patients cerebral palsy affected the patient's health, mobility and social functioning – reviewers' opinion

	Health		Mobility		Social functioning	
	n=	%	n=	%	n=	%
Yes	116	38.2	144	47.8	166	**57.0**
No	188	61.8	157	52.2	125	**43.0**
Subtotal	**304**		**301**		**291**	
Unable to answer	20		23		32	
Not answered	28		28		29	
Total	**352**		**352**		**352**	

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.

Safeguarding

Issues were reported in the last three years by lead clinicians for disability care for 35/208 (16.8%) patients and in one case the clinician reported a delay in the identification of safeguarding issues, although this was not reported to be due to lack of available specialist clinical expertise.

Documentation of adjustments required

Documentation in the case notes of adjustments that patients may require during hospital admissions was reported by 135/263 (51.3%) reviewers, with no such documentation reported by 128/263 (48.7%).

Assessment of needs on discharge from hospital

Adequate 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 153/234 (65.4%) cases, but this was reported as inadequate in 81/234 (34.6%) cases. Reviewers were unable to answer in 82 cases and did not answer this question in 36 cases.

Key Findings – routine national data

- Prospective and focused data collection utilising specific data fields that relate to the cerebral palsies provides rich data to categorise disease severity and to identify healthcare needs on a population basis. Incorporating these fields into Community Services Routine data collection has the potential to improve this knowledge base on a national population scale
- The analysis showed a very similar pattern of disease severity, functional impairment and associated morbidity across two populations of children and young people from different regions of the UK, collected over different time periods
- The data from NECCPS and NICPR showed a greater populations of males for the children and young people with cerebral palsies. There was a strong relationship between cerebral palsies and social deprivation and an overall mortality rate of 4-4.6%
- These datasets gave a picture of the type and severity of cerebral palsies within the general population and showed that 50% were spastic bilateral and 40% spastic unilateral. Data recorded regarding GMFCS level varied across the datasets but showed that approximately one in five had a GMFCS level of V
- The NICPR identified intellectual impairment in 45%; 46% of the children and young people with one of the cerebral palsies attended special schools, 40% attended mainstream and the remainder were home tutored
- Both cerebral palsy registers confirmed communication difficulties in around 45%, visual impairment in 30-36% and hearing impairment in 5-7.7% of children and young people with one of the cerebral palsies.

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

9 – Environmental factors

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Study Advisory Group question: *Are services designed to aid easy access when attending appointments, including the provision of appropriate equipment across all settings?*

Why is this important? *The Equality Act 2010 protects disabled people from discrimination and states that a disabled person should be able to use the services of a healthcare provider as far as is reasonable to the same standard as a non-disabled person and that the service provider must make reasonable adjustments. Equality law recognises that bringing about equality for disabled people may mean changing the way in which services are delivered, providing extra equipment and/or the removal of physical barriers.*

Variations in reported problems in aspects of the outpatient environment and the inpatient environment as reported from different perspectives are shown in Figures 9.1 and 9.2. The scale represents the percentage of respondents and does not end at 100%.

One third to one half of all community paediatric, paediatric outpatient, inpatient and emergency care providers reported having no accessible scales to accurately weigh disabled patients.

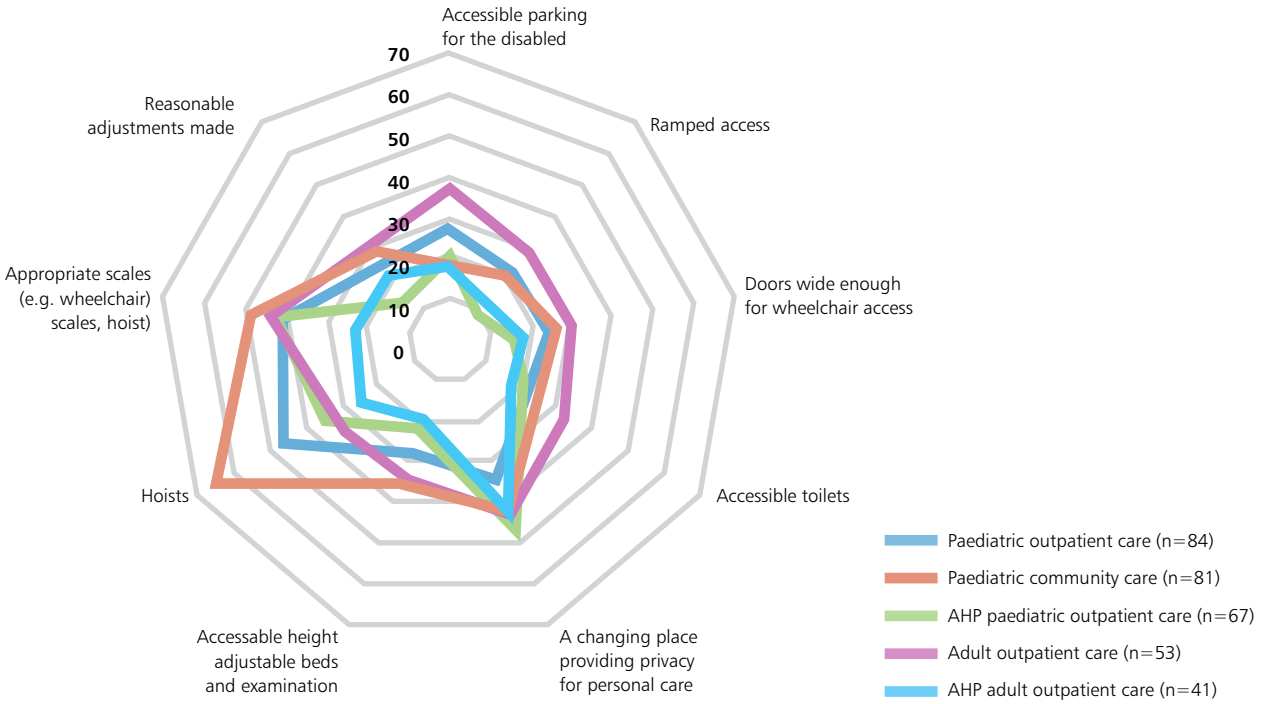

Figure 9.1 Problems with access to facilities in outpatient care

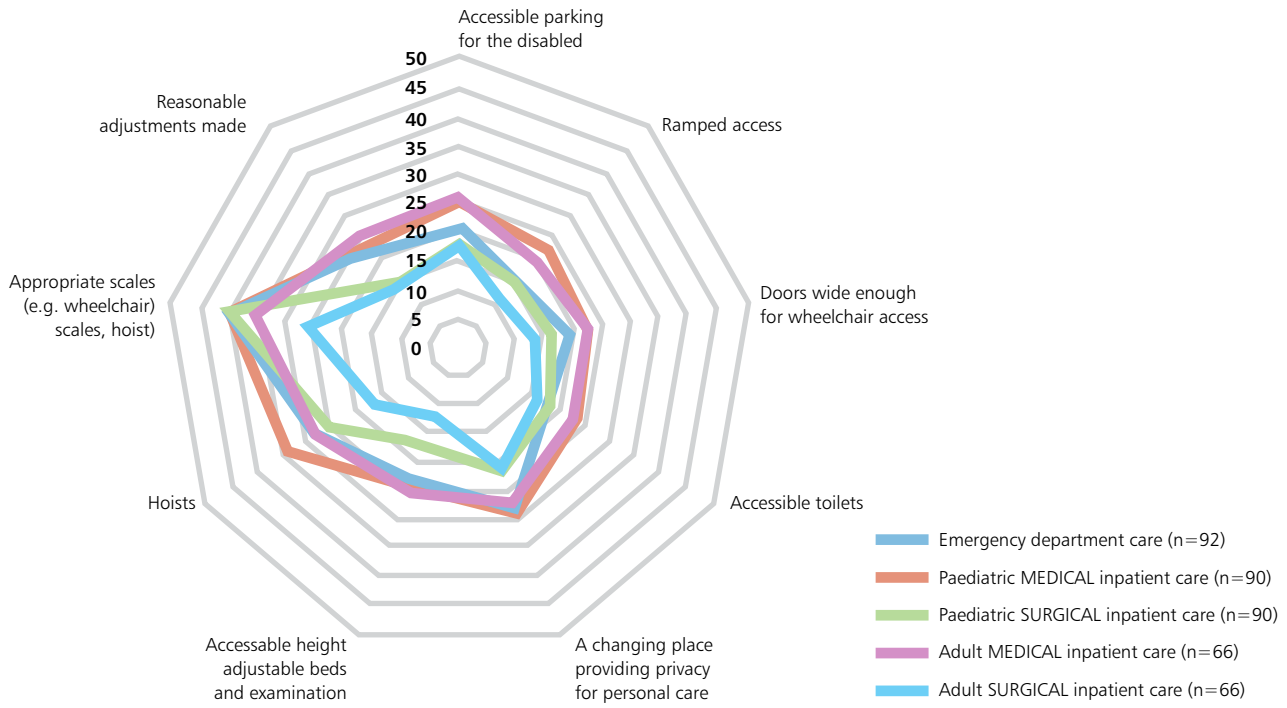

Figure 9.2 Problems with access to facilities in inpatient care

Free text comments given in the organisational questionnaires on environmental factors included:

- Quality of disability facilities not optimal
- Hoists and scales not available in every outpatient setting or child development unit
- Changing area not accessible for a hoist and in one setting was reported to be open so lacked privacy
- Some child development centres were reported to be located in old buildings with no access for the disabled and no specialist equipment
- A number of disability and community paediatric services reported having changing places for infants, but not for older young people or adults.

Variations in access to specialist occupational therapy services to assess the need for housing adaptations are shown in Table 9.1.

Table 9.1 Access to specialist occupational therapy

	AHP Paediatric inpatient	AHP Paediatric outpatient	AHP Adult inpatient
Yes	36	52	33
No	22	12	16
Subtotal	**58**	**64**	**49**
Not answered	5	3	3
Total	**63**	**67**	**52**

Wheelchair services

Organisational data from paediatric allied health professionals indicated that wheelchairs were provided for children and young people from specialist paediatric services in 31/66 organisations, from private providers in 10/66 organisations, from general service (adult or paediatric) in 38/66 organisations and there is no service at all in 6/66 organisations. Organisational data from adult allied health professional reported that wheelchairs were provided for young adults from general wheelchair services in 35/40 organisations, from private providers in 4/40 organisations and there was no service at all in 5/40 organisations.

There was variation in access to wheelchairs and other equipment for inpatients and on discharge, as shown in Table 9.2.

Wheelchair services were reported by the allied health professional outpatient questionnaires, are shown in Table 9.3.

Wheelchair services were reported to be adequate for meeting the needs of the local population (where adequate meant timely assessment, easy access, high quality assessment and provision, clear pathways for maintenance and repair) in only 31/58 paediatric allied health professional outpatient organisational questionnaires and 22/32 for adults, but not by 27/58 for paediatrics and 10/32 for adults.

Table 9.2 Access to wheelchairs at discharge

	AHP Paediatric inpatient care		AHP Adult inpatient care	
	Whilst inpatient	**On discharge**	**Whilst inpatient**	**On discharge**
Yes	29	42	31	27
No	33	19	19	8
Other	NA	NA	NA	15
Subtotal	**62**	**61**	**50**	**50**
Not answered	1	2	2	2
Total	**63**	**63**	**52**	**52**

Table 9.3 Wheelchair services available

	AHP Paediatric outpatient	AHP Adult outpatient
	n=	**n=**
Maintenance/repair	58	32
Emergency out of hours service for maintenance/repair	24	17
Sports wheelchairs	4	4
Bespoke wheelchairs based on individual needs	48	28
Power wheelchairs	54	31
Other specialist wheelchairs	24	18
Subtotal	**58**	**34**
Not answered	2	1
Total	**60**	**35**

**Answers may be multiple*

Other equipment

Organisational data for allied health professional outpatient care reported no access at all to a number of support services (Table 9.4),

Where such equipment was reported to be available, variation was reported between organisations in the availability in different settings, with lack of availability of equipment especially reported in inpatient paediatric settings, but the reverse for adults, where equipment was more likely to be available for inpatients but not in the community.

Issues with waiting times for services and equipment were reported in 40/61 paediatric allied health professional outpatient care questionnaires.
Analysis of the free text comments revealed the following themes:

- Delays (40 comments) due to:
  - Capacity issues in the team assessing and prescribing equipment (19 comments)
  - Complexity of the assessment and provision process (10 comments)
  - Availability of local stock of equipment (15 comments)
  - Funding approval process (10 comments)
  - Delivery of equipment from manufacturers (5 comments)
  - Availability of therapist and or rep to fit equipment (4 comments)
- Competence of the assessors – generic rather than specialist (one comment)

Some respondents gave examples of the positive steps taken to improve equipment provision, including use of equipment toolkits, virtual clinical decision panels and stock recycling.

In the opinion of the case reviewers, adequate attention was given during admission to patient posture, mobility and safe transfers, with timely access to appropriate equipment as required on the ward for 178/245 (72.7%) patients, but not for 67/245 (27.3%). Adequate assessment for equipment needs in discharge from hospital was reported by 153/234 (65.4%) reviewers, but not for 81/234 (34.6%) patients. 10

Table 9.4 No access at all to specific equipment

	AHP Paediatric outpatient	AHP Adult outpatient
	n=67	n=41
Standing frames	7	7
Walking frames/devices	4	2
Sleep systems for children and young people with cerebral palsies at GMFCS levels III-V (non-walkers) based on individual assessment	12	12
Orthoses	3	1
Hand splints	6	1
Low-tech communication aids	12	5
High-tech communication aids	27	12
Specialist seating	14	7
Equipment for self-care including bathing, dressing, mealtimes	16	3

Equipment and technologies reported by lead clinicians for inpatient care to be required to facilitate day to day care are shown in Table 9.5.

Table 9.5 The patient required the following technologies/equipment for day to day care

	n=	%
Gastrostomy or other feeding tube	231	81.9
Ventilation/CPAP	32	11.3
Hearing aid(s)	13	4.6
Hoist for transfer	122	43.3
Other	24	8.5
Subtotal	**282**	
Not answered	254	
Total	**536**	

**Answers may be multiple*

Inpatient accommodation

Adult inpatient care organisational questionnaire data demonstrated variation in the type of accommodations and environmental adjustments available for young adults with cerebral palsies admitted for routine procedures or surgery, findings shown in Table 9.6. 10

Table 9.6 Ward facilities

	Yes	No	Subtotal	Not answered	Total
Single room accommodation	21	21	**42**	24	**66**
En suite toilet facilities	18	24	**42**	24	**66**
Space for special equipment (wheelchairs/ hoist etc)	32	10	**42**	24	**66**
Facility for parent carer to stay on-site/on the ward overnight if required (Adult IP2	36	10	**46**	20	**66**

Emergency department environment

Children and young people were reported to have access to assessment facilities that was audio-visually separate from that for adults in only 78/92 emergency departments, but not in 14/92.

Disabled children and young people were reported to have access to cubicle accommodation with space for family members and equipment in 86/92 emergency departments, but not in 6/92. Cubicles with doors to allow privacy and confidentiality when young people were being seen were reported to be provided in emergency departments in 82/92 organisations, but not in 10/92. This replicates previous NCEPOD study findings. [42]

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

10 – Acute Hospital Care

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Study Advisory Group question: *On admission to hospital, are children and young people with a cerebral palsy being seen in a timely manner and by the correct specialties. Where there are complex needs are opportunities used to enquire about all aspects of the multidisciplinary care pathway?*

Why is this important? *In an acute admission it is important that all the needs of the patient with a cerebral palsy are met.*

This chapter briefly reviews the pathway of care for patients with a cerebral palsy admitted to acute general hospitals and the opportunities for joint working with neurodisability teams. Patients with a cerebral palsy are relatively frequent attendees of acute general hospitals and this is supported by the routine national data findings presented in this chapter and by other published work.[31,43] Children, young people and young adults with a cerebral palsy were identified in this study based on an admission some of which were on a day stay basis.

Approximately two thirds of admissions were emergencies (including urgent) and 23.4% were seriously ill (75/321) which was replicated in the routine national data. The remainder of the sample were planned and usually (135/164) underwent a procedure or surgery and this patient group is discussed in chapter 11

Whilst it is known that patients with a higher level of motor disability (based on GMFCS level) are more likely to require hospital care[44] GMFCS level was very poorly recorded in the study population as shown in chapter 8

Routine national data

The proportion of hospital admissions for children and young people with a cerebral palsy followed the same pattern across the age groups for each of the four countries (Figure 10.1). Within each age group the proportion of these admissions was greatest for Northern Ireland (with the exception of 20-24 year olds) and lowest for Wales. When assessing

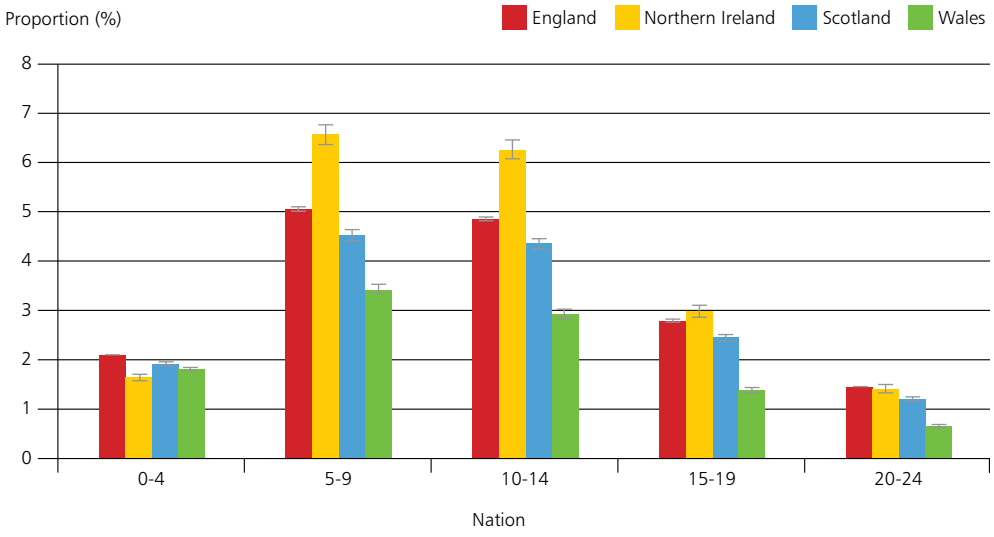

Figure 10.1 Proportion of total hospital admissions for children and young people with a recorded diagnosis of a cerebral palsy for England, Wales, Northern Ireland and Scotland by age group between 2004-2014. (HES, PAS, SMR01, PEDW)

these results the reader should bear in mind the previous finding of a lower prevalence of cerebral palsy in linked datasets from Wales (2.8/1000) than in England (3.5/1000) and the fact that it was not possible to estimate population prevalence figures for Scotland or Northern Ireland.

For children and young people in England, the rate of hospital admissions for children and young people with one of the cerebral palsies (Figure 10.2) was significantly greater than for children and young people without one of the cerebral palsies (Figure 10.3) for all age groups.

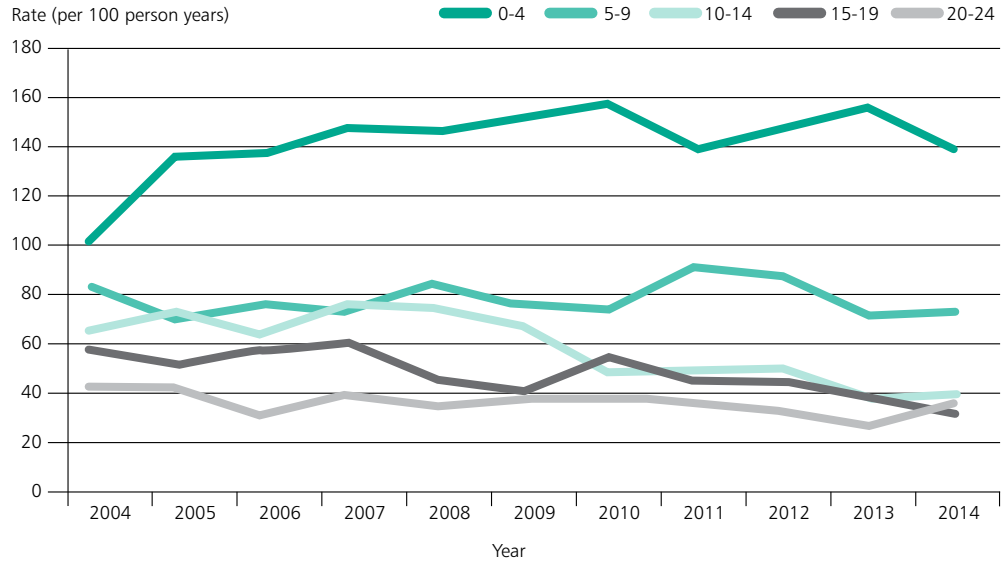

Figure 10.2 Rate of hospital admissions for children and young people with a cerebral palsy by age group and year (CPRD: England HES Linked)

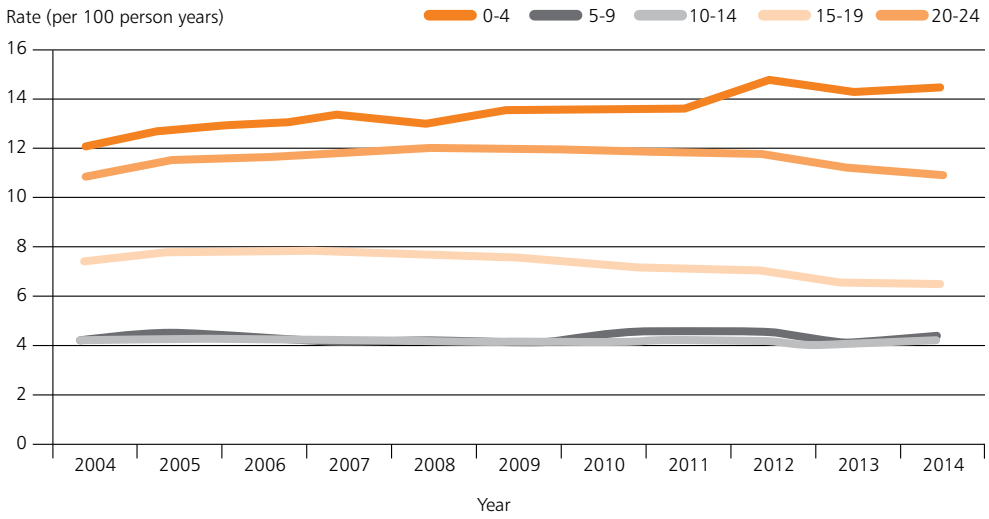

Figure 10.3 Rate (per 100 person years at risk) of hospital admissions for children and young people without a cerebral palsy (with at least one admission) by age and year (CPRD: England HES Linked)

The rate was greatest for those aged 0-4 years and decreased across the age groups. By contrast the rate of hospital admissions was greatest for age groups 0-4 years and 20-24 years for those without a cerebral palsy. Overall the rate of hospital admissions were more than ten times greater for 0-4 year olds and more than three times greater for 20-24 year olds with a cerebral palsy than for those without.

In Wales (PEDW) the hospital admission rate remained constant between 2004 -2014 at an estimated 55 per 100 person years at risk for children and young people with one of the cerebral palsies and at 10 per 100 person years at risk for those without.

The median number and IQR of annual admissions for the two populations across all age groups was less than one admission per year as the majority of children in both groups were not admitted to hospital on an annual basis, with the exception of 0-4 year olds where 50% of children with a cerebral palsy had one or more admissions per year.

Whilst the rate of hospital admissions for children without a cerebral palsy increased with social deprivation, there was no clear relationship between social deprivation and hospital admissions for children and young people with a cerebral palsy (Figure 10.4).

Children and young people with a cerebral palsy had longer hospital stays than those without a cerebral palsy across all age groups. Whilst the rate of hospital admissions decreased across the older age groups for young people with a cerebral palsy, the length of stay increased in the older age groups (Figure 10.5).

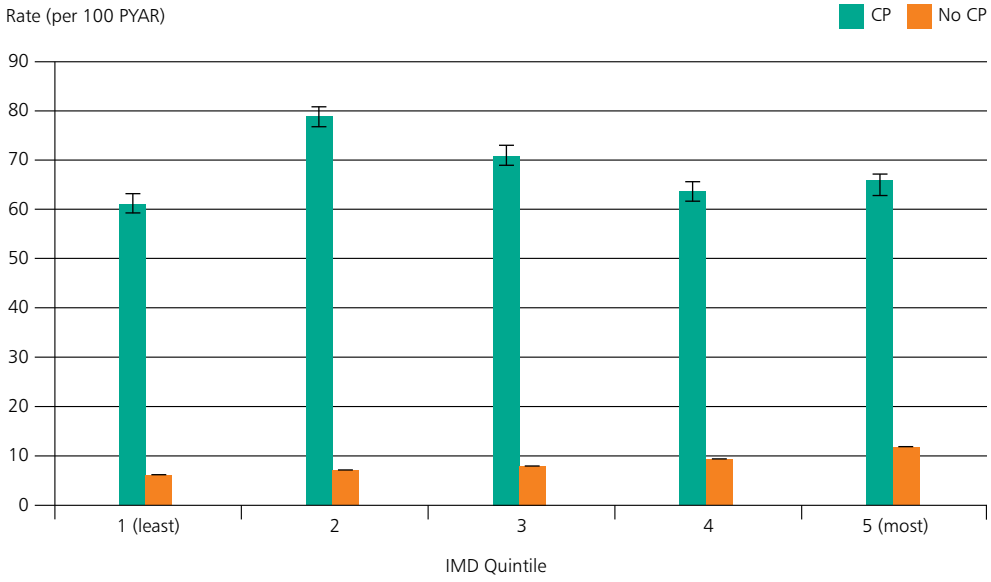

Figure 10.4 Rate of hospital admissions per 100 child years for children and young people with and without a cerebral palsy by IMD quintile (CPRD: England HES Linked)

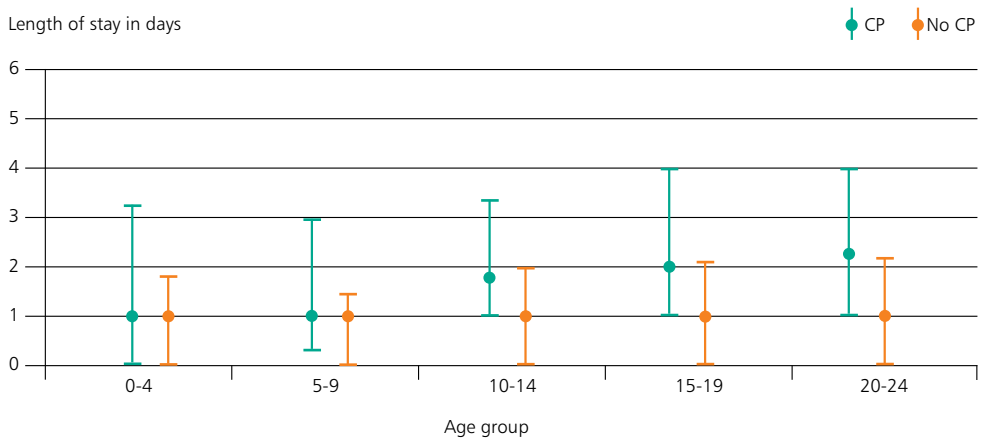

Figure 10.5 Median (IQR) length of stay (in days) of hospital admissions between 2004-2014 for children and young people with and without a cerebral palsy by age group (HES England; NHS Digital)

The rates of day case admissions were significantly greater for children and young people with a cerebral palsy (Figure 10.6) than for those without (Figure 10.7). The rate decreased with age. The rate ratio between those with cerebral palsy and those without decreased as the age groups increased (Overall rate ratio for hospital admissions for those aged 0-4 years old was 15 vs. 4 for those 20-24 years old).

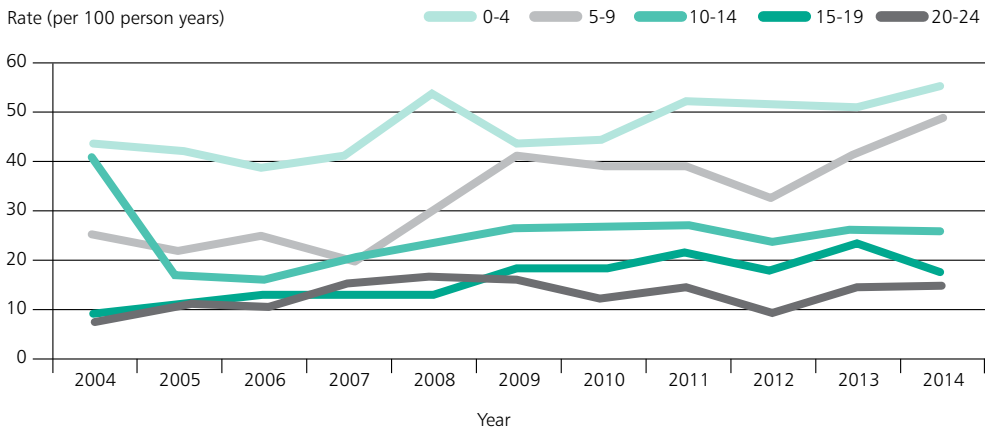

Figure 10.6 Rate of day case admissions per 100 person years at risk by age for children and young people with one of the cerebral palsies between 2004 – 2014 by year and age group (CPRD: England HES Linked)

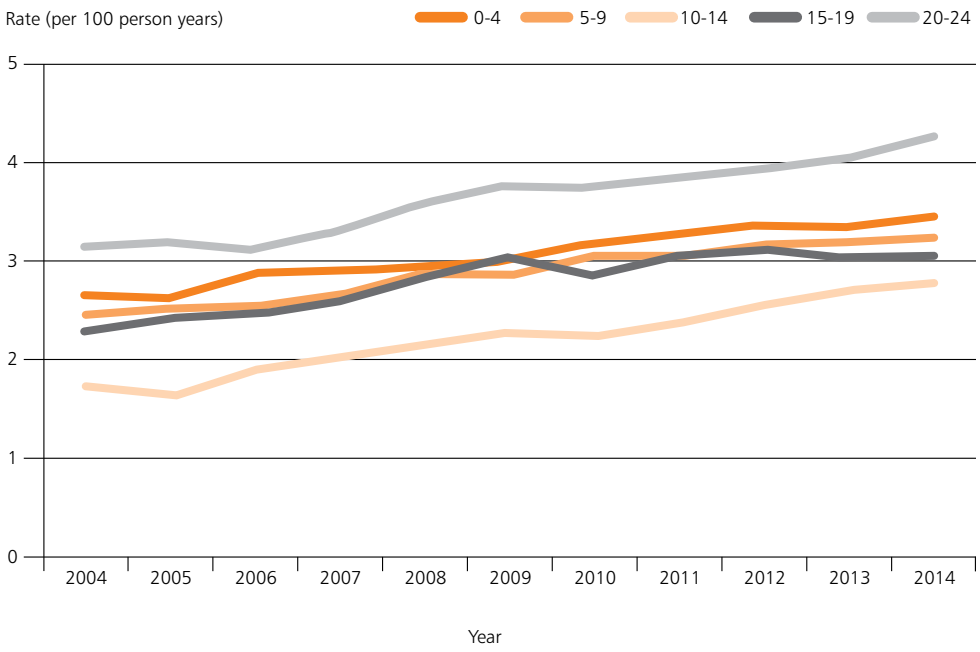

Figure 10.7 Rate of day case admissions per 100 person years at risk by age for children and young people without one of the cerebral palsies between 2004 – 2014 by year and age group (CPRD: England HES Linked)

The specialities that were mostly involved in day case admissions were neurological, trauma and orthopaedics and paediatrics. By contrast for children and young people without cerebral palsies, dental, ENT, genitourinary and surgery prevailed (Figure 10.8). The pattern of specialties most commonly involved for children and young people with the cerebral palsies may well reflect day case admissions for clinical interventions such as botulinum toxin etc. As seen in the outpatient data there was an under representation of dental specialties for those with a cerebral palsy.

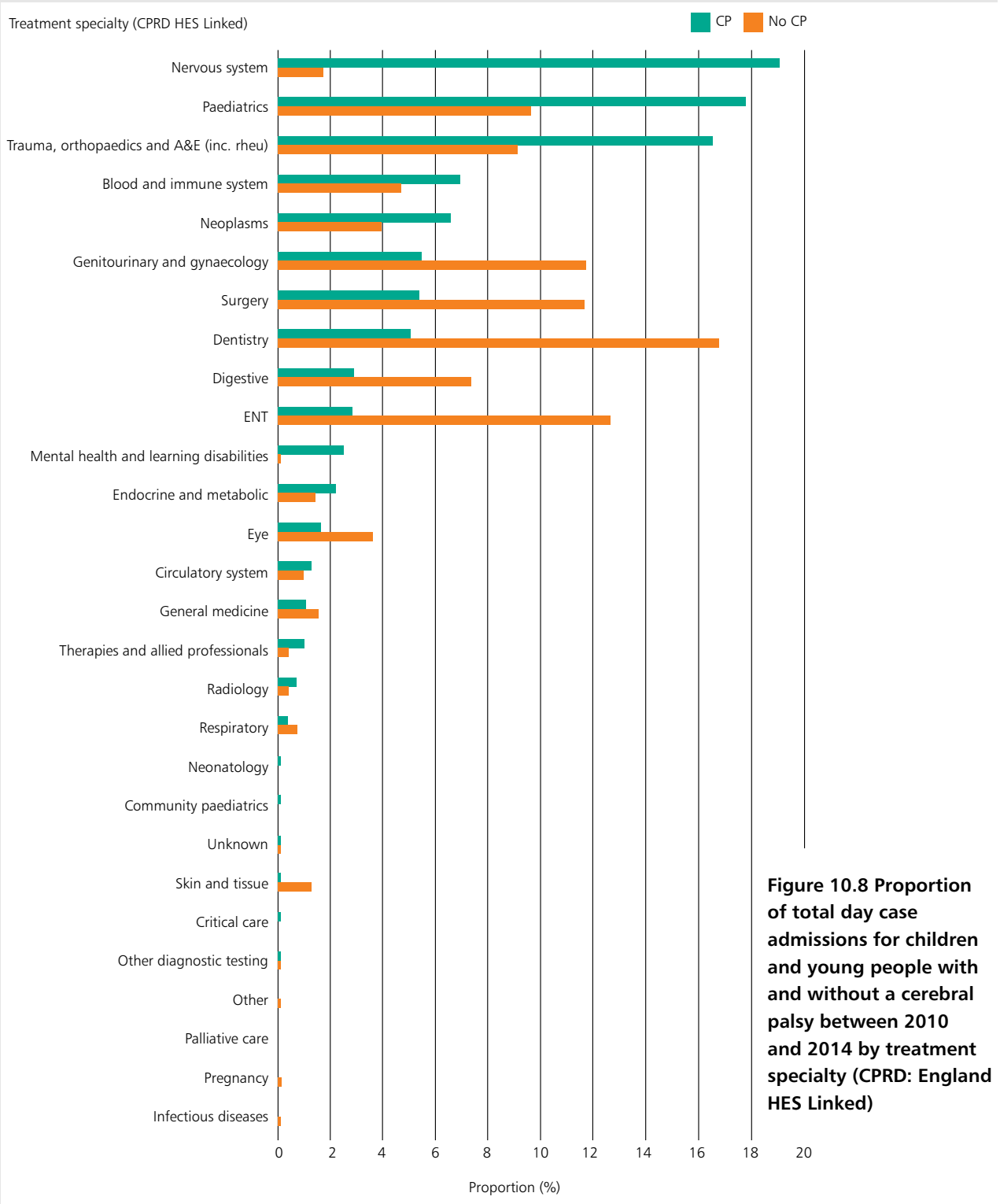

Figure 10.8 Proportion of total day case admissions for children and young people with and without a cerebral palsy between 2010 and 2014 by treatment specialty (CPRD: England HES Linked)

Overall, the proportion of elective admissions within NHS Digital HES APC data recorded (42.9% (95% CI: 42.7 -43.1%)) was significantly greater for children and young people with a cerebral palsy than for those without (16.8% (95% CI; 16.7-16.8)), and decreased between 2004 and 2010 for both groups (Figure 10.9).

The same trend of admissions was seen in Wales (PEDW), Scotland and Northern Ireland. Elective admissions accounted for 56.9% of admissions for children and young people with cerebral palsy vs. 15.3% for those without in Northern Ireland, 25.9% vs. 11.6% for Wales and for the period 2008-2014 the proportion with elective admissions was 43.7% for those with a cerebral palsy vs. 20.6% for those without, in Scotland.

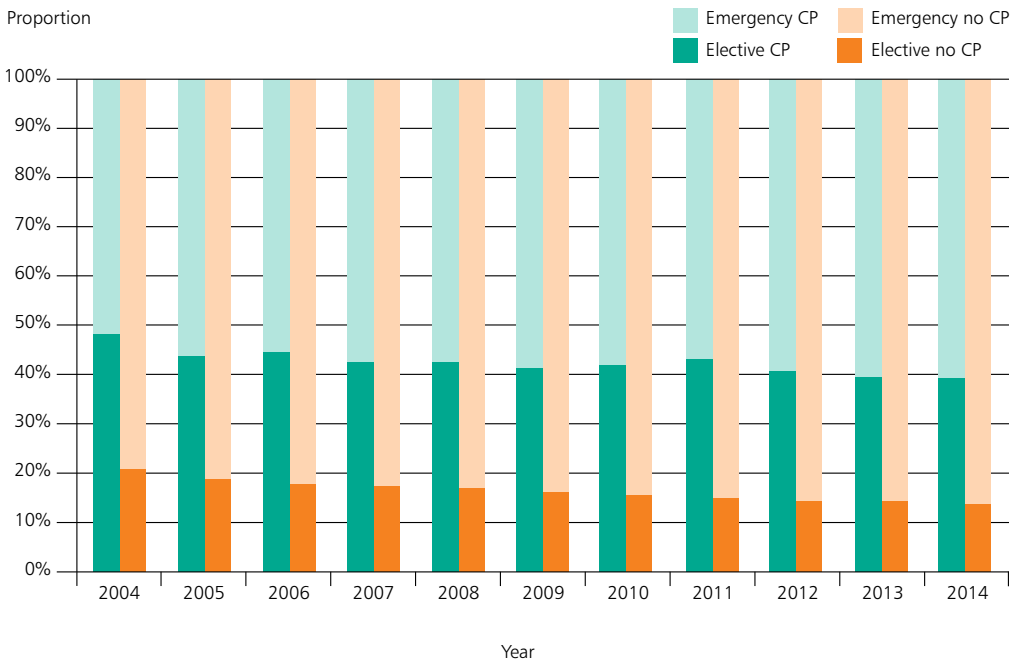

Figure 10.9 Proportion of emergency and elective hospital admissions for children and young people with and without cerebral palsies 2004-2014 (HES England: NHS digital, 4N person spell) (maternity admissions excluded)

The three most common primary diagnostic categories for elective admissions were neurological, mental health and behavioural and musculoskeletal concerns for children and young people with one of the cerebral palsies (Figure 10.10). For emergency admissions these were respiratory, neurological, external causes and injury and poisoning (Figure 10.11).

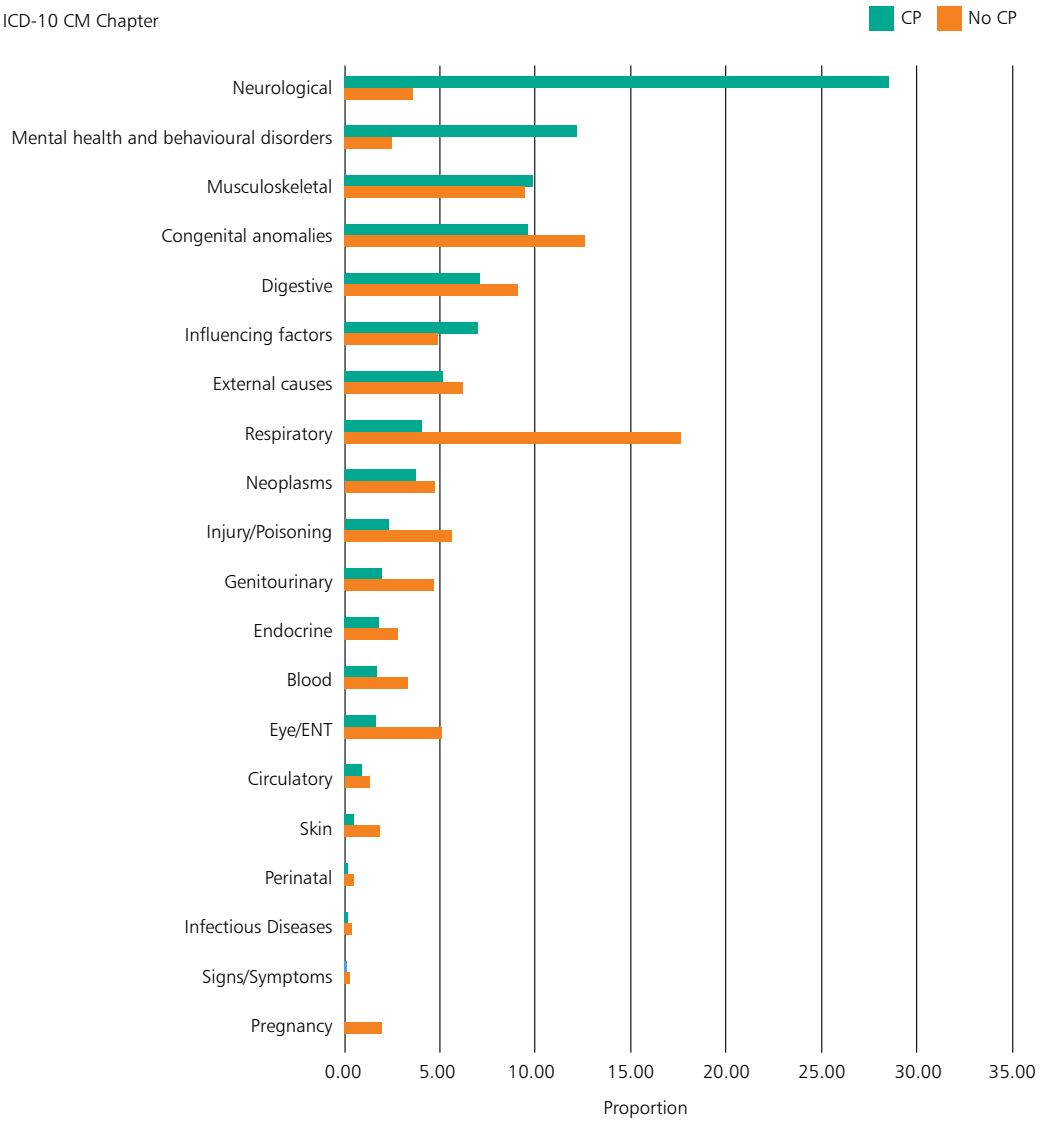

Figure 10.10 Proportion of elective hospital admissions according to primary diagnosis for children and young people with and without a cerebral palsy by ICD-10 Chapter (cerebral palsy n=102,682; No cerebral palsy n=2,092,957) (HES England: NHS Digital, 4N person spell)

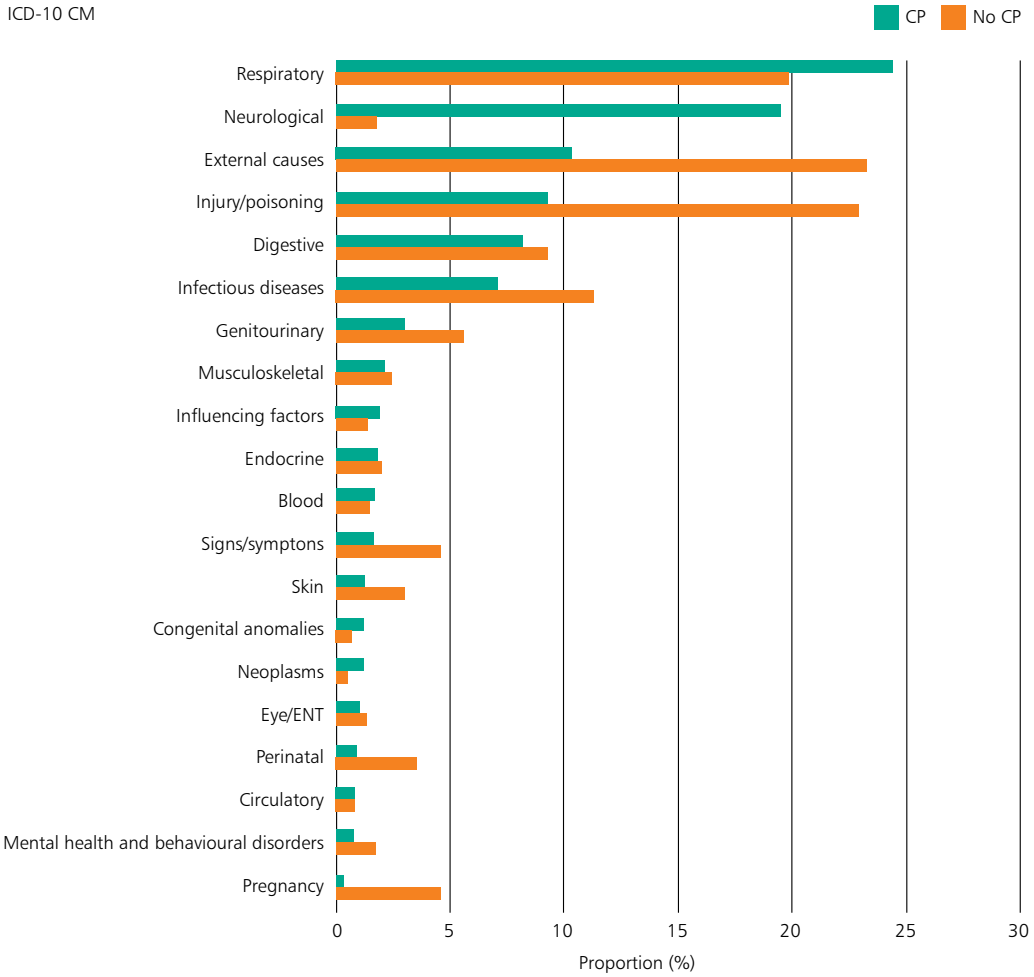

Figure 10.11 Proportion of emergency hospital admissions according to diagnosis for children and young people with and without a cerebral palsy by ICD-10 CM Chapter (cerebral palsy n=175,438; no cerebral palsy n=9,579,888) (HES England: NHS Digital, 4N person spell)

The data in Figure 10.12 includes all procedures performed at any time during the study period regardless of procedure position and regardless of the type of hospital admission (ordinary, day case etc.). The rate of procedures within the total study period for children and young people with a cerebral palsy was 231 per 100 person years at risk and the rate for those without a cerebral palsy was 23 per 100 person years at risk.

Whilst the proportion of operative, diagnostic, neurological and upper digestive tract procedures for children and young people with a cerebral palsy greatly exceeded that for those without the condition, the proportion of dental (mouth), dermatological, ear nose and throat procedures were amongst those that were lower for the cerebral palsy population. [11]

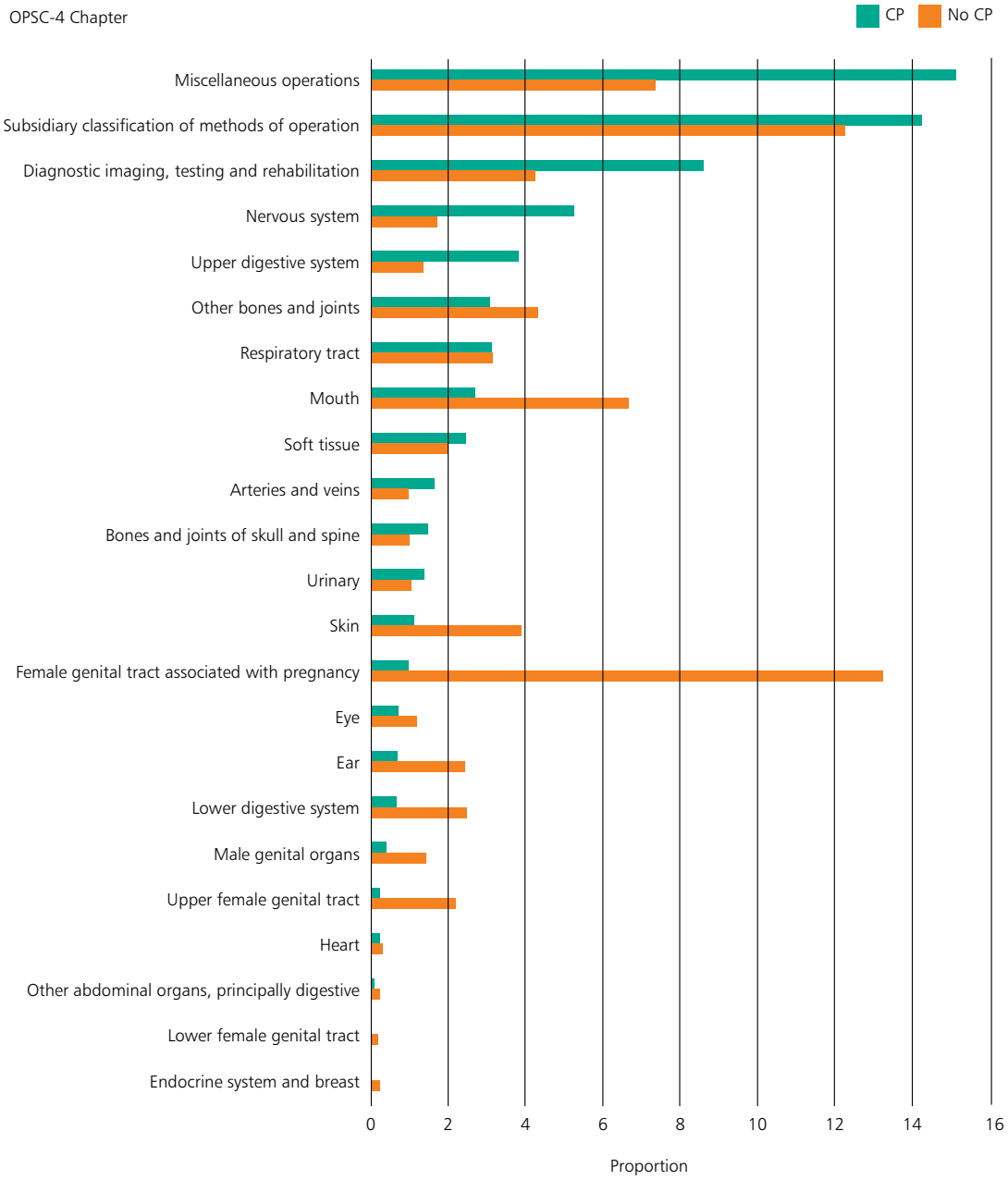

Figure 10.12 Proportion of hospital admissions according to procedures undertaken for children and young people with and without a cerebral palsy by OPSC- 4 Chapter codes (cerebral palsy n=175,438; no cerebral palsy n=9,579,888) (CPRD: England HES Linked)

Many children, young people and young adults with a cerebral palsy have their overall healthcare needs managed in the community, some under the supervision of a multidisciplinary neurodisability team. If admitted to acute general hospitals for whatever reason this offers an opportunity for interface between appropriate specialist teams and the (wider) MDT and therefore potential for improvement in overall patient care.

When admitted to hospital one in three patients with a cerebral palsy in this study did not have a recorded neurodisability lead and this was least likely to be the case in young adults. This important detail was found in only 240/380 (63.2%) records reviewed for children and young people and in 31/133 (23.3%) of young adults with cerebral palsies. [12]

It was also unclear in case notes how the cerebral palsy affected mobility in 101/333 (30.3%) patients who were admitted as inpatients. An important descriptor of motor ability (GMFCS level) was assessed and documented on admission to acute general hospitals in only 51/405 (12.6%) cases, and in just 6.3% of cases thereafter. If information from lead clinicians for neurodisability had been available at this point there would potentially have been better knowledge of GMFCS level since this was recorded by them in almost all cases (211/221). See also Figure 8.3. These data provide an example of where improved routine recording and communication of a key descriptor of function which is assessed by neurodisability teams could facilitate inpatient care if it were made available. Patient held records might also offer a partial solution to the problem, and may be particularly beneficial for patients with the most complex needs and would encourage patient autonomy. [8] (See Appendix 1)

The range of associated medical conditions identified by reviewers is shown in Table 10.1.

Table 10.1 Documented associated medical conditions

	Present	Documented in the case notes	Documented in a clinic letter
Epilepsy	330	275	221
Constipation	179	103	125
Gastro-oesophageal reflux disease	214	138	148
Feeding and swallowing issues	304	231	204
Drooling	130	65	65
Airway issues	158	131	103
Respiratory issues	237	205	144
Scoliosis	148	79	101
Sleep issues	141	58	97
Nutritional issues	258	186	166
Behavioural/Emotional issues	123	73	84
Presence or not of pain	202	159	106

Answers may be multiple

Overall symptom management on admission was assessed by reviewers to be adequate for 299/333 (89.8%) admitted and 136/158 (86.1%) day case patients, but inadequate for 34/333 (10.2%) admitted and 22/158 (13.9%) day case patients. However, other unmet needs were reported by reviewers in 52/237 (21.9%) admitted and 13/110 (11.8%) day case patients, which were evidenced as addressed for 25/50 admitted and 7/12 day case patients, but not addressed for 22/50 admitted and 4/12 day case patients.

Admission also offers an opportunity to review wider aspects of care such as nutrition. However some inpatient wards did not have the appropriate equipment such as slings and hoists available to weigh patients accurately, and in many this was not even estimated. 9

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.

Whilst several other teams were frequently involved with care whilst the patient was in hospital there were very few multidisciplinary team (MDT) discussions. Even though some patients were admitted for very short periods of time offering little opportunity for face to face discussion, the overall mean duration of admission was 7.7 days with a Median of 4 days. However multidisciplinary team meetings occurred for fewer than one in five patients. This may constitute missed opportunities for better joined up care. 7

There were very few examples in cases that were reviewed of this occurring.

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.

Whilst this case illustrates a longer admission there were also patients where it was clear that more opportunities to review and maximise care should have been used.

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 multidisiplinary team which had not been maximised, with consequent deterioration in patient wellbeing.

Clinicians responsible for inpatient admission felt that delays in first assessment for patients with a cerebral palsy were generally minimal (Table 10.2).

Table 10.2 Delays in first assessment

	n=	%
Yes	13	2.9
No	428	97.1
Subtotal	**441**	
Unknown	98	
Total	**539**	

Where data was returned the majority of patients (elective and emergency) were seen by a member of medical staff within six hours of admission (256/273; 93,8%). However, data was missing in 263/536 (49.1%) cases.

Grade and specialty of first assessment

Two-thirds of patients 263/447 (58.8%) had their first medical assessment performed by a consultant or senior specialist trainee. In most they were seen by a specialist in paediatrics (55.1%), however 14% were seen by a general or other medical specialty and 10.2% by orthopaedics. In 135/536 (25.2%) patients this question was not answered by the senior admitting clinicians. This may be because of poor/incomplete recording of the episode in the patient notes.

Timing of senior review

The RCPCH and RCP have stated that emergency admissions should receive senior review by a consultant or a senior doctor with equivalent competences/level of responsibility within 14 hours of admission (Figure 10.3). In total and where timings were recorded 180/247 of all patients admitted (72.9%) were seen by a consultant within 14 hours. Just 116/170 patients (68.2%) admitted urgently or as an emergency were seen within 14 hours by a consultant. The purpose of early senior review is generally to provide timely decision making and these data suggest that this was more likely to occur in elective than urgent or emergency cases.

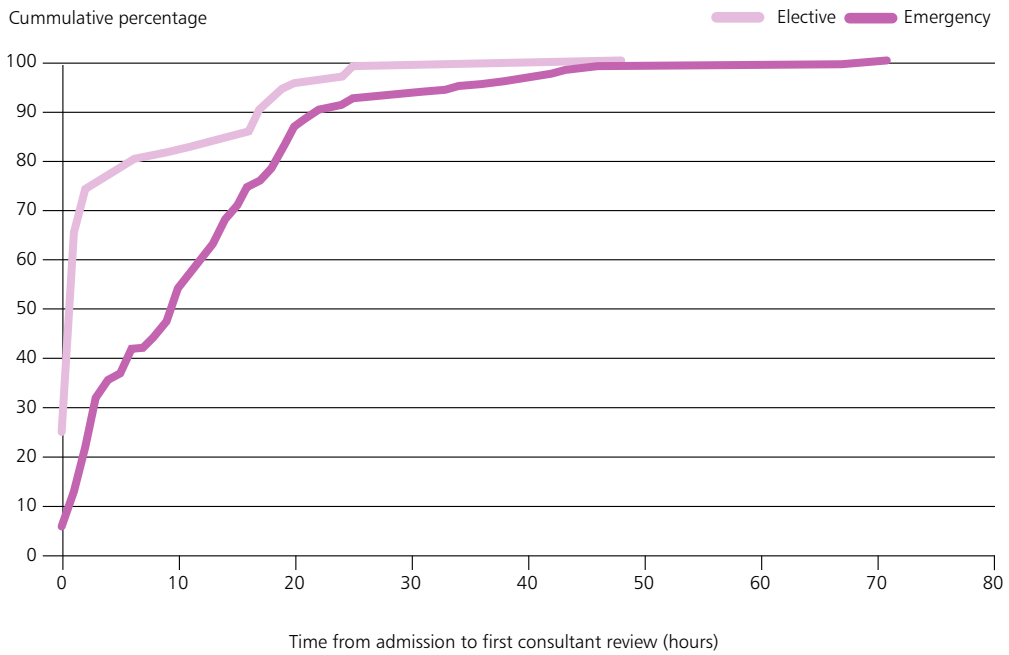

Figure 10.13 Time from admission to first consultant review

The seriously ill patient

About a quarter of patients with a cerebral palsy and admitted to hospital were seriously ill (75/321; 23.4%) Table 10.3. This was defined as a patient who required or potentially required critical care at Level 3 whether their condition was medical or surgical. A recent seven year study from Australia has also shown that patients with the cerebral palsies have a higher rate of presentation with illness with higher levels of acuity than the general population of the same age.[44]

Table 10.3 The patient was seriously ill on admission

	n=	%
Yes	75	23.4
No	246	76.6
Subtotal	**321**	
Unknown	6	
Not answered	10	
Total	**337**	

Virtually all seriously ill patients (70) had long-term/chronic comorbidities, often more than one. The most common was epilepsy (57/70) and/or lung disease (24/70) (Table 10.4).

Table 10.4 Comorbidities of the seriously ill patient

	n=
Epilepsy	57
Lung disease	24
Scoliosis	22
Endocrine disease	5
Congenital heart disease	1
Other	27
Total	**70**

**Answers may be multiple*

Many patients also had "associated conditions" (65/73). For about half this included gastro-oesophageal reflux (32) and/or nutritional problems (34). A substantial number had airway (25) and/or respiratory issues (33).

Many of those patients who were seriously ill on admission were reliant on additional technologies, with most requiring artificial feeding and a quarter receiving ventilation or continuous positive airway pressure (CPAP) prior to this hospital admission (Table 10.5).

Table 10.5 Additional technologies required by the seriously ill patient

	n=
Gastrostomy or other feeding tube	55
Ventilation/CPAP	15
Hearing aid(s)	3
Hoist for transfer	25
Other	4
Subtotal	**58**
Not answered	17
Total	**75**

**Answers may be multiple*

The 2015 RCPCH revised acute care standards state that all children admitted to a paediatric department with an acute medical problem should be seen by a healthcare professional with the appropriate competences to work on the tier two (middle grade) paediatric rota within four hours of admission.[45]

Table 10.6 shows that most seriously ill patients with a cerebral palsy, where data was available, underwent a medical assessment within the first 4 hours following admission. However, in 19/75 patients the data on timings were incomplete and could not be provided by responsible admitting clinicians.

Table 10.6 Timing of medical assessment - seriously ill patient

	n=
On admission	16
4 hours or under	16
5 - 10 hours	4
More than 10 hours	3
Assessment prior to admission	17
At least one date or time missing	19
Total	**75**

In sick patients it is particularly important to have a baseline set of observations and other essential patient parameters (e.g. weight) on which to base management decisions and monitor change. In all patient groups early warning scoring on admission can assist with triage and allocation of the patient as to the most appropriate level of care/nurse dependency. An early warning score (EWS) was recorded in 79% 298/377 of all patients on admission but was recorded slightly more often (in 84%) in the seriously ill. Whilst there is no universal agreement as to the most important elements within a paediatric physiological scoring system to identify serious illness, the use of a Paediatric Early Warning Scores (PEWS) is recommended by the RCPCH and others in the triage of all hospitalised patients.[46] Patients with chronic neurodisability that are admitted to hospital are more likely to have multiple associated co-morbidities and even when well their acuity may differ markedly from other children and young people when admitted e.g. in the context of elective surgery. Certain parameters of the score may be more difficult in the presence of high levels of neurodisability e.g. recording blood pressure if the patient has a movement disorder or severe contractures. At least one evaluation of PEWS has specifically included patients with a cerebral palsy in the patient cohort and noted no deterioration in score performance.[47]

Despite the fact that not all patients with serious illness were seen within 4 hours of admission by a member of the medical team and in others this was not recorded, admitting clinicians felt that delays in identifying serious illness and providing resuscitation in all emergency admissions were minimal and reported that in just eight patients presenting as an emergency (3.1% of total admissions) there were delays in providing specific treatment.

Where delay occurred in those patients who were admitted as an emergency there were four cases where there was diagnostic uncertainty, in three delays was attributed to technical difficulty and in just two uncertainties about how aggressive treatment should be. Whilst these are common reasons for delay in a paediatric population, their significance may be greater given the possibility of severe associated co-morbidity.

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.

Generally the largest proportion of seriously ill patients who present to hospital in the paediatric age range are under the age of five years and this age group of patients more frequently require paediatric critical care admission.[48] Whilst numbers in the sample were small and some data were missing, the patients with a cerebral palsy and serious illness in this study broadly reflected this age group. However, there were also a number of young people and young adults admitted with serious illness (28/84 in the

Table 10.7 Age of the patients who were seriously ill on admission

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Subtotal	Not answered	Total
	n=	n=	n=	n=	n=	n=	n=	n=
Yes	19	17	11	13	15	**75**	0	**75**
No	56	63	42	33	51	**245**	1	**246**
Subtotal	**75**	**80**	**53**	**46**	**66**	**320**	**1**	**321**
Unknown	3	3	2	2	6	**16**	0	**16**
Total	**78**	**83**	**55**	**48**	**72**	**336**	**1**	**337**

15-25 age range) (Table 10.7). This may reflect the longer term significance of severe chronic illness in those patients with greater levels of neurodisability. This also makes it more likely that acute respiratory and/or neurological events will lead to decompensation to a level requiring intensive care admission. This was reflected in cases reviewed and has been reported in similar patient populations.[31,49]

It is reflected in the routine national data findings within this study stated on page 121.

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.

Critical care admission

Children, young people and young adults with a cerebral palsy may require all or part of their hospital care delivered within a critical care environment as a result of acute severe illness and/or particular technology dependencies. Admissions may be planned (e.g. peri-operative) or unplanned. In this study 5% (25/471) of patients were admitted directly to critical care. This included elective as well as emergency admissions.

Of all patients who were admitted 1 in 10 required ventilation or CPAP (Table 10.8). In some hospitals use of non-invasive ventilation, CPAP and/or a tracheostomy will dictate some level of critical care provision, particularly if the patient is very young and/or has other complex co-morbidity.

Table 10.8 Technologies/equipment required by the patient to facilitate day to day care

	n=	%
Gastrostomy or other feeding tube	231	81.9
Ventilation/CPAP	32	11.3
Hearing aid(s)	13	4.6
Hoist for transfer	122	43.3
Other	24	8.5
Subtotal	**282**	
Not answered	254	
Total	**536**	

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.

Clinicians were asked whether patients were admitted to critical care at a later date during their admission. Thirty patients were subsequently referred to critical care with the majority of referrals occurring during the normal working day, and nine overnight (18.00 to 08.00). The majority of the critical care admissions (32/49) where data was provided were unplanned.

Not all hospitals have paediatric critical care facilities on-site but almost all will have a general critical care facility. Initial referrals to critical care were most commonly to on-site intensive care teams be they paediatric or primarily adult.

Table 10.9 Group of clinicians to which the referral made

	n=
On-site paediatric critical care team	13
On-site adult critical care team	14
Off-site paediatric critical care or transfer team	3
Off-site adult critical care team	0
Total	**30**

10/13 referrals to on-site paediatric critical care were for patients aged 15 years or under. However, there were three referrals to off-site paediatric critical care and all were of patients aged 18 years (Table 10.9). When paediatric critical care is not available on-site, initial resuscitation and stabilisation and/or or short term care is often initiated on a general (adult) unit with subsequent transfer as required or requested due to local unit competences. In total there were around 600 admissions of children and young people under 16 years in 2015 to adult general critical care and according to recent national PICANet data. Most of these patients were in the 11-15 age range.[48]

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.

Overall there were 11 admissions of patients of 18 years and older to critical care. Whilst numbers are very small this tended to mirror the data already presented suggesting that there were slightly more older patients with a cerebral palsy that are admitted with serious illness and this may result in critical care admission. Many of these patients have very complex needs and some had pre-existing Emergency Health Care Plans and "Do not attempt cardiopulmonary resuscitation" (DNACPR) plans in place. However case reviewers found that in only 241/305 (7.9%) of cases was there an Emergency Health Care Plan recorded in the patient notes. DNACPR status was recorded in just 124/176 (70.4%) of emergency admissions. Ideally clinicians who know the patient and family well and been involved with care for some time are involved in such important decision making well in advance of a serious illness or event such as emergency admission to hospital. This requires a "team approach" and the involvement of senior clinicians is extremely important as is the documentation and ready availability of a well worked Emergency Health Care Plan which the patient and family own and recognise. The lack of robust systems for good communication in this circumstance is highlighted in chapter 6. It is particularly important that this advance planning takes place well before transition to adult services. 12 6

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.

The care of children, young people and young adults in paediatric critical care was also reflected in the national datasets.

National routine data

PICANet is a clinical audit that collects critical care data across all 34 paediatric intensive care units (PICU) in the UK and Ireland and 6 specialist transport organisations. PICANet data were analysed for all admissions (2008-2014). Whilst it is standard practice for PICUs to provide healthcare for children (0-16 years) the dataset received from PICANet included data for children and young people aged 0-24 years 2008-2014.

During this time period 3,314 (2.65%) admissions were for children and young people with a cerebral palsy (3,314) from a total of 121,646 PICU admissions (Table 10.10). This is approximately 10 times greater than would be expected given that the estimated population prevalence of a cerebral palsy is 0.2-0.3%. There was little variation in the proportion of admissions for cerebral palsy between 2008 and 2014.

Table 10.10 Demographic details of PICU admissions for children and young people with and without a cerebral palsy by age and gender at admission (n=3,301) (2008-2014) (PICANet data)

	Cerebral palsy (n=3,314)	No cerebral palsy (n=121,646)	All admissions (n=124,960)
Male	1,867 (56.3%)	68,768 (51.0%)	70,635 (56.5%)
Female	1,447 (43.7%)	52,842 (48.5%)	54,289 (43.4%)
Ambiguous	0 (0%)	30 (0.4%)	30 (0%)
Unknown	0 (0%)	6 (0.1)	6 (0%)
Age Group			
<1	102 (3.1%)	55,972 (46.0%)	56,074 (44.9%)
1-4	919 (27.7%)	31,414 (25.8%)	32,333 (25.9%)
5-9	901 (27.2%)	13,861 (11.4%)	14,762 (11.8%)
10-14	926 (27.9%)	14,121 (11.6%)	15,047 (12.0%)
15-19	453 (3.7)	6,223 (5.1%)	6,676 (5.3%)
20-24	13 (0.4%)	55 (0.1%)	68 (0.1%)

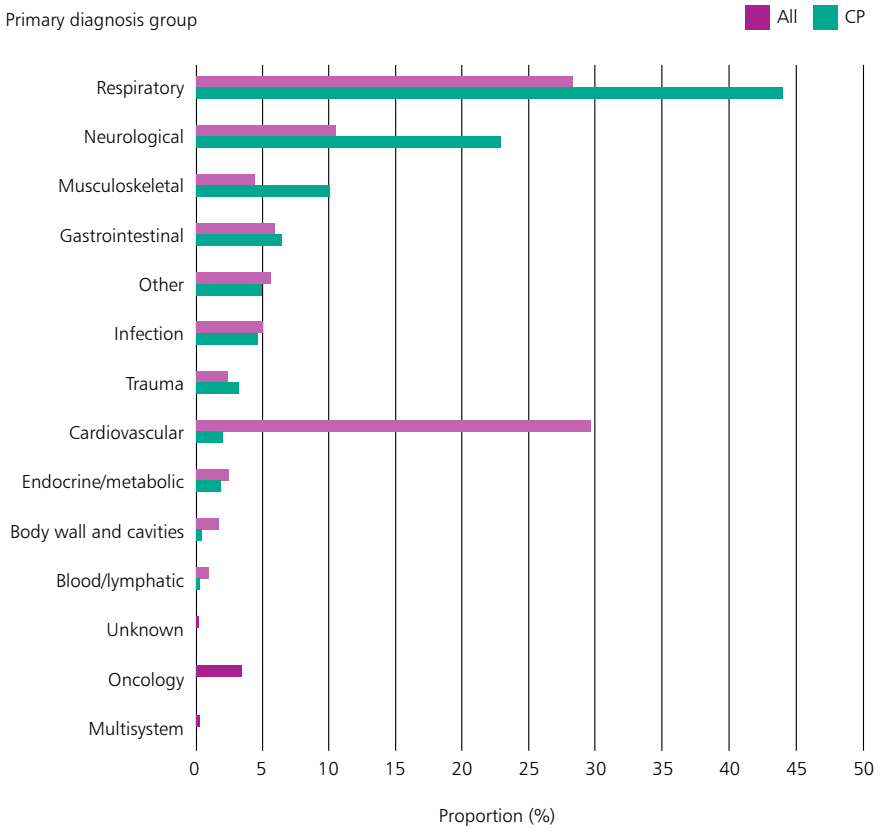

Figure 10.14 Proportion of PICU admissions for children and young people with a cerebral palsy compared with all admissions by primary diagnosis group. (Data presented for 2012-2014 where comparative data were available from the Paediatric Intensive Care Audit Network: 2015 Annual Report (published November 2015): Universities of Leeds and Leicester)

The most common reason for admission to PICU for children and young people with a cerebral palsy was for respiratory conditions (43.8%). Children and young people with a cerebral palsy had significantly greater proportions of admissions for musculoskeletal, respiratory and neurological conditions than for all children and young people admitted to a paediatric intensive care unit (Figure 10.15). Of the 1,322 admissions with a primary diagnosis of a respiratory condition (2008-2014), 339 (26%) were described as lower respiratory tract admissions, 286 (22%) for pneumonia and 202 (15%) for respiratory failure.

Where data were returned, the majority of referrals to critical care were made by a consultant or senior specialist trainee (24/26) and the majority of patients were reviewed by a member of the critical care team on-site (23/28). Most referrals were accepted with just four patients where this was not the case, because severity of illness did not meet the need for critical care.

Overall this data demonstrates that children, young people and young adults with a cerebral palsy are not infrequent users of critical care services, which relates to both acute severe illness and the requirement for additional physiological monitoring and support in association with surgery. Both situations are likely to be less well tolerated when there are longstanding medical co-morbidities and more often seen in association with severe degrees of motor disability. There was no evidence that critical care admission was delayed or refused in this population. The duration of stay on critical care varied markedly and was between one day and just under four weeks.

The majority of patients (46/49) survived to critical care discharge but there was one death (Table 10.11).

In the routine national data the mortality rate was greatest in the 20-24 year olds with a cerebral palsy. There were only a few admissions to PICU in this age group however the high mortality rate reflects that these young adults were likely to have had complex morbidities (Figure 10.18).

Table 10.11 Outcome of the critical care admission

	n=
Patient survived to critical care discharge	46
Patient died on critical care	1
Subtotal	**47**
Not answered	4
Total	**51**

Length of stay and patient outcome for patients with cerebral palsy receiving paediatric critical care was also consistent with the national routine data.

National routine data

Length of PICU stays for a cerebral palsy compared to all admissions (2008-2014)

Children and young people with a cerebral palsy in all age groups except infants (under one year) had longer stays in PICUs than those without a cerebral palsy (Table 10.12); 2.5% (83) children and young people with a cerebral palsy were admitted to PICUs for longer than 25 days and the longest admission was recorded as 133 days (Figure 10.15).

Discharge destination

The majority of children and young people with a cerebral palsy were transferred to a ward within the same hospital and a greater proportion were transferred to HDU compared to non cerebral palsy group across all age groups (Figure 10.16).

Table 10.12 Median length of stay in PICU with IQR

Age group	Cerebral palsy	All admissions
<1	3.0 (1.8-6.3)	3.08 (1.2-6.3)
1-4	2.3 (0.9-5.7)	1.67 (0.9-4.0)
5-9	2.1 (0.9-5.9)	1.36 (0.8-3.2)
10-14	2.7 (1.0-6.0)	1.22 (0.8-3.2)
15-19	1.9 (1.0-5.6)	1.10 (0.8-2.8)
20-24	2.7 (1.3-4.9)	2.39 (0.9-5.3)

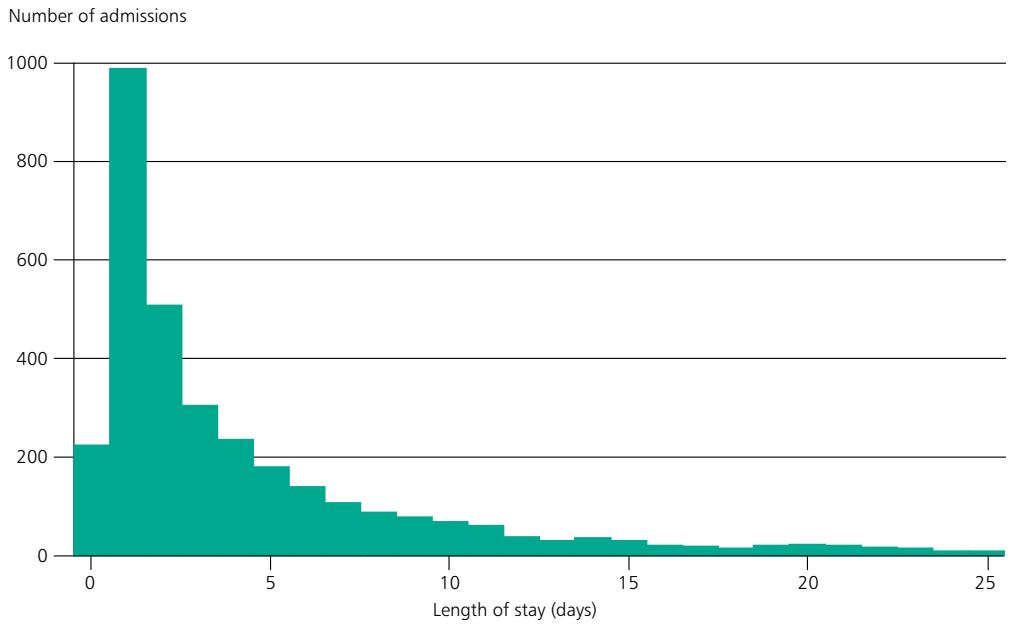

Figure 10.15 Frequency distribution of length of PICU stay for children and young peoplewith a cerebral palsy between 2008 and 2014 n=3,231 (where data were recorded)

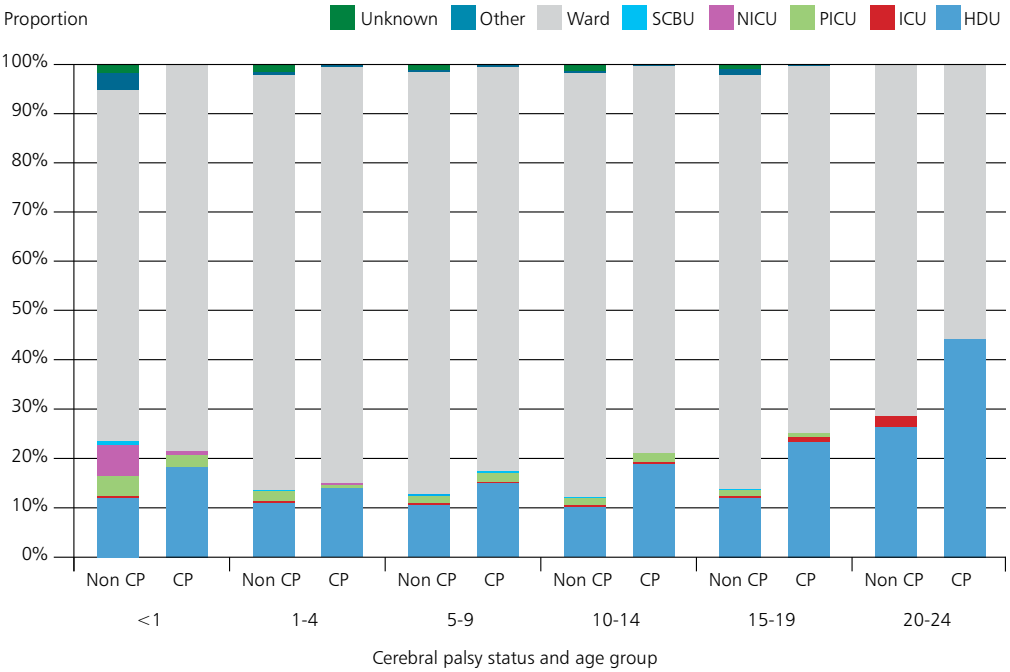

Figure 10.16 Proportion of children and young people with and without a cerebral palsy discharged to another hospital unit by age group (PICANet)

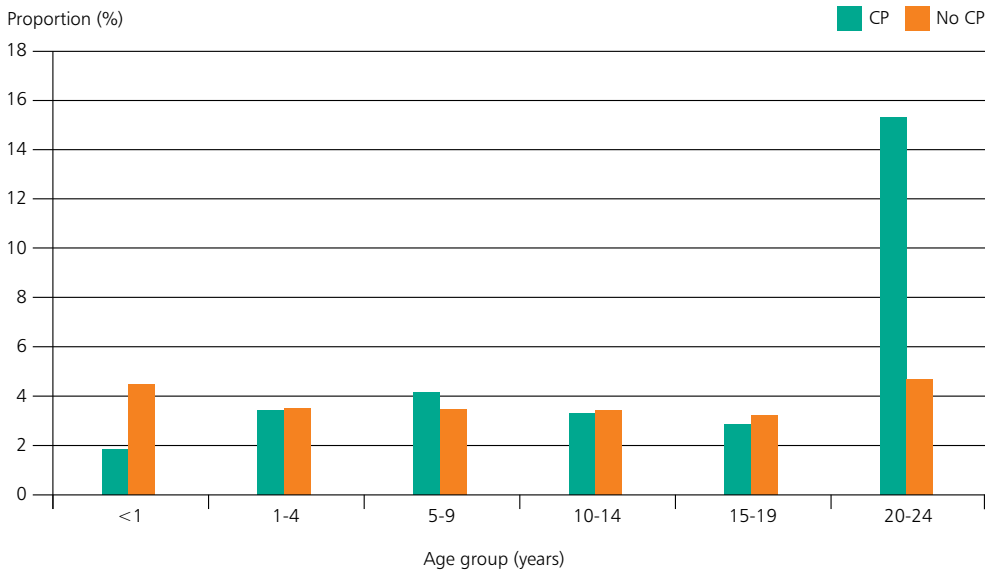

Figure 10.18 Proportion of admissions that resulted in a death in PICUs for children and young people with and without a cerebral palsy by age group

Palliative care

Overall there were three deaths recorded in this study. Where children and young people required palliative care, there was considerable variation in the information provided from various organisations as to who provided it, as shown in Table 10.13. The data collected here suggested that it was most likely to be provided by paediatricians (either general or with specialty training) and/or community paediatric nurses but with significant input from general practitioners. There was considerably less representation from palliative care specialists in organisations responding on behalf of paediatric or adult inpatient care.

NICE standards for paediatric palliative care recently published stress the need for both specialist care leadership and multidisciplinary team involvement to supporting the family.[50]

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.

Table 10.13 Providers of palliative care

	Paediatric outpatient care	Paediatric community care	Paediatric inpatient care	Adult inpatient care
General practitioner	40	42	NA	18
General paediatrician	54	47	60	NA
Community paediatrician	43	51	45	NA
Paediatrician with specific expertise in disability (disability, community or general with specific expertise) and palliative care	39	46	44	NA
Paediatric palliative care consultant	45	58	36	NA
Palliative care physician	NA	NA	NA	37
Adult physician	5	1	NA	24
Adult palliative care consultant	8	8	8	NA
Community children's nurse	53	55	53	NA
Specialist palliative care nurse	41	31	29	NA
Specialist nurse	NA	NA	NA	31
Other (please specify)	2	3	6	23
Subtotal	**82**	**78**	**84**	**43**
Not answered	2	3	6	23
Total	**84**	**81**	**90**	**66**

Duration of overall admission, discharge planning and outcomes

Admission duration

The duration of admission varied considerably (Figure 10.18). Of those cases reviewed, and where data was recorded, 93.8% of patients were admitted for fewer than 21 days and 68.4% fewer than seven days. The mean duration of admission was 7.6 days with a median of four days.

Discharge planning and communication

Given the multiple co-morbidities and additional needs which patients with a cerebral palsy may have, communication at discharge is a particularly important opportunity to update and inform members of the wider multidisciplinary team. Admitting clinicians responsible for inpatient care were asked about the content and inclusion of information from relevant MDT members involved in the inpatient admission in provision of communication at discharge.

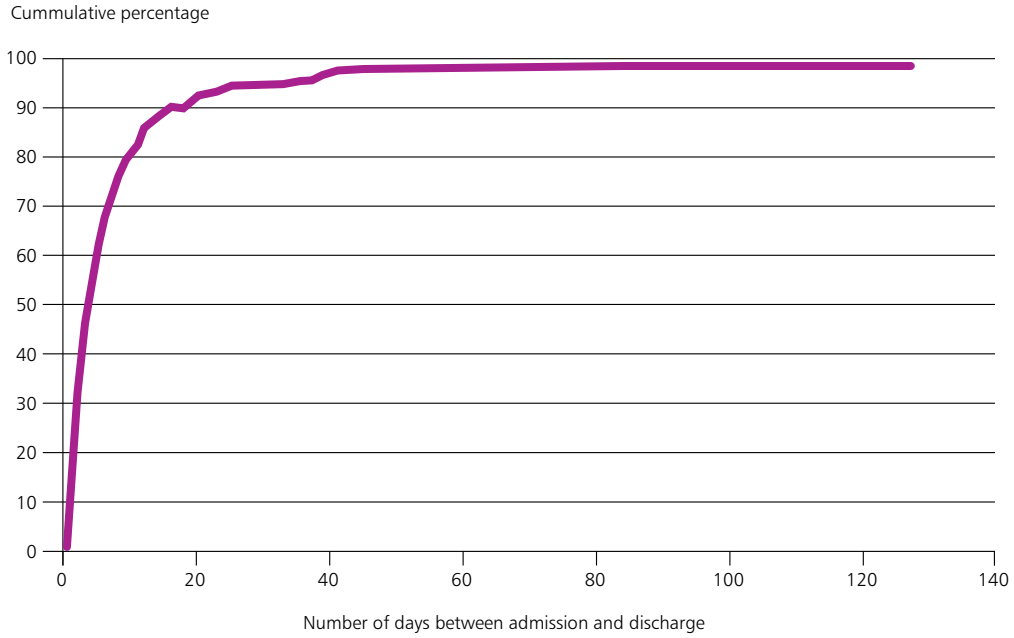

Figure 10.18 Duration of admission

Chapter 6 on 'communication' highlighted that there was evidence of multidisciplinary discharge planning as reported by case reviewers for 105/287 (36.6%) patients, but not for 182/287 (63.4%). 6

Variation in the reported adequacy of communication on discharge by case reviewers is shown in Table 10.14.

The quality of this communication varied and was stated by reviewers to be better with patients and families (adequate in 93.1% and 86.7% respectively) than with lead clinicians and the patients usual MDT.

Table 10.14 Adequate communication - reviewers' opinion

Admitted patients	Patient and their family		General practitioner		The lead clinician for cerebral palsy management?		The patient's usual MDT		Community physiotherapy services	
	n=	%	n=	%	n=	%	n=	%	n=	%
Yes	244	93.1	242	86.7	120	53.8	84	42.9	70	38.0
No	18	6.9	37	13.3	103	46.2	112	57.1	114	62.0
Subtotal	**262**		**279**		**223**		**196**		**184**	
Unable to answer	43		34		57		75		84	
Not applicable	44		36		21		27		30	
Not answered	3		3		51		54		54	
Total	**352**		**352**		**352**		**352**		**352**	

Clinicians in charge of general hospital care stated that in only 210/391 (53.7%) patients did discharge communication contain input from relevant members of the inpatient team. Communication did not necessarily contain information relevant to all members of the multidisciplinary team involved in providing care after admission (Table 10.15) which occurred in 190/368 (51.6%) cases. In a total for 168 cases this information was unknown or was not provided.

Table 10.15 Communication included information to all relevant members of the MDT providing care after admission?

	n=	%
Yes	190	51.6
No	178	48.4
Subtotal	**368**	
Unknown	101	
Not answered	67	
Total	**536**	

Adequate 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 to have occurred in 153/234 (65.4%) cases reviewed, but was felt to be inadequate in 81/234 (34.6%) cases. Reviewers were unable to answer in 82 cases and did not answer this question in 36 cases. This is covered in more detail in chapter 8

Outcome of the admission and overall assessment of inpatient care

Admitting clinicians stated that the majority of patients were discharged with either an improved level of function (25.7%) or the same level as before admission (70.7%).

Table 10.16 Outcome of the admission

	n=	%
Discharged with and IMPROVED level of function/mobility	138	26.9
Discharged with the SAME level of function/mobility	360	70.2
Discharged with a WORSE level of function/mobility	8	1.6
Discharged for a higher level of support including critical care	4	0.8
Death	3	0.6
Subtotal	**513**	
Not answered	23	
Total	**536**	

When the study sample was divided into those patients admitted for any medical reasons vs. those admitted for planned procedures or surgery there were a larger number of patients with planned admissions who left hospital with improved function, which occurred in half of the planned admissions as opposed to about a third of all others. Whilst numbers are small this might be foreseen given that a planned procedure or surgery generally has the explicit aim of improving or rectifying function. In most instances these episodes of care will be undertaken when the patient is relatively well. Patients who underwent emergency medical admission made up the largest number in this study and in these it was least likely that an improvement in function and/or mobility was seen and occurred in only 17.3% (48/277) patients.

Only 12 (2.9%) patients either had a worse level of function or had to be transferred for a higher level of critical care. Three of these patients had initially been admitted for a planned procedure or surgery (Table 10.17). The decision to operate on patients with complex co-morbidity is often a difficult one, the risk of failure is greater and a multidisciplinary team approach is required. This is discussed further in chapter 11 and chapter 7

Table 10.17 Level of function/mobility by admission type

	Elective surgical	Emergency surgical	Elective medical	Emergency medical	Other
Discharged with and IMPROVED level of function/mobility	59	12	8	48	11
Discharged with the SAME level of function/mobility	69	20	20	222	29
Discharged with a WORSE level of function/ mobility	3	0	1	2	1
Discharged for a higher level of support including critical care	0	1	0	2	2
Death	0	0	0	3	0
Subtotal	**131**	**33**	**29**	**277**	**43**
Not answered	4	0	0	5	14
Total	**135**	**33**	**29**	**282**	**57**

Overall quality of general hospital care

Admitting clinicians were asked to comment upon the overall quality of care and whether in their opinion there were aspects of care that could have been improved. In only nine patients there were felt to be preventable or remediable factors in the process of care and these related to delay in recognition or diagnosis in one case and delayed treatment in 1 other. However, In the opinion of the case reviewers and in comparison with community based neurodisability care; overall general hospital care was felt to be less good both for inpatients and day case patients, with room for improvement in both clinical and organisational aspects of care (Figure 10.19).

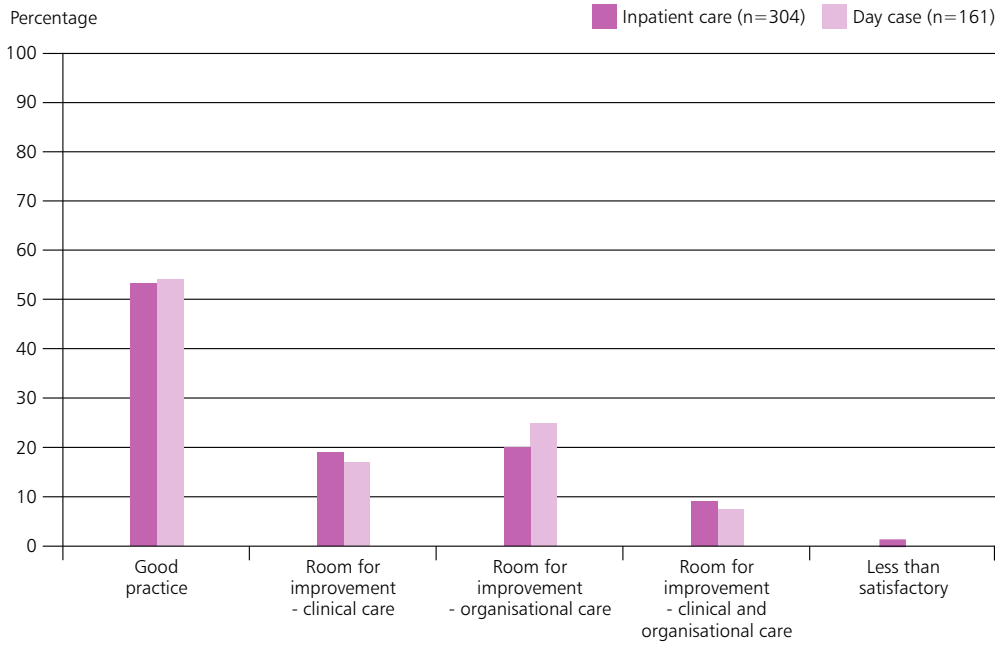

Figure 10.19 Overall quality of care - reviewers' opinion

Overall **inpatient** care was rated as good in 161/304 (53%) cases reviewed. The reviewers stated that there was room for improvement in clinical and/or organisational care in 142/304 (46.7 %). There was one patient where the overall care was felt to be less than satisfactory.

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

Overall **day case patient** care was rated as good in 87/161 (54%) cases reviewed. The reviewers stated that there was room for improvement in clinical and/or organisational care in 74/161 (46%).

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
- 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.

11 – Surgery, procedures and interventions

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Study Advisory Group question: *Are all aspects of care for patients with a cerebral palsy considered for those patients undergoing surgery, particularly perioperative planning and consent.*

Why is this important? *Surgery or interventional procedures are particularly common in this group of patients. It is important that these are planned carefully, communicated well and all members of the multidisciplinary team are aware of what is being undertaken.*

In this study 179/500 patients (35.8%) with a cerebral palsy underwent surgery or a procedure during their admission. This included radiological and endoscopic procedures as well as operative procedures most commonly undertaken under general anaesthesia or sedation (152/175; 86.9%). The majority (153/177; 86.4%) were classed as "planned". This is in keeping with other recent multicentre studies showing that a relatively large number of children with a cerebral palsy undergo surgery.[31] Patients with the cerebral palsies have also been shown in other studies to require more procedures per admission than other patients and for these admissions to generally be longer.[30]

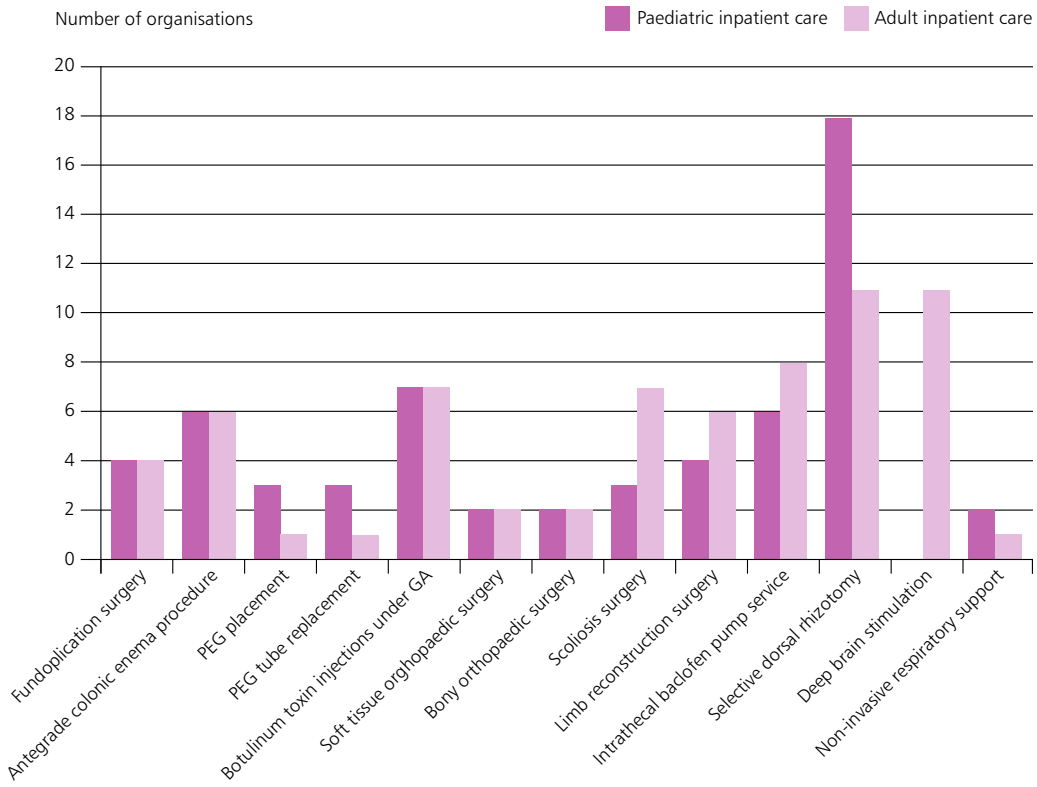

Figure 11.1 Procedures as stated by paediatric and adult inpatient leads as not available in local surgical networks

Respondents from a minority of inpatient organisations stated that they had problems with access to networks of surgical specialty care (Figure 11.1). Where there were, it seemed to be related to particular issues with access to specialist services for spasticity (including botulinum toxin injections, intrathecal baclofen and selective dorsal rhizotomy).

While patients of all ages underwent surgery and procedures a greater number occurred in children over five years, and in young people and young adults (Table 11.1). This differed somewhat from the overall paediatric surgical/anaesthetic population where in data from UK national audits, the greatest level of activity across surgical specialties was in the under five age range much of which relates to correction of congenital anomalies and more minor ENT and dental surgery.[51,52] Some of these issues will still occur in the cerebral palsy population but they will also have a greater number of procedures to facilitate diagnosis, manage nutrition and to treat posture and spasticity.

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.

Table 11.1 The patient underwent surgery or a procedure during the admission

	0-4 years	5-9 years	10-14 years	15-19 years	20-25 years	Subtotal	Not answered	Total
	n=	n=	n=	n=	n=	n=	n=	n=
Yes	18	34	39	39	43	**173**	6	**179**
No	74	87	53	47	59	**320**	1	**321**
Subtotal	**92**	**121**	**92**	**86**	**102**	**493**	**7**	**500**
Not answered	8	7	8	5	5	**33**	3	**36**
Total	**100**	**128**	**100**	**91**	**107**	**526**	**10**	**536**

When NCEPOD looked at the procedures undertaken they were in the main for orthopaedic surgery (including scoliosis surgery), management of reflux and nutritional support and alleviation of spasticity.

Preparation for surgery and multidisciplinary care

Given that most procedures and surgery were planned, paediatric inpatient centres reported whether they had a process in place for multidisciplinary team (MDT) discussion and preparation of patients with the cerebral palsies prior to planned surgery.

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.

Only 43 centres had routine pre-assessment clinics with medical/anaesthetic input and just 19 had a MDT discussion even for major surgery (Table 11.2). MDT preparation for major surgery was a recommendation of the 2011 NCEPOD report.[53] In children requiring complex surgery and many adults having all levels of surgical intervention this is now an established standard of care.[54] The advantages are that pre-assessment allows an opportunity for correction of remediable co-morbidity, and prepares the patient, their family and the team caring for them for the peri-operative pathway.[55] It also allows for timely discussion and reflection on the risks and possible complications of a procedure. The fact that MDT discussion and pre-assessment clinics were not currently the standard of care in all centres for a cohort of patients with a cerebral palsy and having major surgery requires further consideration.

There were 72/88 paediatric inpatient centres where it was stated that they had joint care of surgical patients with medical specialties, when patients were admitted for planned surgery. However, just 37 of them reported that this care was joint at all levels (Table 11.3). Very few organisations had existing guidelines and care plans specifically for peri-operative care of patients with cerebral palsies which included management of common co-morbidities. This is notable given that in some centres patients with neurodisability make up a relatively large population of patients.

Table 11.2 MDT preparation for surgery – organisational systems in place

	n=
MDT discussion prior to all planned major surgery	19
MDT discussion for high risk patients and/or major planned surgery	23
MDT discussion for high risk patients and/or major urgent or emergency surgery	15
Routine pre-assessment clinics with medical/anaesthetic input prior to planned surgery	43
Existing guidelines and protocols for peri-operative care of children and young people with severe neurodisability	8
Specific care plans for particular surgical pathways e.g. scoliosis surgery which include management of common co-morbidities associated with cerebral palsies	15

**Answers may be multiple*

Table 11.3 Joint care of surgical patients with paediatric specialists

	n=
Joint care at all levels	37
Senior advice/input as required	36
Trainee input as required	6
Subtotal	**70**
Not answered	2
Total	**72**

**Answers may be multiple*

Children and young people with neurodisability often have complex medical needs. A team approach with paediatric involvement is recommended and may be particularly important when care is delivered by surgeons and anaesthetists who work predominantly in general/adult practice.[56] 7

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.

In the organisational questionnaire for paediatric inpatient care those units that responded stated that it was 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. Where this was not possible the most common reason was surgical/anaesthetic risk (50/73) (Table 11.4). From free text comments respondents stated that disabled children requiring routine surgery were often referred to a regional tertiary centre.

Table 11.4 Reasons for non-availability of day surgery

	n=
Surgical/anaesthetic risk is felt to be too great	50
Physical facilities are inappropriate in day procedure unit (e.g. lack of access, special beds etc.)	12
Lack of nurse competencies	4
Other (please specify)	27
Subtotal	**93**
Not answered	1
Total	**94**

**Answers may be multiple*

There has also been a relative reduction in availability of local surgical services for children in the DGH in the last 20 years[51,52] and this may have impacted on care of patients with complex comorbidity.

However, there were a number of cases reviewed within this study that underwent day admission for a range of procedures under general anaesthetic (e.g. Botulinum toxin injection, MRI, PEG change), and not all were admitted to specialist centres. It may be that the decision to provide surgery or a procedure locally is also dependent on the age of the patient and competence/confidence of local providers. In practice, clinicians within some units may be more flexible in terms of individual care and admission policy than this data reflects.

National data also reflects a high level of day case activity in patients with a cerebral palsy, much of which related to procedure. 9

The Association of Anaesthetists of Great Britain and Ireland states that fitness for a procedure in a day case setting should relate to the patient's health determined at pre-operative preparation and not be limited by arbitrary limits such as ASA status or age and assuming cardiorespiratory stability.[57] This is re-enforced by more recent guidance specific to children and young people which includes recommendations for adequate pre-operative assessment for complex patients e.g. in a dedicated anaesthetic pre-assessment clinic and/or as part of an MDT prior to surgery.[58]

There was evidence in the case notes reviewed of a high level of engagement and input by senior clinicians on the day in those caring for patients with a cerebral palsy and requiring surgery/ procedures. 99.4% (169/170) were seen by the person carrying out the procedure prior to it occurring. The largest group of clinicians providing surgery/ procedures was trauma and orthopaedics (35.5%), with paediatrics being involved in 5.9% of cases reviewed, and general and paediatric surgery accounting for 13% of cases (Table 11.5).

Table 11.5 Specialty of surgeon/operator who saw patient prior to surgery/procedure

	n=	%
Trauma and orthopaedics	60	35.5
General surgery	13	7.7
Paediatrics	10	5.9
Paediatric surgery	9	5.3
Neurosurgery	6	3.6
Other	48	28.4
Subtotal	**146**	
Not answered	23	
Total	**169**	

Patients and /or families 125/138 (90.6%) were also seen by a senior anaesthetist prior to their procedure or operation. Since many children, young people and young adults with a cerebral palsy admitted for surgery are at GMFCS III/IV/V, and have associated co-morbidities, this senior input is essential.[59] 6

Consent

Consent for surgery or a procedure is an important process which involves the responsible clinician providing a clear explanation of what is proposed, the possible alternatives and any risks associated.[60] In children and young people it is important to use appropriate language and an explanation which is age and developmentally adjusted and to seek and respect the patient's view as well as to involve parent carers. In patients of all ages and except in rare and immediate life threatening situations, it should allow time for reflection, for questions to be asked and for these to be satisfactorily answered.[61] Whilst it is good practice to take written consent (usually towards the end of this process to confirm agreement) this was often not done routinely for all patients where a general anaesthetic (GA) is not administered. Where procedures were carried out under a general anaesthetic data indicated that only one in five patients in this study signed the consent form themselves (Table 11.6). Given that 82/179 (45.8%) of patients in this study having surgery or a procedure were 15 years or older this appeared to be an important finding. This may be for a variety of reasons, including difficulties with communication in this population and differing consent practices across the UK countries. 6 12

Table 11.6 Person providing consent if the procedure/ surgery was carried out under general anaesthetic

	n=	%
Patient	29	22.7
Parent/Carer	102	79.7
Clinician	22	17.2
Patient advocate/Proxy	1	0.8
Social services	2	1.6
Subtotal	**156**	
Unknown	6	
Total	**162**	

**Answers may be multiple*

Competent children and young people may sign their consent form for surgery or a procedure. In England and Wales it is generally regarded as good practice to also ask parents to sign up to the age of 16 years. At 16 years, the young person will usually sign or otherwise indicate agreement entirely by themselves if they have capacity. However a parent carer may complete a consent form on behalf of the young person until they reach their 18th birthday if the patient lacks capacity.[62] In Scotland, once deemed competent, the child or young person should do so alone and in practice this will generally be from age 12 - 14 in young people with age appropriate understanding.[63] Again a parent may complete instead and if the patient lacks capacity until the age of 18 years. In this study where written consent was not taken from 24/34 patients, this was because the patient lacked capacity, however, this was not answered in 100 cases, possibly because the patient gave consent. 6 12

Children, young people and young adults with a cerebral palsy may have particularly problems in completing a standard (written) NHS consent form due to either problems with motor skills, intellectual/learning disability or both. With regard to motor disability, various adaptations exist and guidance is available to clinicians on best practice when patients have degrees of motor disability and/or visual and or hearing loss. (Appendix 1)

There were just 15 patients who were aged 17 years or older who signed their own consent form prior to having a general anaesthetic for a procedure or surgery and in 12 they were the (only) signatory. A parent was the only signatory in 11 patients over the age of 16 years, and 10 of these patients were 18 years or older.

After the 18th birthday consent should be signed in the patient's best interests by the clinician undertaking the procedure/surgery. This does not preclude clinicians fulfilling the important responsibility of discussing diagnostic and treatment options and seeking agreement from parent carers/those as well as the patient for any proposed surgery or procedure. Some consent forms allow space for documentation of this discussion, but this is not the same as giving consent on behalf of the young adult.[64,65]

The fact that in 10 cases reviewed it was identified that a parent was the only person to sign the consent form for a patient over 18 years was of concern. It was clear from these cases that there was still confusion and instances of poor practice in relation to the practical and legal application of proper consent procedures in this age group and when there are learning disabilities and/or issues with communication.

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.

It is recommended by the GMC that clinicians taking consent should be appropriately senior in their role so that they can fully explain the procedure or surgery and any risks or complications to the patient and/or parent carers (where appropriate).

In the majority of patients (95/106) consent was taken by a consultant or senior specialist trainee (with or without CCT). It was noted that this question was not answered in 28 cases (Table 11.7).

Good practice requires attention to detail when obtaining consent, including the patient in the discussions and decision making and documenting everything clearly. Further discussion about inclusion and best interest decision making is included in chapter 6 on communication.

Table 11.7 Grade and specialty of the person who took consent

	n=
Consultant	70
Senior specialist trainee	12
Junior specialist trainee	8
Trainee with CCT	7
Staff grade/associate specialist	6
Specialist nurse	2
Allied health professional	1
Subtotal	**106**
Not answered	28
Total	**134**

Pain management

A policy of always asking about the presence of pain at each consultation with a patient with a cerebral palsy was reported to be in place in the paediatric outpatient care questionnaire in 29/80 organisations and in the community or disability paediatric care questionnaire in 33/80 organisations.

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.

Whilst lead clinicians for disability care stated that adequate routine enquiries about pain had been made in 159/184 (86.4%) patients, case reviewers found less frequent documentation of this (173/281; 61.6%) (Table 11.8). Where pain was present, reviewers stated that a documented care plan was in place in 98/126 (77.8%) patients and evidence that pain was adequately addressed in 78/121 (64.5%) (Table 11.9).

Table 11.8 Adequate enquiries were made about the presence of pain - reviewers' opinion

	Lead clinician for disability care		Case note reviewer	
	n=	%	n=	%
Yes	159	86.4	173	61.6
No	25	13.6	108	38.4
Subtotal	**184**		**281**	
Unknown	37		69	
Total	**221**		**350**	

Table 11.9 Where pain was present, a clear management plan made to address this - reviewers' opinion

	If pain was present:			
	Was a clear management plan made to address this?		Is there evidence in the notes that it was adequately controlled?	
	n=	%	n=	%
Yes	98	77.8	78	64.5
No	28	22.2	43	35.5
Subtotal	**126**		**121**	
Unable to answer	59		61	
Not applicable	71		60	
Not answered	94		108	
Total	**350**		**350**	

Reviewers were of the opinion that pain management could have been improved for 102/203 (50.2%) patients. They were unable to answer for 50/350 patients, found the question not applicable for 43/350 patients and did not answer for 54/350 patients. Reviewers reported that pain management could have been improved as detailed in Table 11.10.

Table 11.10 How pain management could have been improved - reviewers' opinion

	n=
Documentation of pain enquiry	85
Use of an appropriate scoring system	65
Evidence of a pain management plan	51
Referral to a specialist pain team	11
Total	**212**

**Answers may be multiple*

Severe acute pain commonly occurs in association with procedures and surgery. In the peri-operative period pain scoring should be routinely employed in children and young people.[66] There are appropriate modifications of pain assessment scales for children of all ages and for children, young people and adults with neurodisability.[67]

In this study peri-operative pain scoring was employed in three of four patients (Table 11.11).

Whilst in some cases pain might have been anticipated to be minimal (e.g. following endoscopy, change of feeding tube) there were many minor procedures in this cohort including e.g. a botulinum toxin injection where pain and discomfort can be substantial albeit generally of short duration. Pain assessment in these situations is still important, and as such procedures may need to be repeated. Pain should be monitored and addressed if longer term patient compliance is to be improved.

Pain scoring in patients with complex neurodisability and reduced cough/gag and/or respiratory drive may also be particularly important to assist with safer monitoring e.g. when delivering opiate based analgesia.

Table 11.11 The patient had regular pain scoring peri-operatively

	n=	%
Yes	100	72.4
No	38	27.5
Subtotal	**138**	
Unknown	29	
Not answered	12	
Total	**179**	

In virtually all cases where the question was answered (111/116) pain relief was felt to be adequate by admitting clinicians (Table 11.12). Without better/more routine use of pain scoring it is unclear how clinicians were able to make a decision about "adequacy" of analgesia. This might explain why for one third of patients this was unknown or was unanswered. Reviewers also felt that in 132/145 cases reviewed there was evidence that peri-operative pain relief was adequate, but again in a third of cases they were unable to answer.

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.

Overall quality of surgical/procedural care

Case reviewers were asked to decide how good they thought surgical and procedure care had been overall, and whether there were areas for improvement (Figure 11.2). The two groups – admitted and day case patients for surgery and procedures were looked at separately. Overall the standard of care in day case surgery seemed to be slightly better but numbers were very small.

Table 11.12 Evidence of adequate peri-operative pain control – reviewers' opinion

	n=	%
Yes	132	91.0
No	13	9.0
Subtotal	**145**	
Unable to answer	50	
Not answered	17	
Total	**212**	

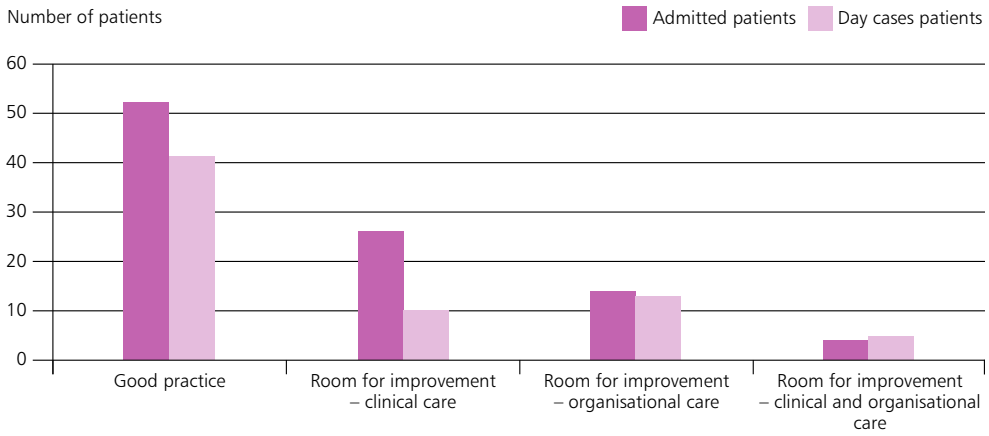

Figure 11.2 Patient underwent an operation or procedure by overall assessment of care - reviewers' opinion

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
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12

12 – Transition to adult services

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Study Advisory Group question: *Is transition planning managed effectively?*

Why is this important? *The transition between paediatric and adult service is a crucial time for a young person with a neurodisability. It often means that all the systems and support and people they were used to have changed. To ensure that this process is managed well, it must start in plenty of time, without causing undue stress to the patient or their family.*

Transition for young people with chronic health needs describes the process of moving from children's to adult healthcare and encompasses the initial planning, the actual transfer between services, and any support provided throughout.[10,68] There is variation in the chronological age at which this journey begins, and best practice suggests that there should be flexibility according to the needs of an individual patient. When not well managed the changes and challenges that young people encounter at transition may be associated with deterioration in their overall health and function. Planning effectively to bridge the gap between child and adult services can reduce and even eliminate the loss of wellbeing.[69,70,71]

Dependent on classification it has been estimated that there are between one in five to 10 children in the UK that have a chronic condition.[72] The greater need for planned transition of care to adult services has in part arisen because of improved health outcomes in the paediatric age group. Whilst there are well described pathways from child to adult services for conditions such as diabetes, cystic fibrosis and congenital heart disease, there is a relative paucity of multidisciplinary teams which provide parallel/equivalent services for young adults with chronic neurodisability and they are likely to be particularly disadvantaged.[73] This study has also found evidence that young people and young adults with a cerebral palsy encounter particular challenges in navigating to adult services as there are often no lead professionals or teams available for neurodisability care which mirror those which now exist in many parts of the UK within paediatrics. The alternatives for young adults with a cerebral palsy encounter variable quality of care in many instances, with lack of leadership, substantial gaps in services and increased reliance on GP services. This is exemplified well in chapter 7 with few leads for adult neurodisability (Table 7.2).

Overall a lead clinician for disability care was reported to be in place in 351/403 (87.1%) hospitals by admitting clinicians. Reviewers found documentation of a lead clinician for neurodisability care in only 31/133 (23.3%) case notes of young adults compared with 240/380 (63.2%) notes for children and young people.

This chapter will discuss the evidence of success or otherwise of the following for young people with a cerebral palsy

- The overall transition process
- Age appropriate care
- Decision making

The transition process

In patients with chronic long term health needs, transition from paediatric to adult based health services should be proactively managed in a similar way to all young people with long term health needs. Ideally planning begins by at least the age of 14 years and provides a progressive and well delineated transfer of care to a team that is able to continue to assess and manage the patient's individual needs.[10,68] All aspects of the transition process may not move at the same speed and at the same time, and this requires leadership and care co-ordination. There is a bountiful amount of guidance available, much of which has already been referenced and which can stimulate and guide practice. Fundamental to transition at an organisational level is whether there is a written pathway. Only 33/90 respondent organisations dealing with paediatric inpatient care had this in place.

Organisational leads for paediatric inpatient care responded to the question as to where young people with a cerebral palsy were cared for when leaving children's services. Patients mainly transferred to general adult medical and surgical services and many (50/84) were those without specific pathways or adjustments for neurodisability care. Only 19/84 organisations mentioned that specialist services for disabled adults would be involved (Table 12.1).

Table 12.1 To what services do young people with cerebral palsies transfer when leaving children's medical/surgical services, when inpatient care is required?

	n=
Specialist service for disabled young adults	19
General medical/surgical/orthopaedic services with pathways/protocols in place for adjustments in view of disability	29
General medical/surgical/orthopaedic services, no specific pathways/protocols for adjustments	50
Other (please specify)	15
Subtotal	**84**
Not answered	6
Total	**90**

**Answers may be multiple*

NICE Guidance suggests that by age 14 the process of transition should have been considered and planning commenced.[10] Leads for neurodisability care might be best placed to understand where their patients were in the process of transition and were asked to comment. They identified just 52 patients who were aged 14 years or older during the study period who were undergoing transition or might have done so. Seventeen patients had not yet transitioned, 19 were currently transitioning and nine had done so within the previous three years (Table 12.2).

Table 12.2 Stage of transition from paediatric to adult services

	n=
Patient has not yet transitioned from paediatric to adult services	17
Patient is currently transitioning from paediatric to adult services or transitioned less than three years ago prior to the stated admission	19
Patient transitioned more than three years ago prior to the stated admission	9
Subtotal	**45**
Not answered	7
Total	**52**

Transition was evident in just over half of 15 to 19 year olds (33/60) in the cases reviewed, and in a third of patients reviewed in the 20-25 age range. (Table 12.3).

Table 12.3 Evidence in the case notes the patient was or had transitioned from paediatric to adult services - reviewers' opinion

	10-14 years	15-19 years	20-25 years	Total
	n=	n=	n=	n=
Yes	1	33	28	**62**
No	49	27	13	**89**
Subtotal	**50**	**60**	**41**	**151**
Unable to answer	4	5	5	**14**
Not answered	17	5	3	**25**
Total	**71**	**70**	**49**	**190**

Leadership of transition

Guidance stresses that for transition to adult care to be successful leadership with a named professional and strong multiagency involvement is important. Reviewers reported that in only just over half the cases reviewed, where transition was occurring/had occurred (12/21), there was evidence of an identified lead worker, and in a third (7/20) there was evidence of multiagency involvement.

NICE guidance (2016)[10] also emphasises the need for primary care involvement in care after transition for young people in the form of a lead general practitioner (GP). Patients with complex neurodisability are often under the care of a very comprehensive multidisciplinary team of professionals during childhood years and may not have much contact with their GP. Once in adult care the GP may be expected to provide a vital hub for support and co-ordination, in part because neurodisability services for patients with a cerebral palsy are rarely replicated in the same way across adult based community and hospital services. Recognition of this pivotal role is particularly important and has recently emerged in national guidance on re-organisation of GP services into Federations, Networks or Clusters.[82-84] Within these larger networks there is improved potential for GPs to specialise in particular areas of care such as paediatrics and neurodisability.

Case reviewers found that for patients who were undergoing transition there was evidence of a lead GP in 39/53 (Table 12.4).

Table 12.4 Evidence in the case notes of a lead GP for this patient - reviewers' opinion

	n=
Yes	39
No	14
Subtotal	**53**
Unable to answer	9
Total	**62**

Routine national data evidence provided within this report points to the fact that young people and young adults with a cerebral palsy are more likely to use GP services than children, young people or young adults without neurodisability. The greatest number of annual GP consultations was seen in the 0-4 year olds and those of 20-24 years. 7

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.

There were a few examples of good transition planning.

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.

Case note review reviewers were asked whether in their opinion they felt there was evidence that there had been difficulty or delay in agreeing a transition pathway for patients. Whilst numbers are very small, in half the cases reviewed (7/14) where it was possible to comment there was evidence that there had been difficulty.

Age appropriate care

Age descriptors

The most relevant groups with regard to transition of care were those in the 10-14 and 15-19 year age ranges. Most clinical leads for inpatient care stated that their hospital would regard a 10-14 year old as a child and a 15-19 year old was an "adolescent or young person" but there was variation (Table 12.5). Defining how a particular age group is described in healthcare terms often underpins decisions about location and organisation of care and this was inconsistent across organisations. For example 24/122 organisations defined 15-19 year olds as an 'adult', 11/315 as a 'child' and 55/87 as an 'adolescent/young person'. This is not unique to care of patients with a cerebral palsy, and transition matters across all diagnoses.

It was of note that the majority of acute inpatient leads stated that age 16 years was the 'usual' upper age limit for paediatric care (51/90) if the patient did not have a neurodisability. Sixteen years was also the most common age which adult unit leads used to describe when adult care began (37/65) but there was more variation here. If the patient had neurodisability, the general trend was for organisations to deliver paediatric care to those with disability until the patient was somewhat older. The upper limit was 18 years for paediatric care in 44/90 cases with 19 stating that 19 years was 'the norm' (Table 12.6) where as for routine

Table 12.5 Definition of the patient by age

	0-9 years	10-14 years	15-19 years	20-25 years	Subtotal	Not answered	Total
	n=	n=	n=	n=	n=	n=	n=
Child	228	76	11	0	**315**	3	**318**
Adolescent/ Young person	0	23	55	9	**87**	1	**88**
Adult	0	0	24	98	**122**	1	**123**
Subtotal	**228**	**99**	**90**	**107**	**524**	**5**	**529**
Not answered	0	1	1	0	**2**	5	**7**
Total	**228**	**100**	**91**	**107**	**526**	**10**	**536**

Table 12.6 Age limits for providing paediatric and adult care

	Up to what age does this hospital provide:		From what age does this hospital provide:	
	Acute paediatric care	Acute paediatric care for disabled	Acute adult care	Acute adult care for disabled
	n=	n=	n=	n=
14 years	2	1	0	0
15 years	1	0	2	2
16 years	51	14	37	37
17 years	8	9	5	4
18 years	26	44	21	21
19 years	2	19	0	0
Other	0	3	0	1
Subtotal	**90**	**90**	**65**	**65**
Not answered	0	0	1	1
Total	**90**	**90**	**66**	**66**

paediatric care in just 28/90 organisations, 18 or 19 was the upper limit. This finding was not mirrored by adult care leads where very little difference was noted. The lag in transition to adult services for young people with a cerebral palsy in secondary care was consistent with national routine data.

Case reviewers highlighted several examples of young people still being cared for in children's services that they might have expected to have been well outside the usual paediatric age limits (Case study 29).

Whilst there is a need for both flexibility and patient choice in location of care and overall delivery of services, these data may also highlight the underlying confusion in healthcare providers around ensuring best age appropriate facilities for older young people with neurodisability as they approach adulthood. This mirrors the considerable professional uncertainty around the best/most appropriate location of care when very few patients transition to have care led by adult neurodisability leads.[74]

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.

Organisation of age appropriate care

A 2001 UK survey of 12-19 year olds demonstrated a significant number of "adolescents" using both inpatient and day case beds in acute general hospitals and recommended that more dedicated provision be considered for this age group even in smaller District General Hospitals (DGHs).[75] Young people have very distinct needs compared to children and these are not the same as for most adults. A host of additional recommendations have strongly re-enforced these needs.[68,76-80]

In this study only 37/90 leads for paediatric inpatient care reported that their hospital had a specific ward or ward area for adolescents/young people.

Young people and adults with physical and/or learning disability may have particular additional needs over and above their normally able peers of the same age. In the context of access to hospital services, those with a high level of motor disability (GMFCS levels III,IV,V) are more likely to be dependent on additional technology which requires the space to accommodate them in a ward area. It is particularly important to consider and prioritise these specific individual needs to help maintain both dignity and independence in young people and so that a stay in hospital does not result in regression of confidence, skills and function. 9

Leads for adult inpatient care reported variation in type of accommodation and environmental adjustments available for young adults with cerebral palsies admitted for routine procedures or surgery. Single room accommodation (21/42), en suite toilet facilities (18/42), and space for special equipment (32/42) was available in only two thirds of ward areas. However almost half the organisations surveyed did not provide a response to these questions.

UK and European recommendations on best practice for child inpatients suggest that parents should be routinely able to stay on-site when their child requires inpatient care.[81] Young people with neurodisability may be particularly vulnerable when admitted to adult wards but parental accommodation was less likely to be provided according to organisational leads whilst leads for adult inpatient care reported that for 32/42 patients a facility was available, a relatively large number (24/66) did not respond to this question.

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.

Whilst the organisational data demonstrates that facilities in adult acute inpatient wards may be unsatisfactory for young people with neurodisability, there may also be problems in delivery of care for this age group in a paediatric ward area. Accommodating young people in a ward where the physical space, layout and processes are much more often employed to deliver care to babies and young children (which make up the larger number of total acute admissions in paediatrics) may be equally unsatisfactory. Patient privacy is also more often an issue as this case study demonstrates. 6 9

Leadership and care pathways for young people and young adults

Leadership in care for young people is fundamental to providing appropriate standards and services in all healthcare settings. There has been increased recognition of this need in guidance from several organisations.[80,85] Clinical leads in acute paediatrics stated that in only a fifth (19/88) of their organisations there was an identified lead clinician or team for adolescent care. The paucity of recorded adult leads for neurodisability has also already been noted in the introduction to this chapter and in chapter 7. 7

Specific healthcare pathways for care of young people can also provide support for this cohort of patients and promote good practice. These provide age and developmentally appropriate adjustments which are embedded in the wider healthcare plan for young people, and where relevant include consideration of wider educational and social needs. They do not necessarily require large resources in terms of additional staffing or funding.

In only 21/89 organisations was the care of adolescents provided as part of a specific care pathway (Table 12.7) and in most patients care fell within paediatric pathways. This finding coupled with the lack of leadership has highlighted a substantial gap.

Table 12.7 Who the care of adolescents fell under

	n=
Paediatric pathway	79
Adult pathway	28
Specific adolescent pathway	21

**Answers may be multiple*

This study has found evidence of less than good diagnostic precision and description of needs in young adult patients with a cerebral palsy. GMFCS level was poorly recorded throughout, and even in care by lead clinicians for neurodisability this was relatively poorly/inconsistently done. 8

In the 15-24 age range GMFCS was particularly poorly recorded. In part this may be a reflection of the fact that older patients may have not benefitted from the same diagnostic rigour as those born more recently. However GMFCS level is not a new descriptive tool[86] and it would have been expected that it would have been applied to ongoing care and needs. Similarly the older patients in this study were less likely to have a more specific diagnosis made. 5

These factors, together with the very different pattern of delivery of care for young adults with neurodisability and alongside a relative lack of appropriate services may have led to young people and young adults receiving less good access to certain essential services. This was demonstrated in relation to physiotherapy which was less likely to be in place for older patients – 54.5% (54/99) in the 15-25 age group vs. 71.3% overall. 7

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.

Routinely collected national data

Where possible medical and surgical specialties were categorised as paediatric or adult services. Generic treatment specialties without a corresponding paediatric designation were categorised as 'other'. These include therapies, psychiatry, radiology and pathology specialties and were excluded from the analysis.

Figures 12.1 and 12.2 show that in England a greater proportion of children and young people with a cerebral palsy over the age of 13 years used paediatric services and continued to do so for longer than those without a cerebral palsy, thus transitioning to adult services later than children and young people without a cerebral palsy. The transition for inpatient care appears to be slower than for outpatient appointments.

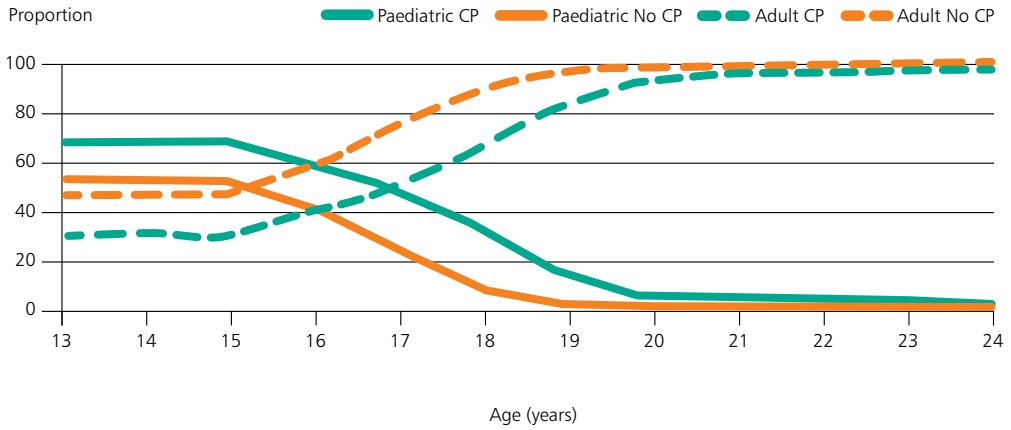

Figure 12.1 Proportion of outpatient appointments between 2007 and 2014 for children and young people with and without a cerebral palsy by age (CPRD HES Linked England)

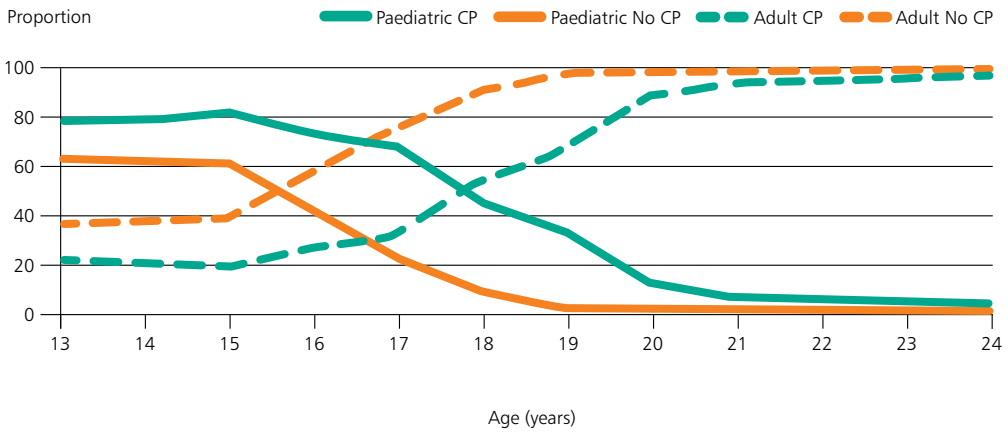

Figure 12.2 Proportion of paediatric and adult hospital admissions between 2007 and 2014 for children and young people with and without a cerebral palsy by age (CPRD: HES Linked England)

Nearly all (99%) of children without a cerebral palsy had transitioned to adult services by 19 years of age; this was extended to at least 21years of age for those with a cerebral palsy.

In Wales (Figure 12.3) the transition to adult outpatient services appeared to start later than in England at around the age of fifteen years. The transition to adult inpatient services appears to happen more slowly (Figure 12.4).

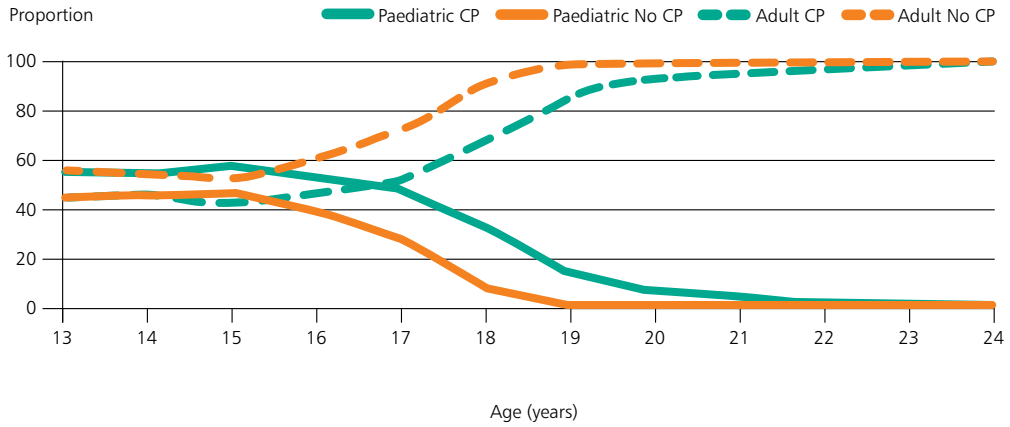

Figure 12.3 Proportion of paediatric and adult outpatient appointments for children and young people with and without a cerebral palsy children and young people with and without a cerebral palsy by age. (OPDW)

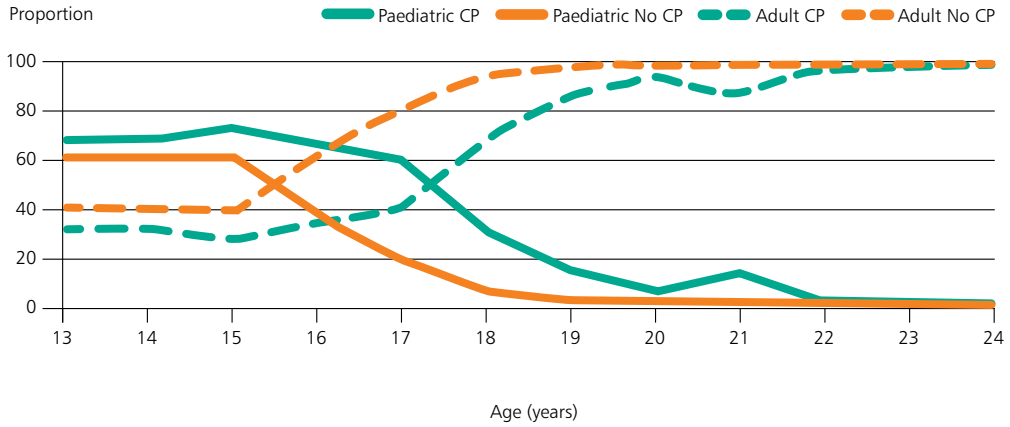

Figure 12.4 Proportion of total hospital admissions for children and young people with and without a cerebral palsy by age and specialty type (PEDW; 2004-2014) Note - 'other' and 'unknown' specialties excluded

Inpatient hospital admissions – CPRD HES linked

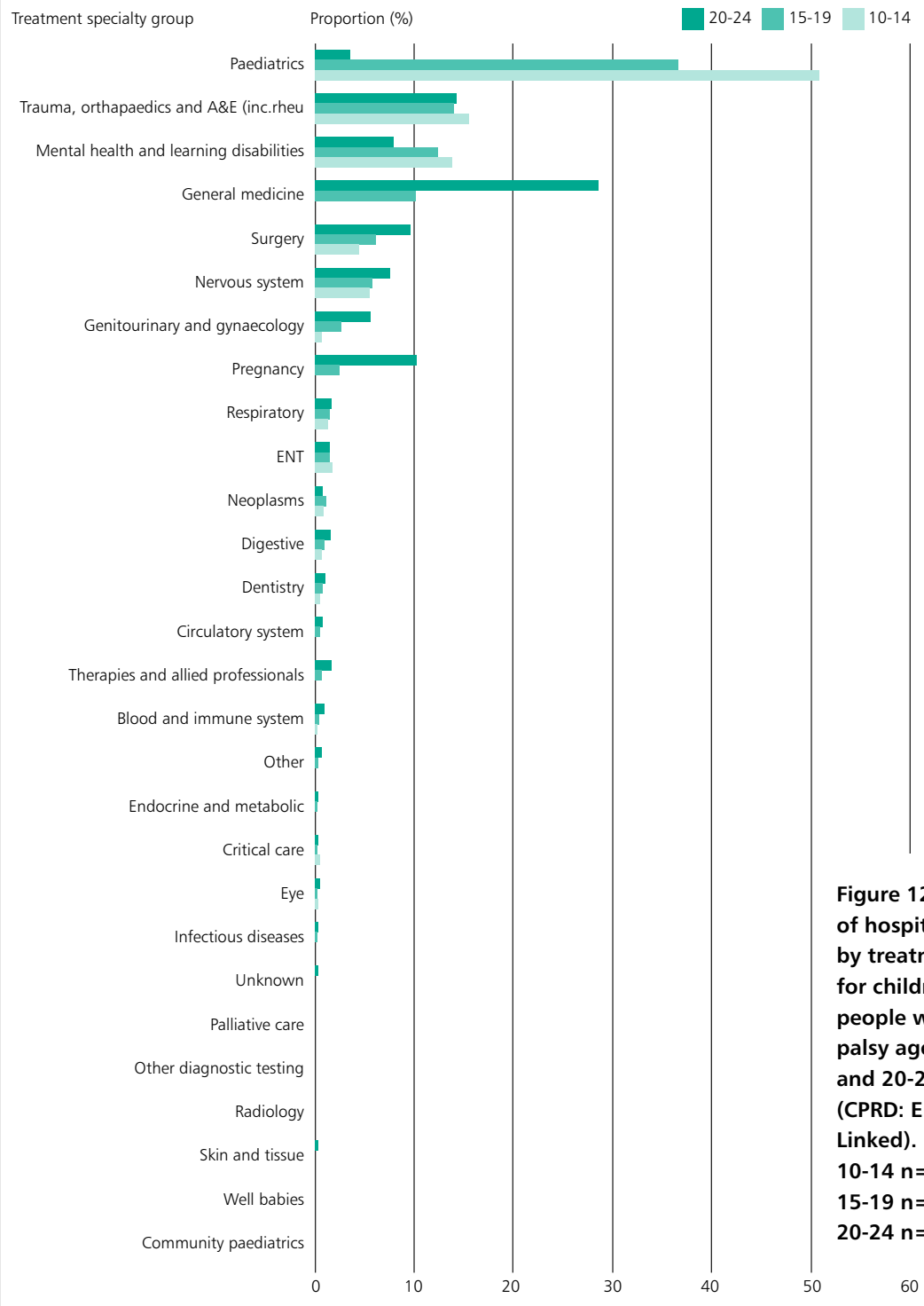

Figure 12.5 Proportion of hospital admissions by treatment specialty for children and young people with a cerebral palsy aged 10-14, 15-19 and 20-24 years (CPRD: England HES Linked). Denominators: 10-14 n=2,848, 15-19 n=2,284 and 20-24 n=1,864

The burden of hospital admissions changed between the ages of 10 and 24. The proportion of paediatric admissions fell dramatically for children and young people with (Figure 12.5) and without a cerebral palsy (Figure 12.6) but less quickly for those with a cerebral palsy. General medicine admissions increased significantly between 14 and 24 years of age.

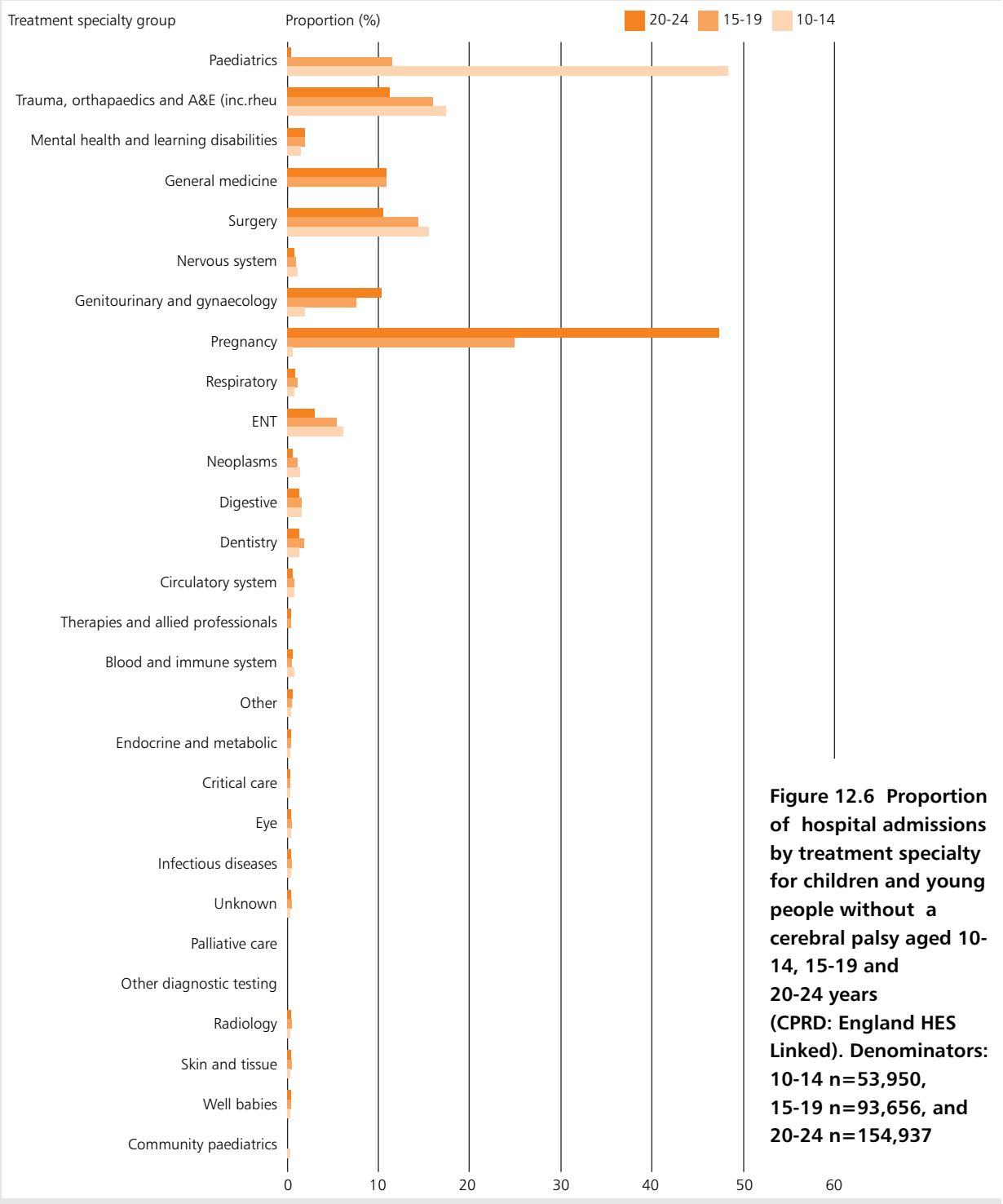

Figure 12.6 Proportion of hospital admissions by treatment specialty for children and young people without a cerebral palsy aged 10-14, 15-19 and 20-24 years (CPRD: England HES Linked). Denominators: 10-14 n=53,950, 15-19 n=93,656, and 20-24 n=154,937

A greater proportion of children and young people with a cerebral palsy had admissions to mental health and learning disability specialists than for those without a cerebral palsy, the latter fell between the ages of 10-24 years.

The proportion of surgical admissions increased with age for children and young people with a cerebral palsy but decreased for those without a cerebral palsy where the greatest change was seen for obstetrics.

Outpatient appointments – CPRD HES linked

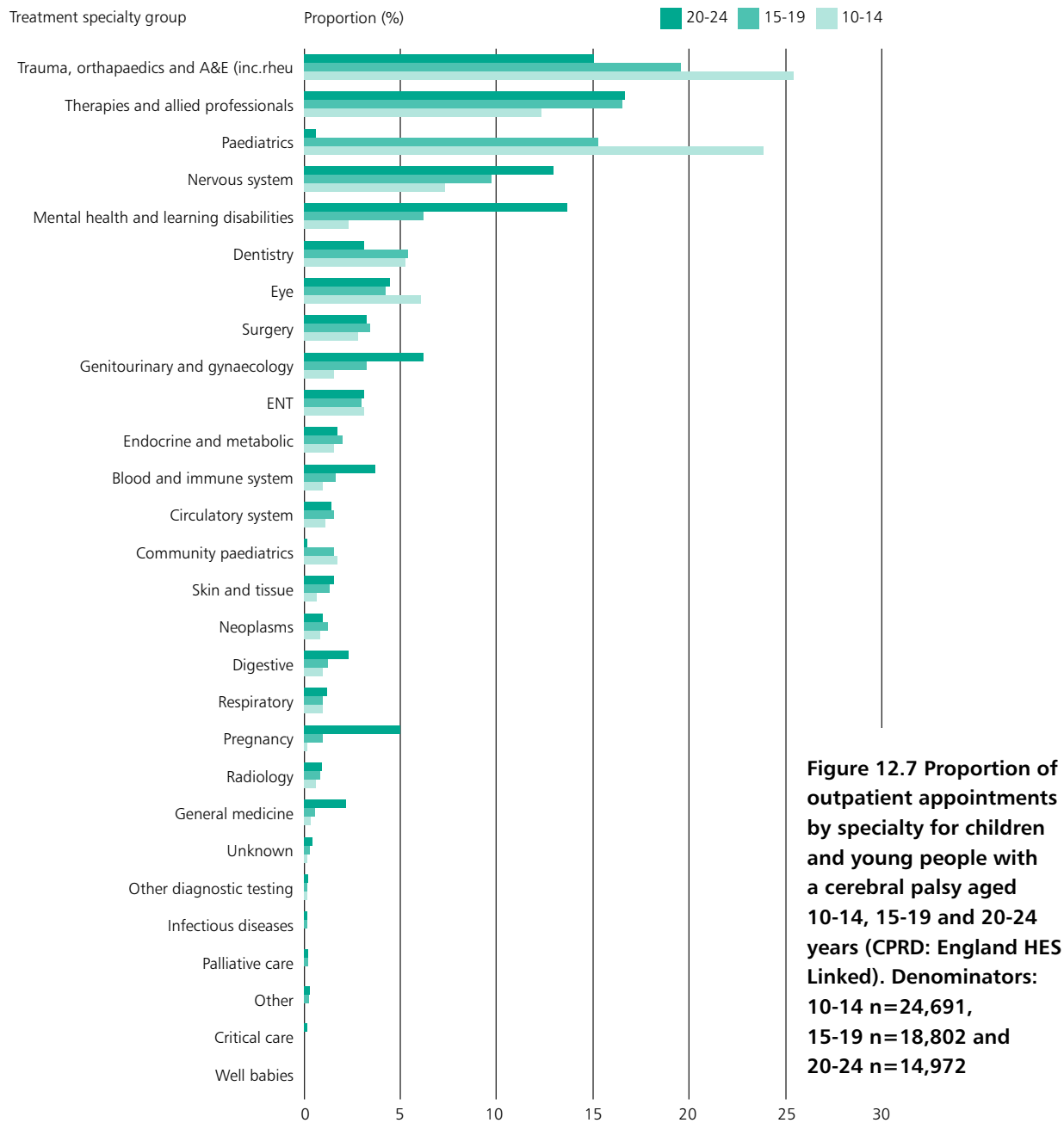

Figure 12.7 Proportion of outpatient appointments by specialty for children and young people with a cerebral palsy aged 10-14, 15-19 and 20-24 years (CPRD: England HES Linked). Denominators: 10-14 n=24,691, 15-19 n=18,802 and 20-24 n=14,972

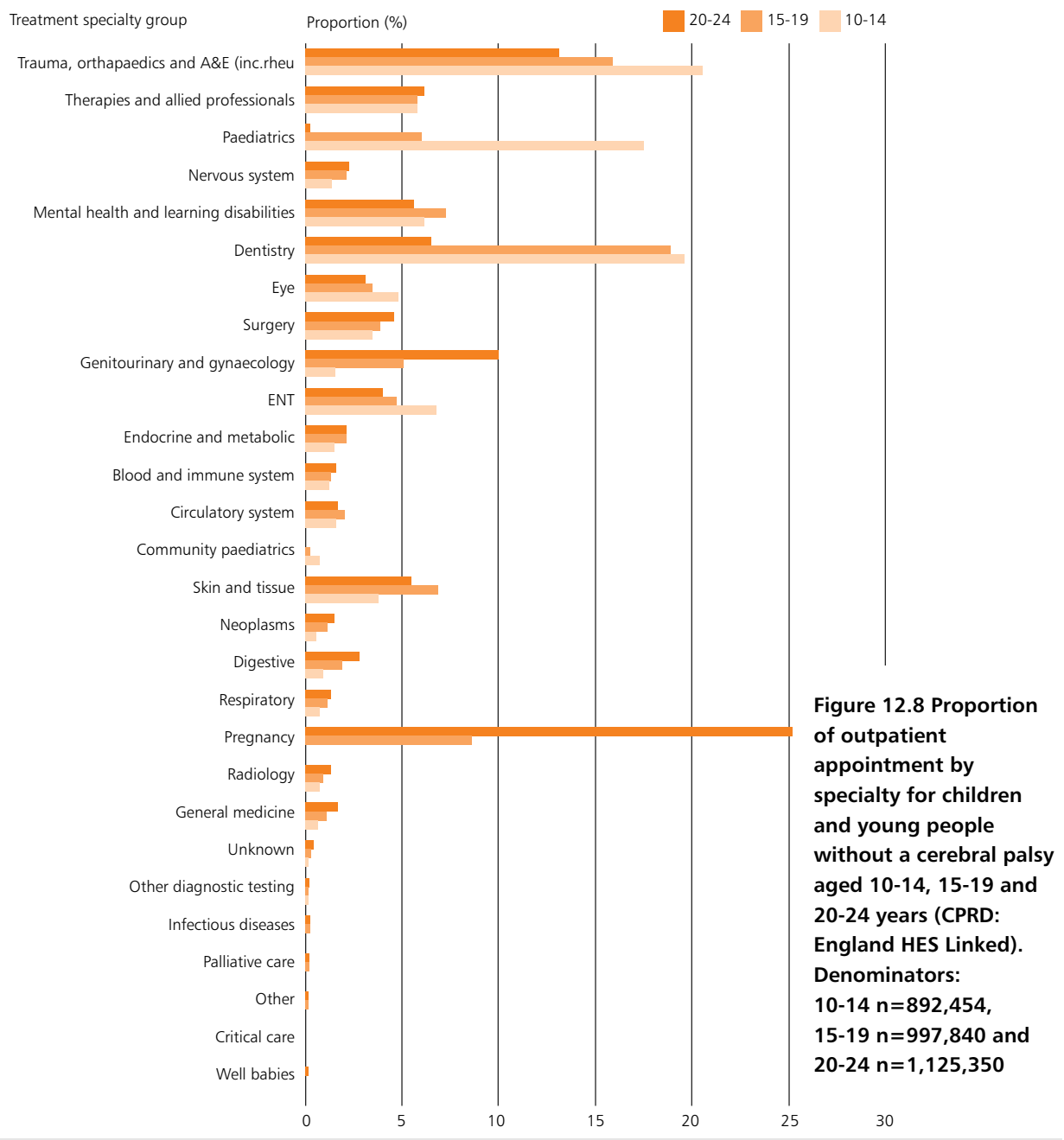

Figure 12.8 Proportion of outpatient appointment by specialty for children and young people without a cerebral palsy aged 10-14, 15-19 and 20-24 years (CPRD: England HES Linked). Denominators: 10-14 n=892,454, 15-19 n=997,840 and 20-24 n=1,125,350

The proportions of outpatient appointments for therapies and allied health professional, neurological services and mental health and learning difficulties increased with age and were significantly greater for children and young people with a cerebral palsy (Figure 12.7) than those without a cerebral palsy (Figure 12.8). The proportion of paediatric outpatients decreased in both groups but remained higher for children and young people with a cerebral palsy than those without.

The proportion of dentistry outpatient appointments decreased with age but was significantly fewer than for children and young people without a cerebral palsy.

Communication and decision making

Communication and decision making for young people with neurodisability can provide particular challenges some of which have been discussed in chapter 6. 

Inpatient care ward rounds can be an intimidating situation for young people, and it may be difficult to express views and ask questions openly in the time provided, especially if there is no provision for confidential discussion and parent carers are routinely present. Joint RCP/RCN guidance from 2012 outlined good practice in the conduct of ward rounds but made no specific reference to young people or young adults.[87] In this study leads for inpatient care of children and young people were asked whether young people were given an opportunity to be seen separately e.g. in medical and surgical ward rounds, and in one in four organisations stated that this was not offered (Table 12.8).

Admitting clinicians were also asked whether the patient was given a choice as to whether a parent was present in all discussions and as appropriate for their age, and for 15/101 patients they stated that this did not occur.

Table 12.8 Young people were offered the opportunity to be seen separately from their parent/carer in the acute medicine and surgical service, e.g. on ward rounds

	Acute medicine service	Acute surgical service
	n=	n=
Yes	71	61
No	16	19
Subtotal	**87**	**80**
Not answered	3	10
Total	**90**	**90**

Capacity and best interests

Children and young people should be encouraged to be involved in decisions about their care.[61] When a young person has no obvious disability of mind or body, their competence and capacity are often assumed without formal testing. Specific legislation in different parts of the UK guides what to do when there is doubt.[62,88] In practice capacity tends to be considered at points in time where key decisions such as e.g. consent for a procedure or surgery are required.

Organisational data from leads in emergency departments, child and adult inpatient areas and from adult outpatient facilities were asked whether capacity was routinely assessed. The most likely place for assessment to take place seems to have been in emergency departments where it was a routine in 69/86 organisations and adult inpatient units 43/47. In contrast, assessment took place in only half the organisations providing paediatric inpatient care (Table 12.9).

In just 50/88 inpatient paediatric units and 43/47 adult units it was reported to be routine practice to assess mental capacity of young people 16 years and over and who were thought to have an impaired ability to make decisions. Case note reviewers were also asked whether mental capacity assessment was recorded where the patient was over the age of 16 years and there was a documented learning disability, and this occurred in only one in three cases (42/135).

Chapter 11 discussed specific issues with regard to approved consent procedures in young people undergoing a surgery or a procedure, and where it was clear that in some instances there were cases where parent carers had been asked to be the sole people to consent for older young people/young adults without capacity. 11

Leads for different aspects of service reported whether (or not) a best interests decision-making process was embedded for young people aged 16 years and over who had been assessed as not having capacity to make a specific decision at a specific time and in a specific circumstance. Adult services within organisations were more likely to have this in place. Since many young people with neurodisability over the age of 16 years are still under the umbrella of paediatric services, it is of particular note that only 44/77 paediatric community leads reported that their organisations had a process (Table 12.10).

Table 12.9 The extent to which capacity was reported to be routinely assessed according to local legislation

	Emergency department care	Paediatric inpatient care	Adult inpatient care	Adult outpatient care
Yes	69	50	43	30
No	17	38	4	12
Subtotal	**86**	**88**	**47**	**42**
Not answered	6	2	19	11
Total	**92**	**90**	**66**	**53**

Table 12.10 Organisational arrangements for best interest decision making in patients without capacity

	Paediatric outpatient care	Community paediatric care	Paediatric inpatient care	Adult outpatient care	Adult inpatient care	Emergency department care
Yes	47	44	57	34	40	68
No	30	33	27	9	8	16
Subtotal	**77**	**77**	**84**	**43**	**48**	**84**
Not answered	7	4	6	10	18	8
Total	**84**	**81**	**90**	**53**	**66**	**92**

It has already been noted that case reviewers felt that there was poor evidence of documentation of inclusion in all age groups. There was little difference between patients under or over 16 years (Table 12.11). However, it was particularly unusual that evidence was not stronger in an older age group. 6

Inclusion was more of an issue in children and young people with more profound motor disability, and particularly in those patients over 16s where just 13/40 patients at GMFCS level V seemed to be included. This compared with 11/13 young people at GMFCS level I, and 7/9 at GMFCS level II. Some patients with GMFCS level V motor disability may well have profound difficulties with hearing, vision and understanding. However this must never be assumed and communication aids may be necessary. Documentation of the level of ability together with what is communicated to the young person and parent carer is essential.

Table 12.11 Room for improvement in the documentation of inclusion of the patient in discussions and decision-making – reviewers' opinion

	Admitted patients		Day case patients	
	n=	%	n=	%
Yes	120	40.0	59	39.9
No	180	60.0	89	60.1
Subtotal	**300**		**148**	
Unable to answer	37		21	
Not answered	15		13	
Total	**352**		**182**	

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

SEE RECOMMENDATIONS
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- 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).

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
A&E	Accident and Emergency
ADDE	Annual District Death Extract
AMH	Adolescent Mental Health
Ataxia	Lack of voluntary coordination of muscle movements that includes gait abnormality
BSO	Business Services Organisation
Cerebral palsy	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.
CI	Confidence interval
Congenital heart disease	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.
Continuous Positive Airway Pressure - CPAP	A therapy that increases air pressure in the throat so the airway does not collapse when someone breathes in
CP	Cerebral Palsies
CPRD	Clinical Practice Research Database
CYP	Children and young people
Diplegia	Paralysis affecting symmetrical parts of the body
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
Dorsal rhizotomy	An operation used to improve spasticity (muscle stiffness)
Dyskinetic	Involuntary muscle movements
EDDS	Emergency Department Dataset
Emergency Health Care Plan/Emergency Care Summary	An Emergency Health Care Plan makes communication easier in the event of a healthcare emergency.
EPD	Enhanced Prescribing Dataset

Term	Definition
Epilepsy	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.
Fundopliction	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.
Gastrostomy	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.
GMFCS levels	Gross Motor Function Classification System - https://canchild.ca/en/resources/42-gross-motor-function-classification-system-expanded-revised-gmfcs-e-r
HBS	Honest Broker Service
Hemiplegia	A condition that affects one side of the body
HES (APC)	Hospital Episode Statistics (Admitted Patient Care)
HQIP	Healthcare Quality Improvement Partnership
HSCIC	Health and Social Care Information System
ICD	International Classification of Diseases
IMD	Index of Multiple Deprivation
ICD-10	International Classification of Diseases, version 10
Intrathecal baclofen	Baclofen is delivered directly into the spinal fluid to help muscle stiffness
ISAC	Independent Scientific Advisory Committee
ISD	Information Services Scotland
Levels of care (adults)	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.
MHLDD	Mental Health and Learning Disabilities Dataset
Monoplegia	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	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. Level 2 PCCU: A discrete area or unit where Level 1 and Level 2 paediatric critical care are delivered. 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. 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).
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

Term	Definition
PYAR	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
Quadriplegia/Tetraplegia	Affecting all four limbs and the torso
SAIL	Secure Anonymised Information Linkage
Scoliosis	Scoliosis is where the spine twists and curves to the side
Seriously ill patient	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.
SMR	Scottish Morbidity Records
SMR00	Scottish Morbidity Records - Outpatients Attendances and Appointments
SMR01	Scottish Morbidity Records - General Acute Inpatient and Day Case
SNOMED CT	
SNS	Support Needs System
SOSCARE	Social Services Client Administration and Retrieval Environment
Status epilepticus	Convulsive seizures lasting more than 30 minutes
Transition	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.
WDS	Wales Demographic Service
WECC	Welsh Electronic Cohort of Children
WLGP	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

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

Appendix 2 - Routine National Data - approvals and costs and data preparation

Timeline and costs

There was a continuous need to update and inform governance throughout the project. Duration from first contact to receipt of data was longest for NHS Digital data England. Special negotiations with the Northern Ireland Cerebral Palsy Register were approved and data received June 2017.

	Applied	Approved	Approved by	Received	Ready for analysis	Analysis complete
UK						
CPRD	Jan-16	May-16	Information Centre and the Independent Scientific Advisory Committee (ISAC) - Protocol No: 16_033R	Dec-16	Dec-16	Sept-17
PICANet	Nov-15	Oct-16	PICANet Clinical Advisory Group May-16	Feb-17		Jun-17
ENGLAND						
NHS DIGITAL (formally HSCIC)	Oct-15	Dec-16	Data Access Advisory Group	Jan-17	Oct-17	Dec-17
NECCPS	Dec-15	Feb-16	Regional Maternity Survey Office (RMSO)	Mar-16	Mar-16	Jun-16
WALES						
WALES	Sep-15		Information Governance Review Panel (IGRP) within the Secure Anonymised Information Linkage Databank (SAIL)	Jan-16	Jan 2017 (amended June 2017	Sept-17

	Applied	Approved	Approved by	Received	Ready for analysis	Analysis complete
SCOTLAND						
SCOTLAND	Nov-15	April-16	Privacy Advisory Committee (PAC), consisting of medical professionals and general public	Aug-16	June-17	Nov-17
NORTHERN IRELAND						
NORTHERN IRELAND	Feb-16	Jul-16	Honest Broker Service (HBS) within the BSO	Dec-16 Mar-17 (SOSCARE/ Mortality/ Prescribing)	June-17	Dec-17
NICPR	Aug-16	Oct-16	Research governance at Queen's University, Belfast	Mar-16	Mar-16	Jun-16

Costs for data

The costs charged by data providers to extract the data ranged considerably. Costings are outlined in the table below. These costs do not include updates or renewal of licenses.

Data source	Cost
SAIL	£500 base costs for access to SAIL data plus £81,197 (includes SAIL analyst time for preparation of Wales, Scottish, Irish and NHS Digital datasets for analysis, data storage, infrastructure and access by team members for all other data sets)
NHS Digital	£18,100 + VAT
ISD	£3,322
HBS	No charge
CPRD	£30,000 towards Cardiff License
PICANet	No charge
NECCPS	No charge
NICPR	No charge

Appendix 3 - Data preparation and Linkage

1. SAIL Databank and NHS Wales Informatics Service – Welsh data
See Appendix 4

2. NHS Digital (formerly the Health and Social Care Information Centre) – English data
Generating the Health Episode Statistics Identifier (HESID)
The method for the creation of the HESID is discussed in detail in a methodology document published by Health and Social Care Information Centre (HSCIC).[13] In summary, the HESID is created by applying a matching algorithm which assesses various combinations of the NHS number, date of birth, sex, postcode, provider code and local patient ID variables. These fields are combined to create a patient key for each row of data. An individual HESID may match to more than one patient key, for example where they have moved house, been treated under multiple provider codes or had more than one local patient ID, but a patient key can match to only one HESID. A HESID index contains the mapping between HESID and patient key. The matching process attempts to match the patient key for each row of data to the patient key held in the HESID index. It is carried out using three passes (attempts to match). The first pass centres on NHS number and requires exact match on NHS number and sex and at least partial match on date of birth. The second pass centres on local patient identifier (the unique individual number assigned by each hospital provider) and requires exact match on local patient identifier and provider code, postcode and sex and at least partial match on date of birth. The third pass centres on date of birth and requires and exact match on date of birth, sex and postcode. Where a match is obtained the match is created and the existing HESID assigned to the record. Where no match is obtained, a new HESID is created and added to the HESID index and assigned to the record.

Information governance requirements
Data received from NHS Digital are stored in an environment that allows complete separation from any other data. These data are stored in the Data Science Building UK Secure eResearch Platform (UKSeRP). This is to ensure that backup and archive requirements are met, and to facilitate the deletion requirements stipulated by NHS Digital. Data extracts received from Scotland and Northern Ireland were stored within the SAIL Databank.

3. Honest Broker Service (HBS) for Health and Social Care (HSC) – Northern Irish data
Data linkage in Northern Ireland is based on Health and Care Number (HCN). This is a unique identifier within Northern Ireland for an individual person, and is allocated at birth. Some patients may not have an HCN (e.g. visitors to Northern Ireland). No probabilistic matching method is used in Northern Ireland and therefore data for individuals without an HCN number cannot be included in any extracts as it cannot be linked. It is possible that an individual may have more than one HCN, but this is very rare. There are systems in place to detect and merge potential duplicates and also to correct "false positives" where records deemed to be matching relate to different patients.

4. Information Services Division, NHS National Services Scotland – Scottish data
Detailed information regarding the history and processes of creating the unique ID is provided in this document.[89]
The National Health Service Centre Register (NHSCR) is a centralised register containing a single record for "everyone who was born, or has died, in Scotland plus anyone else who is (or has been) on the list of a general medical practitioner in Scotland".[90] It is a population register containing basic demographic information but holds very little clinical information.

The unique health record identifier in Scotland is known as the Community Health Index (CHI) number.[91] The CHI is a population register for all residents of Scotland. CHI numbers are issued at birth; visitors and short-term residents can be assigned a temporary CHI number if required. The CHI is based on data held in a number of regional CHI databases and controlled by the Scottish NHS Boards.[92]
The CHI regional indexes "were initially compiled on an opportunistic basis and there was a general perception that there were gaps in its coverage and that there was a high proportion of duplicate records for people who had moved from one area of Scotland to another".

It is possible for an individual on the NHSCR to be associated with more than one CHI number but the NHSCR contains only one record per individual. When creating linkage fields for health data, records containing the CHI number are matched against records held in the NHSCR and linked where a match is found (using either deterministic or probabilistic matching). The NHSCR is also updated to maintain a record of all CHI numbers associated with an individual NHSCR record and the current CHI number (or most recent number for those who have died or moved outside Scotland) is noted and, once encrypted, is used as the linkage field. Any records that cannot be matched are excluded from data extracts.

CPRD

Person years at risk

The basis for the calculations was CPRD's (anonymised) list of patients indicated to have data of an acceptable standard for research purposes who were aged 0 up to 25 at any point during the study period of 1 January 2004 to 31 December 2014. 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 and when the GP's data met CPRD's quality standard. An individual's total time at risk within the study was then broken down by age band, year, gender and Index of Multiple Deprivation (IMD) quintile.

SAIL

Person years at risk

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 1 January 2004 to 31 December 2014. Not all GP practices in Wales (~70%) contribute to data to SAIL but SAIL's coverage of NHS secondary care outpatient and inpatient activity is complete. Data collection began either from GP registration or at study onset whichever was the later. Data collection ended at the end of registration with a SAIL GP, date of death, 25th birthday or the study end date, whichever was sooner. An individual's total time at risk within the study was then broken down by age band, year, gender and IMD quintile.

Appendix 4 - The Secure Anonymised Information Linkage (SAIL) databank

1. Background and overview

The purpose of this document is to summarise the processes undertaken to create a denominator cohort of individuals born between specified dates, a series of case flags indicating presence or otherwise of conditions of interest/comorbidities, and a series of health activity extracts, which will together be used to answer the hypotheses put forward in the 0298 and 0463 project(s), for both the Cerebral Palsy (CP) and Adolescent Mental Health (AMH) arms of the project.

All tables provided to members of the project team have been project encrypted. This means that any field containing information relating to a single individual (such as a patient identification number) or an identifiable geographical or administrative feature (such as a GP practice) is encrypted with a key unique to each project.

This is a summary version of the project documentation. A full version is available which provides greater technical detail about the creation of specific variables, field names and source data.

2. Creation of the denominator cohort

This table is named ALF_COHORT_TABLE_V1_0.

The ALF Cohort Extract (the ALF Cohort) was created from three main data sources; the Welsh Demographic Service Dataset (WDSD), the National Community Child Health Dataset (NCCH) and the Welsh Electronic Cohort for Children (WECC).

Selection of main ALFs

Anonymised Linkage Fields (ALFs) were extracted from WDSD and NCCH (extracted separately and then merged to form a single ALF list) where the Week of Birth (WOB) was between 1/1/1979 and 31/12/2015. The study period is from 2004 to 2014 (calendar year) so the WOB selection ensures that there are individuals present in each year of the study period whose ages range from 0-25 years of age. All non-null ALFs were selected from WDSD and NCCH.

From NCCH only ALFs with an ALF Status Code of 1, 4 or 39 were included; this excludes fuzzy matches where match probability is <0.5 and mirrors the WECC methodology. From NCCH, stillbirths were excluded. There are a greater number of null ALFs in NCCH in earlier years ($>=4000$ in 1988, around 1000-1500 in the 1990s, around 200 by 2004 and <100 by 2010).

In addition to the WDSD and NCCH ALFs, the WECC dataset was searched and any ALFs in neither the WDSD nor NCCH datasets were appended to the ALF Cohort. These ALFs were flagged separately. The reason that there are ALFs in WECC but not in either WDSD or NCCH is because WECC was created based on older versions of WDSD and NCCH. These ALFs were in the older versions of WDSD and/or NCCH but not in the most recent ones. They have been flagged so can be included or excluded as required.

Please note that as NCCH contains only births from 1998 onwards, for births prior to this time WDSD is the only available source.

Selection of supplementary ALFs

The Patient Episode Database for Wales (PEDW), the Emergency Department Dataset for Wales (EDDS), the Outpatient Department Dataset for Wales (OPDW) and the Annual District Deaths Extract (ADDE) were searched for individuals who were not in WDSD, NCCH or WECC but who had been in contact with one or more of these services (or who had died according to the ADDE) when they were under 25 years of age. Only those ALFs with a Welsh Local Super Output Area (LSOA) were included (those where the first character is 'W'). These are individuals who have never had a GP registration with a Welsh GP or appeared in the NCCH, but who have for some reason had at least one contact with Welsh health services. They may be short-term visitors to Wales or they may be resident but in temporary or insecure accommodation or be transient. It was felt important to capture these individuals, but they are supplementary to the main ALF Cohort. They are flagged within the ALF cohort so they can be easily identified and analysed separately.

There is no date of birth, gender or other demographic information available within the ALF cohort dataset for these individuals. This is because WOB is not a variable in the PEDW, EDDS, ADDE or OPDW datasets and an accurate WOB cannot be derived for these individuals as age is provided in years only. There are fields for age in years at time of activity (but not WOB), gender, LSOA etc for these individuals available in each of the activity extracts (see section 5).

Inclusion and creation of other variables

The WDSD extract includes WOB, gender and date of death (DOD) and WDSD-specific variables are populated with these data for all ALFs in WDSD.

The NCCH extract included WOB, gender and DOD variables and also additional variables specific to the NCCH dataset, and NCCH-specific variables are populated with these data for all ALFs in NCCH. Variable details are in the full data specification document.

To each of these ALF extracts, the age/date at first GP registration was added. This was derived from WDSD and based on the WOB within each extract (e.g. the first registration date for the NCCH ALFs was based on the WOB as given for that ALF in NCCH). There is an age at first registration for NCCH and WDSD. This is important to note, as the WOB is not necessarily the same in WDSD and NCCH, which means the age at first registration for the same individual may be different according to WDSD and NCCH. Both fields are provided.

The WDSD and NCCH extracts include a number of ALFs with >1 Person ID (the ostensibly unique ID within each dataset) and also a number of Person IDs which have >1 ALF. These individuals have not been excluded but have been flagged so they can easily be identified and excluded if required (please refer to the full data specification document for details of field names).

For all ALFs present in the WECC dataset, selected WECC variables were appended into the ALF Cohort for each individual. Variable details are in the full data specification document.

Using the WECC prioritisation rules, combined WOB, gender and Date of Death (DOD) variables were created. These variables provide a master WOB, gender and DOD field for analysis purposes. This is necessary as the data held in WDSD and NCCH for these variables is sometimes inconsistent so it was felt that a standard approach was required. The priority orders are obtained from the WECC documentation.[97] Where the ALF was in the WECC extract, WECC values were taken. For all ALFs not in WECC the following priorities were applied:

For WOB the priority order is:

a. WDSD
b. NCCH
c. Annual District Births Extract (ADBE)

For DOD the priority order is:

a. ADDE
b. NCCH
c. WDSD

For gender the priority order is:

a. WDSD
b. ADBE
c. ADDE
d. NCCH

Flags were created to state whether an ALF was present in specified SAIL datasets, namely PEDW, Welsh Longitudinal General Practice events (WLGP), EDDS, OPDW and ADDE. Two levels of variable were created for each of these datasets: one to show whether the ALF had been present in the dataset prior to 25th birthday with an event date at any point in time (labelled as ever_u25), and one to show whether the ALF had been present in the dataset prior to 25th birthday AND where the event date was between 1/1/2004 and 31/12/2014 (the study period – labelled as 2004_14_u25). Only those ALFs with a WOB available were attributed flags – this means that the ALFs which were derived from non WDSD/NCCH/WECC sources do not have flags present.

Variables were created to categorise ALFs according to age at time of first GP registration. Flags for registrations before the age of 0 (suggesting data quality issues), between 0 and 10, between 0 and 15 and between 0 and 17 were created Variable naming convention for these variables is 'reg_before_X'.

Finally a variable was added to flag those ALFs where, according to NCCH the individual had a WOB which fell between the specified date range, but the data for that individual in WDSD showed a WOB outside the range. As WDSD takes precedence over NCCH according to the WECC rules, it may be necessary to exclude these individuals.

3. Creation of follow up time extract

Extracts were created to allow the calculation of follow up time for each individual. These extracts were created using stored procedures written by Dan Thayer, Senior Analyst in the SAIL Analyst Team. These procedures "clean" the data and produce an output based on a series of rules and criteria. Documentation for the GP Cleaner is available in a separate document. Two extracts were provided:

- **This table is named W_OUTPUT_GP_CLEANER_V1_0.** The WLGP extract shows the patient's GP registration history, with a row for each registration period with a GP. There is a variable to show whether each registration period for each ALF has data present in SAIL (where pre-agreed quality standards are met regarding the volume of data recorded by each practice). Where a patient has had two registration periods with the same GP, there will be two separate lines present, with different start and end dates. The practice codes have been encrypted, which means that the actual practice cannot be identified, but different practices can be distinguished from each other.

- **This table is named W_OUTPUT_ADDRESS_CLEANER_V1_0.** The address extract shows the patient's residential history, with a row for each period of residence at an address. This is based on the Unique Postcode Reference Number (UPRN) for an address which is used to create a Residential Anonymous Linkage Field (RALF) for each address. Start and end dates are provided for periods of residence at each address. Deprivation indicators have been added to this table. These give the Welsh Index of Multiple deprivation (WIMD) quintile and decile for each residence (based on the residence LSOA). The LSOA codes have been encrypted, which means that the actual LSOA cannot be identified, but different LSOAs can be distinguished from each other.

Please note that at present, due to problems with the WLGP data extract, there are a number of GP practices which do not have data for all patients; patients who died or were deregistered 18 months or more prior to the data extract date have been excluded from the extracts of some practices. It is hoped that this will be rectified in early 2017. When this happens a new extract will be provided.
There are a number of ALFs in the ALF cohort which are absent from the Address Cleaner table. This is where the ALF did not have a RALF in the WDSD data (which is the source for the Address Cleaner output).

These tables can be joined to the ALF Cohort table and the activity tables using the ALF field. An outer join should be used (unless only the individuals in the cleaner table are required) as there are some individuals in the ALF cohort who are not in the GP Cleaner or the Address Cleaner tables.

4. Creation of alf cohort case flag extracts

The ALFs in the cohort list were used to create extracts from PEDW, EDDS, ADDE, OPDW and WLGP which allowed case flag variables to be created. These variables were based on lists of clinical codes grouped into conditions of interest/ comorbidities. International Classification of Diseases (ICD10) codes were used for PEDW, OPDW and ADDE. READ codes were used for WLGP and a combination of local (Wales-specific) codes and ICD10 codes were used for EDDS. The ICD10 and READ code lists were provided by the project team to SAIL. SAIL analysts provided summary output data based on provided code lists, in order to validate the lists, in order to create final validate lists of codes.

Where the codes for the condition of interest were present in the patient history, the ALF was flagged as '1' in the variable field for that condition. Two levels of case flags were created; one set where the individual was under 25 at time of contact and where the contact was between 1/1/2004 and 31/12/2014, and another set where the where the individual was under 25 at time of contact and where the contact was at any point.

Please note that as EDDS data starts in 2009 flags for this dataset will capture only cases from 2009 onwards.

The flags were saved into separate tables for each dataset. It is very important to note that the case flag tables do not contain a full list of all ALFs in the cohort. They contain only ALFs where there has been contact with the specified service (e.g. only ALFs that have had an inpatient admission feature in the PEDW extract). In addition the PEDW and OPDW extracts will include only those ALFs where there has been at least one clinically coded contact. This means that where the entire ALF cohort is required, outer joins should be used when joining these tables to the main ALF cohort. The case flag tables on their own cannot be used to calculate denominators for the ALF cohort as they do not contain all ALFs (except where the required denominators are specific to the service type e.g. the proportion of all patients who have at least one clinically coded record in PEDW that have condition X).

These tables are named:

- W_PROC1_PEDW_OUTPUT_TABLE_U25_2004_14_YYYYMMDD
- W_PROC1_PEDW_OUTPUT_TABLE_U25_YYYYMMDD
- W_PROC1_OPDW_OUTPUT_TABLE_U25_2004_14_YYYYMMDD
- W_PROC1_OPDW_OUTPUT_TABLE_U25_YYYYMMDD
- W_PROC1_WLGP_OUTPUT_TABLE_U25_2004_14_YYYYMMDD
- W_PROC1_WLGP_OUTPUT_TABLE_U25_YYYYMMDD
- W_PROC_1_EDDS_FLAG
- W_PROC_1_ADDE_FLAG

These tables can be joined to other tables using the ALF field. Please bear in mind that the case flag tables do not include all ALFs in the cohort, and therefore an outer join may be required.

5. Creation of activity extracts from sail datasets

The ALF cohort was used to create extracts of contacts with services for all patients in the cohort. Extracts were created from PEDW, WLGP, EDDS, ADDE and OPDW datasets. These extracts contain every contact that the ALF has ever had with the service, with no date-related exclusion criteria. Dates are included in each extract so date can be extracted for specified periods as required. Each extract includes key variables from the dataset, including gender, age (or WOB if available), LSOA at time of contact, administrative variables relating to the contact, and then a series of variables which contain 0/1 flags for presence or absence of a target clinical code. Please note that the WOB, gender and LSOA values in the extracts may differ from those in the ALF cohort, as they are derived from different sources. This may be where the patient given information different from that in the GP record e.g. the patient has moved to a new address but not notified their GP.

These tables can be joined using the ALF field. As with other tables, care should be taken when joining. Where joining to the ALF Cohort, if the full cohort is required then an outer join should be used as these tables do not contain the full ALF cohort, but only those ALFs that have had contact with the named service.

PEDW

This table is named W_PROC2_PEDW_ACTIVITY_OUTPUT_YYYYMMDD. The PEDW extract contains a single row for each diagnosis code attributed to contacts for that individual. Contacts for each ALF are organised into Person Spells using the Person Spell Number created for SAIL by NWIS, using the agreed methodology.[98] The start and end dates for the Person Spell have been derived and are included as variables. For each Person Spell, the full list of ICD10 diagnosis codes and OPCS4 Procedure codes are available where they are present in the patient record (coding is not 100% so there are a small number of uncoded episodes).

PEDW OPER

This table is named W_PROC2_PEDW_OPER_ACTIVITY_OUTPUT_YYYYMMDD. The PEDW OPER table is identical to the PEDW table except that instead of a row per diagnosis code, there is a row per procedure (OPCS4) code.

OPDW

This table is named W_PROC2_OPDW_ACTIVITY_OUTPUT_YYYYMMDD. The OPDW extract is a row per appointment. This includes appointments that were not attended by the patient (DNAs) and appointments that were cancelled (either by the hospital or by the patient). Administrative codes are present allowing new and follow up appointments and attendances, DNAs and cancellations to be distinguished. As with the PEDW extracts there is a row per diagnosis code.

OPDW OPER

This table is named W_PROC2_OPDW_OPER_ ACTIVITY_OUTPUT_YYYYMMDD. The OPDW OPER table is identical to the OPDW table except that instead of a row per diagnosis code, there is a row per procedure (OPCS4) code.

WLGP

This table is named W_PROC2_WLGP_ACTIVITY_ OUTPUT_YYYYMMDD. The WLGP table contains all contacts (including the issue of prescriptions, the recording of observations such as weight, administrative codes, referrals, symptoms and diagnoses) which are recorded in the form of Read coded events. The table contains a row per event.

EDDS

This table is named W_PROC2_CP/AMH_EDDS_ ACTIVITY_OUTPUT_YYYYMMDD. The EDDS table contains a row per attendance at and A&E department. It includes new and follow up attendances (administrative fields are provided that identify the attendance type of each record).

ADDE

This table is named W_PROC2_ADDE_ACTIVITY_ OUTPUT_YYYYMMDD. The ADDE table contains a row for each ALF where the individual has died and is present in the ADDE dataset. The ADDE extract differs slightly from the other extracts in that there were no condition-specific variables created. Instead the description for each of the Cause of Death fields was added into the extract, along with the ICD10 codes.

6. Periods of data availability in sail datasets

Data available

Data not available

	Notes
Deriving cohorts ALFs	
WDSD (based on Week Of Birth)	Due to refresh - should update to 2015
NCCH (based on Week Of Birth)	
WECC (based on Week Of Birth)	
ADBE (based on Birth Registration Date)	
ADDE based on Death Registration Date)	
Deriving cohorts ALFs	
PEDW (based on admission date	
GP (based onevent date)	2015 may not be complete. Data from around 75% of all Welsh GP practices. Coverage will vary from practice to practice - GP cleaner data will provide "good" start date. Due for refresh - currently excludes some deceased/ deregistered patients.
OPDW (based on appointment date	
EDDS based on attend date	
CARIS	

1979 1980 1981 1982 1983 1984 1985 1986 1987 1988 1989 1990 1991 1992 1993 1994 1995 1996 1997 1998 1999 2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 2010 2011 2012 2013 2014 2015 2016

Activity extracts required only for 11-year studt period (2004-2014). Data will be provided outside these dates where available, for other work

Appendix 5 - The role and structure of NCEPOD

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is an independent body to which a corporate commitment has been made by the Medical and Surgical Royal Colleges, Associations and Faculties related to its area of activity. Each of these bodies nominates members on to NCEPOD's Steering Group.

Steering Group as at 8th March 2018

Dr M Nathanson	Association of Anaesthetists of Great Britain and Ireland
Vacancy	Association of Surgeons of Great Britain and Ireland
Mr K Altman	Faculty of Dental Surgery, Royal College of Surgeons of England
Vacancy	Faculty of Public Health Medicine
Mr S Barasi	Lay Representative
Ms S Payne	Lay Representative
Dr J C Carey	Royal College of Anaesthetists
Dr K Ramachandran	Royal College of Anaesthetists
Dr J Butler	Faculty of Intensive Care Medicine
Dr C Mann	Royal College of Emergency Medicine
Dr A Tavaré	Royal College of General Practitioners
Mrs J Greaves	Royal College of Nursing
Mr T Hillard	Royal College of Obstetricians and Gynaecologists
Mr W Karwatowski	Royal College of Ophthalmologists
Dr I Doughty	Royal College of Paediatrics and Child Health
Dr L Igali	Royal College of Pathologists
Mr M McKirdy	Royal College of Physicians and Surgeons of Glasgow
Dr M Jones	Royal College of Physicians of Edinburgh
Dr A McCune	Royal College of Physicians of London
Dr M Ostermann	Royal College of Physicians of London
Dr M Cusack	Royal College of Physicians of London
Dr J Carlile	Royal College of Psychiatrists
Prof R McWilliams	Royal College of Radiologists
Mr W Tennant	Royal College of Surgeons of Edinburgh
Mr J Abercrombie	Royal College of Surgeons of England
Mr M Bircher	Royal College of Surgeons of England

Observers

Dr D Sharpstone	Coroners' Society of England and Wales
Mr J Campbell	Healthcare Quality Improvement Partnership

Trustees

Professor L Regan – Chair | Dr D Mason – Honorary Treasurer | Mr I Martin | Ms J Barber | Professor R Endacott Professor T J Hendra

NCEPOD is a company, limited by guarantee (Company number: 3019382) and a registered charity (Charity number: 1075588) | Company Secretary Dr M Mason

Clinical Co-ordinators

The Steering Group appoint a Lead Clinical Co-ordinator for a defined tenure. In addition there are 8 Clinical Co-ordinators who work on each study. All Co-ordinators are engaged in active academic/clinical practice (in the NHS) during their term of office.

Lead Clinical Co-ordinator:
Dr V Srivastava (Medicine)

Clinical Co-ordinators:
Dr M Juniper (Medicine)
Dr K Wilkinson (Anaesthesia)
Dr A P L Goodwin (Anaesthesia)
Mr M Sinclair (Surgery)
Dr S McPherson (Interventional Radiology)
Dr K Horridge (Paediatrics)
Dr M Allsopp (Adolescent Psychiatry)
Dr A Michalski (Paediatric Oncology)

Lay Representatives

NCEPOD has a number of lay representatives who assist in all aspects of NCEPOD's work.
Alice Joy | Ron Newall | Sharon North | Hayley Topping Nigel Buck | Constantinos Regas

Commissioning and supporting organisations

The Clinical Outcome and Review Programme into Medical and Surgical Care is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England, NHS Wales, the Health and Social care division of the Scottish Government, the Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS), the States of Jersey, the Bailiwick of Guernsey, and the Isle of Man.

Members of the Clinical Outcome Review Programme into Child Health Independent Advisory Group:
Stuart Logan | Claire Lemer | Sarah Bridges
Jacqueline Cornish | Brian Godfrey | Linda Partridge
Heather Payne | Paul Ramchandani | Maggie Rogers
Prakash Thiagarajan | Verena Wallace | Jayne Wheway
Dick Churchill | Susan Gallacher | Odette Burgess
Carolyn Wilson

Members of the HQIP team

James Campbell | Mirek Skrypak | Sue Latchem
Sarah Walker

Appendix 6 – Participation

Trust	Clinical Data Returned	Organisational Data Returned
Abertawe Bro Morgannwg University Health Board	Yes	Yes
Aintree Hospitals NHS Foundation Trust	Yes	Yes
Airedale NHS Foundation Trust	Yes	No
Alder Hey Children's NHS Foundation Trust	Yes	Yes
Aneurin Bevan University Health Board	Yes	No
Anglian Community Enterprise (ACE) CIC	NA	Yes
Ashford & St Peter's Hospitals NHS Trust	Yes	Yes
Barking, Havering & Redbridge University Hospitals NHS Trust	Yes	No
Barnet, Enfield and Haringey Mental Health NHS Trust	NA	Yes
Barnsley Hospital NHS Foundation Trust	Yes	Yes
Barts Health NHS Trust	Yes	Yes
Basildon & Thurrock University Hospitals NHS FoundationTrust	Yes	No
Bedford Hospital NHS Trust	Yes	No
Belfast Health and Social Care Trust	Yes	Yes
Berkshire Healthcare NHS Foundation Trust	NA	Yes
Betsi Cadwaladr University Local Health Board	Yes	Yes
Birmingham Community Healthcare NHS Trust	NA	Yes
Birmingham Women's and Children's NHS Foundation Trust	Yes	No
Black Country Partnership NHS Foundation Trust	NA	No
Blackpool Teaching Hospitals NHS Foundation Trust	Yes	Yes
BMI Healthcare	NA	No
Bolton Hospital NHS Foundation Trust	Yes	Yes
Bradford District Care NHS FoundationTrust	NA	Yes
Bradford Teaching Hospitals NHS Foundation Trust	Yes	Yes
Bridgewater Community Healthcare NHS Foundation Trust	NA	Yes
Brighton and Sussex University Hospitals NHS Trust	Yes	Yes
Buckinghamshire Healthcare NHS Trust	Yes	Yes
Burton Hospitals NHS Foundation Trust	Yes	Yes
Calderdale & Huddersfield NHS Foundation Trust	Yes	Yes
Cambridge University Hospitals NHS Foundation Trust	Yes	Yes
Cambridgeshire Community Services NHS Trust	NA	Yes
Cardiff and Vale University Health Board	Yes	Yes
Central and North West London NHS Foundation Trust	Yes	Yes
Central London Community Healthcare NHS Trust	Yes	NA
Chelsea & Westminster NHS Foundation Trust	Yes	No
Chesterfield Royal Hospital NHS Foundation Trust	Yes	Yes
City Hospitals Sunderland NHS Foundation Trust	Yes	Yes
Colchester Hospital University NHS Foundation Trust	Yes	Yes
Countess of Chester Hospital NHS Foundation Trust	Yes	Yes
County Durham and Darlington NHS Foundation Trust	Yes	Yes
Croydon Health Services NHS Trust	Yes	Yes
Cumbria Partnership NHS Foundation Trust	NA	Yes

Appendix 6 – Participation (continued)

Trust	Clinical Data Returned	Organisational Data Returned
Cwm Taf University Health Board	Yes	Yes
Dartford & Gravesham NHS Trust	No	No
Derby Teaching Hospitals NHS Foundation Trust	Yes	Yes
Derbyshire Healthcare NHS Foundation Trust	NA	Yes
Doncaster and Bassetlaw Hospitals NHS Foundation Trust	Yes	Yes
Dorset County Hospital NHS Foundation Trust	Yes	Yes
Dorset Healthcare University NHS Foundation Trust	NA	Yes
East & North Hertfordshire NHS Trust	Yes	Yes
East Cheshire NHS Trust	Yes	Yes
East Coast Community Healthcare CIC	NA	Yes
East Kent Hospitals University NHS Foundation Trust	Yes	No
East Lancashire Hospitals NHS Trust	Yes	Yes
East Sussex Healthcare NHS Trust	Yes	Yes
Epsom and St Helier University Hospitals NHS Trust	Yes	Yes
Frimley Health NHS Foundation Trust	Yes	Yes
Gateshead Health NHS Foundation Trust	Yes	No
George Eliot Hospital NHS Trust	Yes	NA
Gloucestershire Care Services NHS Trust	NA	No
Gloucestershire Hospitals NHS Foundation Trust	Yes	No
Great Ormond Street Hospital for Children NHS Trust	Yes	Yes
Great Western Hospitals NHS Foundation Trust	Yes	Yes
Guy's & St Thomas' NHS Foundation Trust	Yes	Yes
Hampshire Hospitals NHS Foundation Trust	Yes	Yes
Harrogate and District NHS Foundation Trust	Yes	Yes
Heart of England NHS Foundation Trust	Yes	Yes
Hertfordshire Community NHS Trust	NA	Yes
Hillingdon Hospitals NHS Foundation Trust	Yes	Yes
Homerton University Hospital NHS Foundation Trust	Yes	Yes
Hounslow and Richmond Community Healthcare NHS Trust	NA	No
Hull and East Yorkshire Hospitals NHS Trust	Yes	Yes
Hywel Dda University Health Board	Yes	Yes
Imperial College Healthcare NHS Trust	Yes	Yes
Ipswich Hospital NHS Trust	Yes	Yes
Isle of Man Department of Health & Social Security	Yes	Yes
Isle of Wight NHS Trust	Yes	Yes
James Paget University Hospitals NHS Foundation Trust	Yes	Yes
Kent Community Health NHS Foundation Trust	Yes	Yes
Kettering	Yes	No
King Edward VII's Hospital Sister Agnes	Yes	Yes
King's College Hospital NHS Foundation Trust	Yes	No
Kingston Hospital NHS Trust	Yes	Yes
Lancashire Care NHS Foundation Trust	NA	Yes

Appendix 6 – Participation (continued)

Trust	Clinical Data Returned	Organisational Data Returned
Lancashire Teaching Hospitals NHS Foundation Trust	Yes	Yes
Leeds Community Healthcare NHS Trust	NA	Yes
Leicestershire Partnership NHS Trust	NA	No
Lewisham and Greenwich NHS Trust	Yes	Yes
Lincolnshire Community Health Services NHS Trust	NA	No
Liverpool Community Health NHS Trust	NA	Yes
LIVEWELL South West	NA	No
Locala Community Partnerships CIC	NA	Yes
London North West University Healthcare NHS Trust	Yes	Yes
Luton and Dunstable Hospital NHS Foundation Trust	Yes	No
Maidstone and Tunbridge Wells NHS Trust	Yes	NA
Manchester University NHS Foundation Trust	Yes	Yes
Medway Community Healthcare CIC	NA	Yes
Medway NHS Foundation Trust	Yes	Yes
Mid Cheshire Hospitals NHS Foundation Trust	Yes	Yes
Mid Essex Hospitals NHS Trust	Yes	Yes
Mid Yorkshire Hospitals NHS Trust	Yes	No
Milton Keynes University Hospital NHS Foundation Trust	Yes	Yes
Newcastle upon Tyne Hospitals NHS Foundation Trust	Yes	Yes
NHS Ayrshire & Arran	No	No
NHS Borders	No	No
NHS Dumfries & Galloway	No	NA
NHS Fife	No	No
NHS Forth Valley	No	No
NHS Grampian	Yes	Yes
NHS Greater Glasgow & Clyde	No	No
NHS Highland	Yes	No
NHS Lanarkshire	Yes	Yes
NHS Lothian	No	No
NHS Tayside	No	No
NHS Western Isles	No	No
Norfolk & Norwich University Hospital NHS Trust	Yes	Yes
Norfolk Community Health & Care NHS Trust	NA	Yes
North Bristol NHS Trust	Yes	No
North Cumbria University Hospitals NHS Trust	No	Yes
North East London NHS Foundation Trust	NA	Yes
North Middlesex University Hospital NHS Trust	Yes	Yes
North Staffordshire Combined Healthcare NHS Trust	NA	Yes
North Tees and Hartlepool NHS Foundation Trust	Yes	Yes
North West Anglia NHS Foundation Trust	Yes	NA
Northampton General Hospital NHS Trust	Yes	Yes
Northamptonshire Healthcare NHS Foundation Trust	NA	Yes

Appendix 6 – Participation (continued)

Trust	Clinical Data Returned	Organisational Data Returned
Northern Devon Healthcare NHS Trust	Yes	No
Northern Health & Social CareTrust	No	Yes
Northern Lincolnshire & Goole NHS Foundation Trust	Yes	Yes
Northumbria Healthcare NHS Foundation Trust	Yes	Yes
Nottingham University Hospitals NHS Trust	Yes	Yes
Nottinghamshire Healthcare NHS Foundation Trust	NA	Yes
Oxford Health NHS Foundation Trust	NA	No
Oxford University Hospitals NHS Foundation Trust	Yes	Yes
Pennine Acute Hospitals NHS Trust (The)	Yes	No
Pennine Care NHS Foundation Trust	NA	Yes
Plymouth Hospitals NHS Trust	Yes	Yes
Poole Hospital NHS Foundation Trust	Yes	Yes
Portsmouth Hospitals NHS Trust	Yes	Yes
Queen Victoria Hospital NHS Foundation Trust	Yes	Yes
Ramsay Health Care UK	NA	No
Robert Jones and Agnes Hunt Orthopaedic Hospital NHS Foundation Trust	Yes	Yes
Rotherham NHS Foundation Trust	Yes	Yes
Royal Berkshire NHS Foundation Trust	Yes	Yes
Royal Bournemouth and Christchurch Hospitals NHS Trust	NA	Yes
Royal Cornwall Hospitals NHS Trust	Yes	Yes
Royal Devon and Exeter NHS Foundation Trust	Yes	Yes
Royal Free London NHS Foundation Trust	Yes	Yes
Royal Liverpool & Broadgreen University Hospitals NHS Trust	Yes	Yes
Royal National Orthopaedic Hospital NHS Trust	Yes	Yes
Royal Orthopaedic Hospital NHS Foundation Trust	Yes	Yes
Royal Surrey County Hospital NHS Trust	Yes	Yes
Royal United Hospitals Bath NHS Foundation Trust	Yes	Yes
Salford Royal Hospitals NHS Foundation Trust	Yes	Yes
Salisbury NHS FoundationTrust	Yes	Yes
Sandwell and West Birmingham Hospitals NHS Trust	Yes	Yes
Sheffield Children's NHS Foundation Trust	Yes	Yes
Sheffield Teaching Hospitals NHS Foundation Trust	Yes	Yes
Sherwood Forest Hospitals NHS Foundation Trust	Yes	Yes
Shrewsbury and Telford Hospitals NHS Trust	Yes	No
Solent NHS Trust	Yes	Yes
South Eastern Health & Social Care Trust	No	Yes
South Staffordshire & Shropshire Healthcare NHS Foundation Trust	Yes	NA
South Tees Hospitals NHS Foundation Trust	Yes	Yes
South Tyneside NHS Foundation Trust	Yes	Yes
South Warwickshire NHS Foundation Trust	Yes	Yes
Southend University Hospital NHS Foundation Trust	Yes	Yes
Southern Health & Social Care Trust	Yes	No

Appendix 6 – Participation (continued)

Trust	Clinical Data Returned	Organisational Data Returned
Southport & Ormskirk Hospitals NHS Trust	Yes	Yes
St George's University Hospitals NHS Foundation Trust	Yes	Yes
St Helens and Knowsley Teaching Hospitals NHS Trust	Yes	Yes
Staffordshire & Stoke on Trent Partnership NHS Trust	NA	Yes
States of Guernsey Committee for Health & Social Care	NA	No
States of Jersey Health & Social Services	Yes	Yes
Stockport NHS Foundation Trust	Yes	Yes
Surrey & Sussex Healthcare NHS Trust	Yes	No
Sussex Community NHS Foundation Trust	Yes	Yes
Tameside and Glossop Integrated Care NHS Foundation Trust	Yes	Yes
Taunton & Somerset NHS Foundation Trust	Yes	Yes
The Dudley Group NHS Foundation Trust	Yes	Yes
The Leeds Teaching Hospitals NHS Trust	Yes	Yes
The Princess Alexandra Hospital NHS Trust	Yes	NA
The Queen Elizabeth Hospital King's Lynn NHS FoundationTrust	Yes	Yes
The Royal Marsden NHS Foundation Trust	Yes	No
The Royal Wolverhampton Hospitals NHS Trust	Yes	Yes
The University Hospitals of the North Midlands NHS Trust	Yes	No
The Walton Centre NHS Foundation Trust	Yes	Yes
Torbay and South Devon NHS Foundation Trust	Yes	Yes
United Lincolnshire Hospitals NHS Trust	Yes	Yes
University College London Hospitals NHS Foundation Trust	Yes	Yes
University Hospital Southampton NHS Foundation Trust	Yes	Yes
University Hospitals Birmingham NHS Foundation Trust	Yes	Yes
University Hospitals Coventry and Warwickshire NHS Trust	Yes	Yes
University Hospitals of Bristol NHS Foundation Trust	Yes	No
University Hospitals of Leicester NHS Trust	Yes	Yes
University Hospitals of Morecambe Bay NHS Trust	Yes	Yes
Walsall Healthcare NHS Trust	No	Yes
West Hertfordshire Hospitals NHS Trust	Yes	Yes
West Suffolk NHS Foundation Trust	Yes	Yes
Western Health & Social Care Trust	Yes	Yes
Western Sussex Hospitals NHS Foundation Trust	Yes	Yes
Whittington Health NHS Trust	Yes	Yes
Wirral University Teaching Hospital NHS Foundation Trust	Yes	Yes
Worcestershire Acute Hospitals NHS Trust	Yes	Yes
Worcestershire Health and Care NHS Trust	Yes	No
Wrightington, Wigan & Leigh NHS Foundation Trust	Yes	Yes
Wye Valley NHS Trust	Yes	Yes
Yeovil District Hospital NHS Foundation Trust	Yes	Yes
York Teaching Hospitals NHS Foundation Trust	Yes	Yes

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