Chronic Neurodisability

Protocol February 2016

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Introduction

Literature review

"Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may never be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour".[1]

The cerebral palsies (CP) are permanent disorders of movement and posture resulting from non-progressive injury to immature brains.[2] They are one of the most common causes of physical disability in early childhood[3], and affect around 1 child in every 400 born[4, 5], which equates to approximately 1800 new cases a year[5]. There are different types of cerebral palsy; spastic which is the most common form accounting for around 75% of cases; dyskinetic (subdivided into choreo-athetoid or dystonic) accounting for around 20% of cases; ataxic cerebral palsy accounting for around 5% of cases and Worster Drought Syndrome, which predominantly affects eating, swallowing and speech production. Many people are affected by more than one type of CP with varying degrees of severity.[4,5]

The majority of children with CP will be diagnosed within the first 2 years of life. In those with milder symptoms diagnosis may not be possible until 4-5 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.[6]

Associated conditions can include 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.[4, 5, 6, 7]

Children and young people with CP 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 CP; 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.

A study carried out in Canada[8] explored the most common reasons for admission to hospital and associated length of stay. They compared the primary reasons for admissions to hospital over a 4 year period within a group of youths (classified as 13-17.9yrs, n=587) with CP, and a group of young adults (aged 23-32.9yrs, n=477) with CP. The primary reasons for admission for youths were epilepsy, respiratory conditions and orthopaedic conditions (pneumonia and epilepsy each accounted for around 13% of admissions). For young adults reasons were more diverse, with mental illness having a significant impact. Pneumonia was the most frequent cause (15.5%), followed by epilepsy, 7.5% and mental illness, 6.5%.

From their analysis of The Healthcare Utilization Project Kid Inpatient Database, which is a weighted survey of paediatric discharges from US hospitals in 1997, Murphy et al[9] found that children with CP (n=14, 947) had longer lengths of stay, higher hospital care costs, more diagnoses and more procedures per admission than children without CP. Five major diagnostic categories (respiratory system, nervous system, musculoskeletal, connective

tissue, digestive, nutritional, endocrine and metabolic systems) accounted for 83.2% of the discharge diagnoses for children with CP, compared to 48.6% of those without CP.

A UK study[10], explored the role of the acute assessment unit and consequent hospital admissions for children presenting to hospital with CP. Data were accessed via a district special needs register (701 children) and were analysed over a five year period; of the 701 children, 73 had a diagnosis of CP. Across the whole cohort, respiratory tract infections and seizures were the most common presenting problems and reason for admission. In addition to clinical factors, the authors also highlighted social circumstances and parental perception as important contributors in the decision to admit a child with special needs.[10]

As described previously, people with cerebral palsy may also experience learning disability. In 2011/12, approximately 190,000 children in England were identified as associated as having a primary SEN with learning disability, these range from moderate to profound. Children with SEN associated with learning disabilities have poorer educational attainment than their peers.[11]

Due to the wide range in severity of CP educational experiences of children and young people will vary. Whilst some children with CP move through mainstream curricula with minimal adjustments, intervention and support, others with more complex needs require tailored support within mainstream settings or special school placement.[6] The SPARCLE study[12], 2013, examined the determinants of inclusive education of 804 8–12 year-old children with cerebral palsies in nine European regions. This study demonstrated marked differences in the percentages of children with CP attending mainstream schools ranging from 98% in central Italy compared to 20% in north-west Germany. In the Northern England cohort, 61% of children with CP attended mainstream schools, 34% special schools and 5% special units within mainstream schools.[12]

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'.[13,14,15,16] 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.[16] Suboptimal transition to adult services has been linked to a decrease in the utilisation of services by adolescents.[17]

Stevenson et al[18] compared service utilized by 15-18 year olds as compared to 20-22 year olds with CP, in the Liverpool Health District. There were statistically significant differences in the proportion of inpatient admissions, outpatient attendances, regular check-ups and contact with physiotherapy, speech and language therapy and occupational therapy in the past twelve months, with the older age-group having less contact.

In 2013 the Royal College of Paediatrics and Child Health published the '*Overview of child deaths in the four UK countries'* report under their Child Health Review (CHR-UK) project which highlighted a number of key issues. One finding 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 deaths in healthy children. Policies to reduce child deaths need to focus on quality of care in children with chronic conditions to prevent premature deaths and recognise that some are not preventable[19]. The aim of the current project is to build on and extend the work of previous child health confidential enquiries and

clinical outcome review programmes using cerebral palsy as an exemplar of chronic neurodisability.

Guidelines and standards

Department of Health. 2004. *National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs.*[20]

National Institute for Health and Care Excellence. 2012. *Spasticity in children and young people with non-progressive brain disorders. Management of spasticity and co-existing motor disorders and their early musculoskeletal complications. NICE clinical guideline 145.*[21]

National Institute for Health and Care Excellence. 2010. *Selective dorsal rhizotomy for spasticity in cerebral palsy. NICE interventional procedure guidance 373.*[23]

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. 2013 *Overview of Child Deaths in the four UK countries: Report September 2013*.[24]

National Institute for Health and Care Excellence. 2012. *Epilepsy-diagnosis and management NICE clinical guidance 137.*[25]

Scottish Intercollegiate Guidelines Network. 2015. *SIGN 143.Diagnosis and management of Epilepsy in adults. A national clinical guideline*.[26]

Together for Short Lives. 2013. *A core pathway for children with life limiting and life threatening conditions. 3rd edition*.[27]

Department of Health. 2011. *"You're Welcome"- Quality criteria for Young People friendly health services.*[28]

National Institute for Health and Care Excellence. 2016. *Transition from Children's to adult services (NG43)*. *NICE guideline.*[29]

Aims and objectives

Overall aim:
To identify the remediable factors in the quality of care provided to children and young people with chronic disabling conditions, focusing in particular on cerebral palsies.

To examine the interface between different care settings

To examine the transition of care

Objectives
Organisational

- Access to services (including pathways of care and clinical leadership)
- Service delivery (including uni/multi disciplinary care, outreach clinics, co-location of services)

Clinical

- Services for families with children and young people with cerebral palsies (including professionals with a range of 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, support in school, access to leisure activities, housing, finance and support at transition to adulthood)
- Communication (including 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, capacity and best interest decision making)
- Palliative and end of life care

Data linkage

- The number of admissions and readmissions
- Primary reason for hospital admission
- Measures of morbidity
- The rates of consultation in primary care
- Educational achievement at KS1 and KS2 and the proportion of children with SEN

Methods

Population/Inclusions
Data will be collected on all patients aged 25 and under, at the time of admission, who are admitted to hospital with one of the included diagnosis codes, during the study period. Data will be collected over a 6 week period, from Monday 7th September – Sunday 18th October 2015.

The following ICD10 codes will be used to help identify patients for inclusion:

G80.0 Spastic quadriplegic cerebral palsy
G80.1 Spastic diplegic cerebral palsy

G80.2 Spastic hemiplegic cerebral palsy
G80.3 Dyskinetic cerebral palsy
G80.4 Ataxic cerebral palsy
G80.8 Other cerebral palsy
G80.9 Cerebral palsy, unspecified

G81.0 Flaccid hemiplegia
G81.1 Spastic hemiplegia
G81.9 Hemiplegia, unspecified

G82.3 Flaccid tetraplegia
G82.4 Spastic tetraplegia
G82.5 Tetraplegia, unspecified

G83.0 Diplegia of upper limbs
G83.1 Monoplegia of lower limb
G83.2 Monoplegia of upper limb
G83.3 Monoplegia, unspecified

Patients will be identified across both acute and community hospitals

Exclusions
None

Participating Trusts/Health Boards
All Trusts/Health Boards where children and young people (under 25) with cerebral palsy are cared for will be requested to participate in the study. These will include acute and community Trusts/Health Boards, as well as independent providers of care.

Sample size (to be determined)
In England, between 2013-2014, there were 32,288 admissions in children and young people (aged under 25), with an ICD10 code relating to cerebral palsy, (recorded anywhere). This equates to 620 admissions per week.

During the six week study period, a sample of approximately 3720 patients will be identified initially from which 1500 will be randomly selected for inclusion in the study.

Method of data collection

Case identification spreadsheet
Within each Trust/Health Board NCEPOD has a Local Reporter (usually employed in clinical audit) who is responsible for providing the details of cases for inclusion to NCEPOD. At the start of the study the Local Reporter will be contacted and sent details of the study criteria. They will then use these details to populate the case identification spreadsheet.

Local reporters will be asked to populate the study spreadsheet using the listed ICD10 codes for patents admitted during the six week study period (Monday 7th September – Sunday 18th October 2015). Data collected will include patient identifiers (hospital and NHS/CHI number, date of birth, gender), date of admission, (the included) ICD10 code, date of discharge, discharge destination and the details of the clinicians who were involved in the care of the patient.

Details will also be requested on the spreadsheet of any previous admissions the patient has had in the four weeks prior to the study time period (Monday 10th August – Sunday 6th September 2015).

Questionnaires

Organisational questionnaire

An organisational questionnaire will be sent to all Trusts/Health Boards where children and young people with cerebral palsy may be cared for, to collect data on the organisational aspects of care. Trusts/Health Boards will include both acute, community, and independent hospitals. Data collected will include information around pathways of care, transition, policies and protocols and communication.

The organisational questionnaire has been split into 10 sections which relate to the following specific areas of care:

1. Emergency Department
2. Inpatient care - paediatrics
3. Outpatient care - paediatrics
4. Community paediatrics
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

Local reporters will be sent an initial questionnaire which asks them to identify which of the 10 services they provide, and who the lead is for that service. The relevant sections of the organisational questionnaire will then be sent on to the service leads (via Local Reporters) to complete. The Medical Director will also be contacted and informed the questionnaire has been sent. The questionnaire will also be made available to download via the NCEPOD website.

Commissioning Bodies Organisational Questionnaire

A short organisational questionnaire will also be sent to commissioning bodies for completion. This will again be disseminated electronically, and will gather data around the commissioning of services.

Service User and Carer Questionnaire

A short patient questionnaire will be disseminated electronically via NCEPOD's network of local reporters and patient networks in order to gather data on young people and carers views on the services provided to them. This questionnaire will also be available on the NCEPOD website.

Clinician questionnaire

Two questionnaires will be used to collect data for this study:

1) Admitting physician/paediatrician questionnaire: A clinical questionnaire will be sent to the named consultant caring for the patient at the time of admission for completion and will ask for details of the care provided during the patient's admission. The clinician details will be identified from the data collection spreadsheet.

2) Lead (usual) clinician questionnaire: A clinical questionnaire will be sent to the (lead) clinician who is responsible for the overall clinical care of the patient. It is anticipated the details of this clinician will be identified from the casenotes or the admitting physician/paediatrician questionnaire.

Where clinician details are not routinely recorded on PAS/RiO systems, NCEPOD will review the case notes in order to try and identify the correct clinician to send the questionnaire to for completion.

The clinical questionnaire will either be sent to the NCEPOD local reporter for dissemination or directly to the relevant clinician. Reminder letters will be sent at six weeks and ten weeks where the data is outstanding. Clinicians will be asked to return copied extracts of the patients case notes to NCEPOD alongside the completed questionnaire.

Casenotes
Acute care:
The following case note extracts will be requested from the time of admission until the time of discharge, day 30 or death:

- Emergency Department records (where applicable)
- Clinical notes from the time of arrival at hospital until the time of discharge
- Electronic notes from the time of arrival at hospital until discharge
- Operation notes and consent forms (where applicable)
- *Nursing notes from the time of arrival at hospital until discharge*
- Emergency health care plans
- Passports of care
- Discharge note
- Community therapy notes
- Any outpatient appointment correspondence
- Copies of General Practitioner (GP) notes where applicable
- Clinical notes from any previous admissions (including discharge summaries) (between the 10th August – 18th October 2015)
- Any separate orthopaedic notes
- The most recent community discharge summary

Previous notes (going back three years from the included* admission)
*The admission for which the patient was identified as part of the sample

- Clinic letters
- Discharge letters/Summaries for any previous hospital admissions

Community care:
The following case note extracts will be requested for 3 years prior to the stated admission:

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

Upon receipt at NCEPOD the case notes will be made anonymous in terms of the patient's details.

Reviewer assessment form
A multidisciplinary group of reviewers (details below) will be recruited to assess the case notes and questionnaires and give their opinions on the quality of care via the reviewer assessment form.

Data linkage
National datasets will be used to identify trends in the management of children and young people with cerebral palsies. Data from sources such as the Office of National Statistics and clinical and public health datasets can be linked using NHS/CHI numbers and then anonymised. The data can then be used to answer specific questions about people's journeys through the health system. Experienced data analysts will be employed to manage, quality control (clean, de-duplicate and check) and analyse the datasets. An epidemiologist/statistician will provide a descriptive analysis of the data and comparisons will be made according to socio-demographic characteristics such as social deprivation, age of the child, across devolved nations.

Pilot Study
A pilot study will be undertaken to test the data collection methods and materials to ensure they are robust.

Analysis and Review of Data

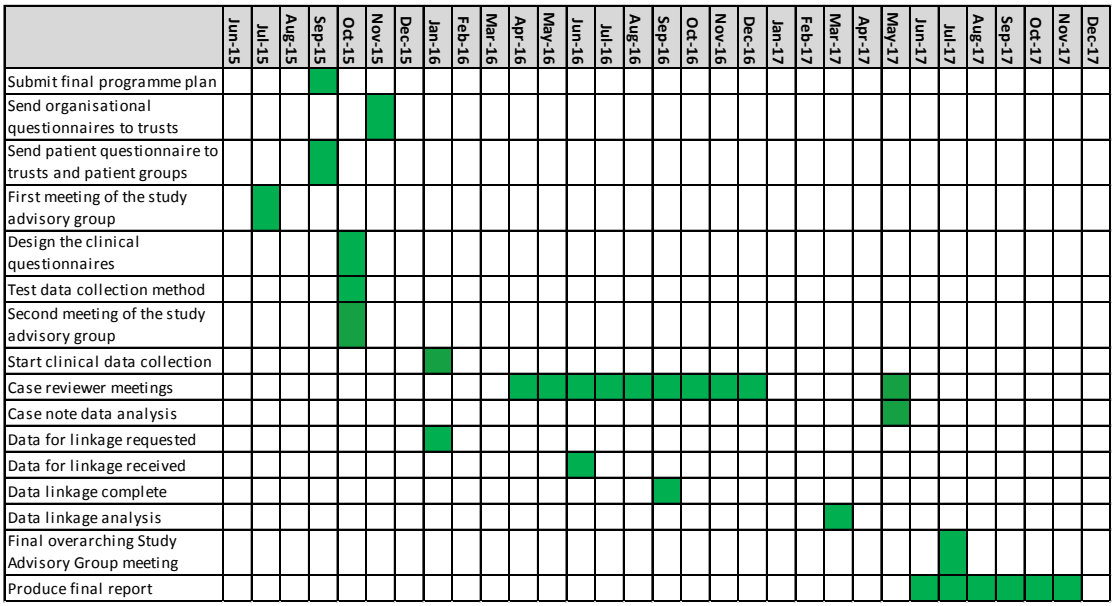
Reviewers
A multidisciplinary group of reviewers will be recruited to assess the case notes and questionnaires and provide their opinion on the care the patients received. The advisor group will be made up of paediatricians, paediatric gastroenterologists, physicians/neurorehabilitation specialists, paediatric surgeons (including orthopaedics and neurosurgery), paediatric neurologists, neurologists, anaesthetists, specialist children's nurses, physiotherapists, occupational therapists, speech and language therapists, orthotists, dieticians, palliative care specialists, psychiatrists, learning disability psychiatrists including for children and GPs. An advert will be sent to Local Reporters to disseminate throughout the relevant departments that NCEPOD are recruiting study reviewers. An advert will also be placed on the NCEPOD website. Successful applicants will be asked to attend a training day where they will assess the same two cases to ensure consistent marking. A number of meeting dates will be arranged, and each reviewer will then be asked to attend a further 6 meetings. NCEPOD staff will ensure there is a mix of specialties at each meeting. Each meeting will be chaired by a clinical coordinator who will lead discussion around the cases under review. Towards the end of the study the reviewers will be invited to attend a meeting where the data will be presented to and discussed with them. The reviewers will also be sent two copies of the draft report for their comment as this is developed.

Confidentiality and data protection
Once the data have been extracted by the NCEPOD researchers, the questionnaires and casenotes will be anonymised to remove patient, clinician and hospital identifiers prior to review by the Advisory Group.

All electronic data are held in password protected files and all paper documents in locked filing cabinets. As soon as possible after receipt of data NCEPOD will encrypt electronic identifiers and anonymise paper documents. Section 251 approval has been obtained to perform this study without the use of patient consent.

Dissemination
On completion of the study a report will be published and widely disseminated.

Timescale



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