

Health service use among young people with cerebral palsy in England

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Physiotherapy UK, CSP Annual General Meeting 2018

CP is the most common form of childhood disability, with prevalence rates of between 1.5 and 3.8 per 1000 births reported worldwide (*SCOPE 2012*). In 2005 the Department of Health, released *The National Service Framework for Long-term Conditions*. It identified that approximately 110,000 people in the United Kingdom (UK) are currently living with a diagnosis of cerebral palsy, with a prevalence rate of 186 per 100,000 cases of population (*Department of Health, 2005*).



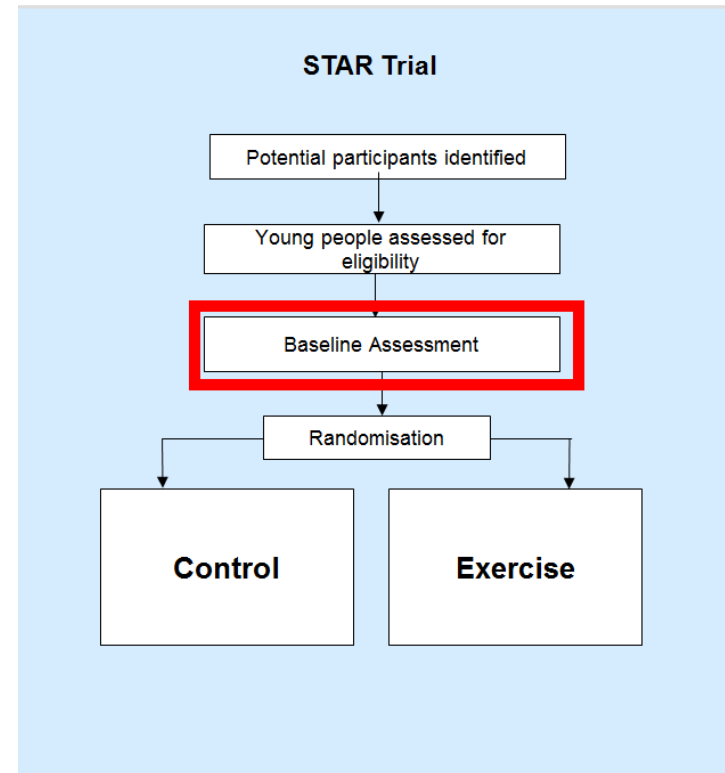
The National Service Framework for Long-term Conditions

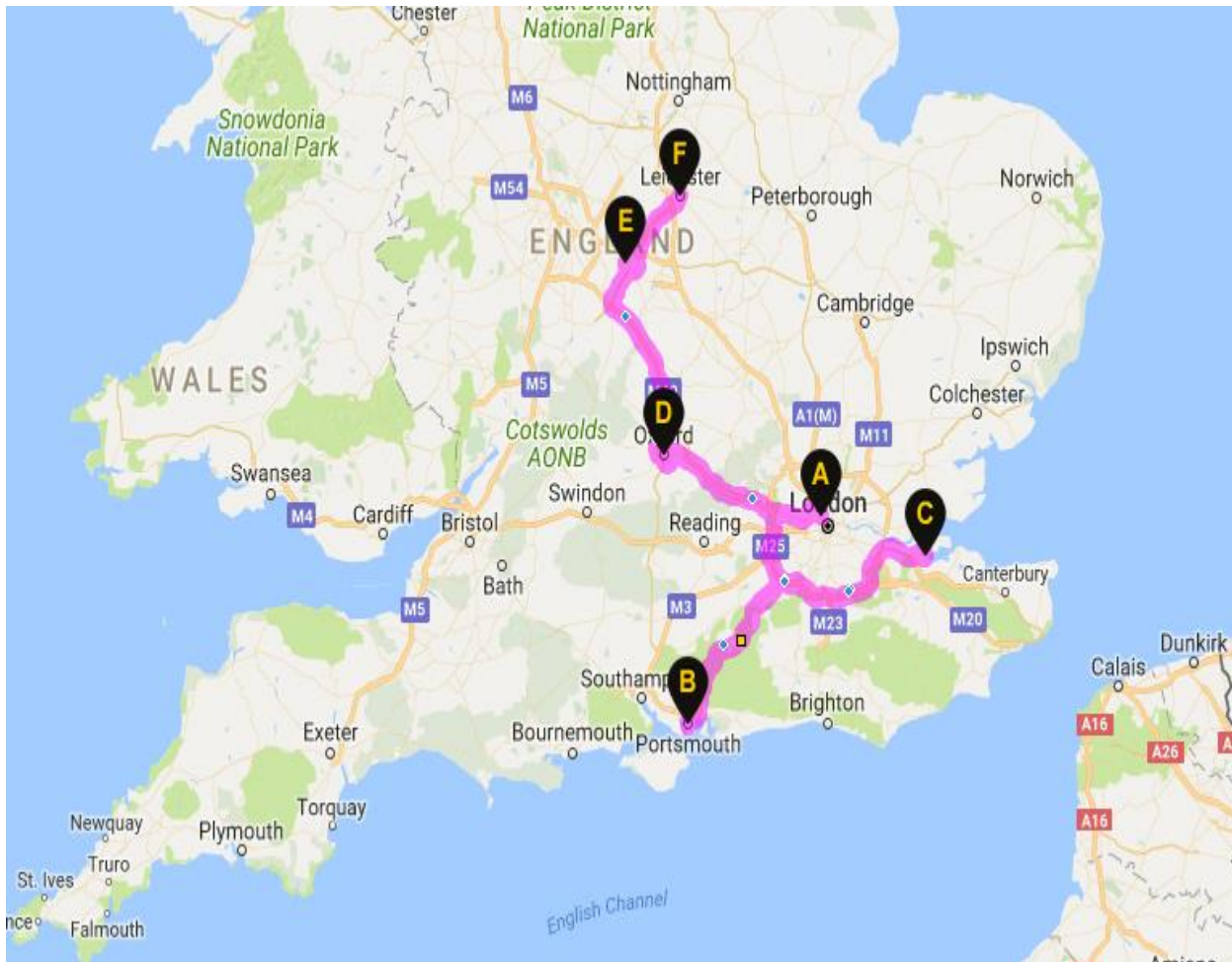
Condition	Incidence (new cases per year per 100,000 of population)	Prevalence (cases per 100,000 of population)	Approximate total numbers
Cerebral palsy	N/k	186	110,000
Charcot-Marie-Tooth disorder	N/k	40	23,600
Dystonia ⁱⁱ	N/k	65	38,000
Early onset dementia ⁱⁱⁱ	N/k	N/k	18,000
Epilepsy ^{iv}	24–58	430–1,000	182,750–425,000
Essential tremor	N/k	850	500,000
Huntington's disease	N/k	13.5	6,000–10,000
Migraine ^v (England)	400	15,000	8,000,000
Motor neurone disease	2	7	4,000
Multiple sclerosis^{vi}	3–7	100–120	52,000–62,000
Muscular dystrophy	N/k	50	30,000
Parkinson's disease	17	200	120,000
Post-polio syndrome	N/k	N/k	120,000
Spinal cord injury ^{vii}	2 ^{viii}	50	36,000
Spina bifida and congenital hydrocephalus	N/k	24	14,000
Young onset stroke ^{ix}	55 ^x	N/k	N/k
Traumatic brain injury leading to long-term problems ^{xi}	175 requiring admission to hospital	1,200 with long-term problems	420,000 upto 65 years

Despite these figures there is a dearth of information detailing health service use and provision of care for people with CP, in England.

Therefore the primary aim of this study was to determine the type and frequency of health service use by young people with CP in England.

A secondary aim was to examine the physical factors associated with the frequency of attendance to each health care professional.





A = London – Brunel University London, John Chilton School, Swiss Cottage School, Chelsea and Westminster Hospital

B = Portsmouth

C = Medway Community Healthcare

D = Oxford

E = Coventry

F = Leicester

Participants were identified by:

1. Clinicians across NHS Trusts (n = 10) that provide either primary care, hospital and community paediatric services. (Royal Free NHS, Central and North West London NHS, North West London CCG, Medway NHS, Solent NHS, Leicestershire NHS, Oxford University Hospitals NHS, Guy's and St. Thomas's NHS, Chelsea and Westminster NHS, and Coventry and Warwickshire NHS)
2. promotion via cerebral palsy support network (e.g. CP sport), word of mouth, study flyers and advertisements
3. Brunel University London Disability and Dyslexic Service and local schools



Participant ID:
DOB:
Date:



Health Service Use Economic Evaluation

Excluding contact with the research team, please tick the services that you have accessed in the **previous 3 months**. Please enter "0" if the service has not been used.

	Total Number of Contacts	Provider Sector (e.g. NHS/Voluntary/Private)	Home/School/Clinic Visit	Average contact time (hours)
General Practitioner				
Nurse				
Paediatrician				
Orthopaedic Surgeon				
Neurologist				
Other Consultant (please specify)				
Physiotherapist				
Occupational Therapist				
<u>Orthotist</u>				
Speech and Language Therapist				

- A negative binomial model was fitted to examine the association between age, gender and GMFCS level, and number of visits to each health professional.

Results

Participant Characteristics (n = 62)	
Gender	
Male, n (%)	36 (58.1)
Female, n (%)	26 (41.9)
Age (yr) mean (SD)	13.6 (2.5)
Height (cm) mean (SD)	154.5 (12.4)
Mass (kg) mean (SD)	49.6 (13.6)
GMFCS	
Level 1, n (%)	28 (45.2)
Level II, n (%)	25 (40.3)
Level III, n (%)	9 (14.5)
Education Level	
Primary, n (%)	11 (17.7)
Secondary, n (%)	46 (74.2)
University, n (%)	3 (4.9)
Other, n (%)	2 (3.2)
Distribution	
Unilateral, n (%)	29 (46.8)
Bilateral, n (%)	33 (53.2)

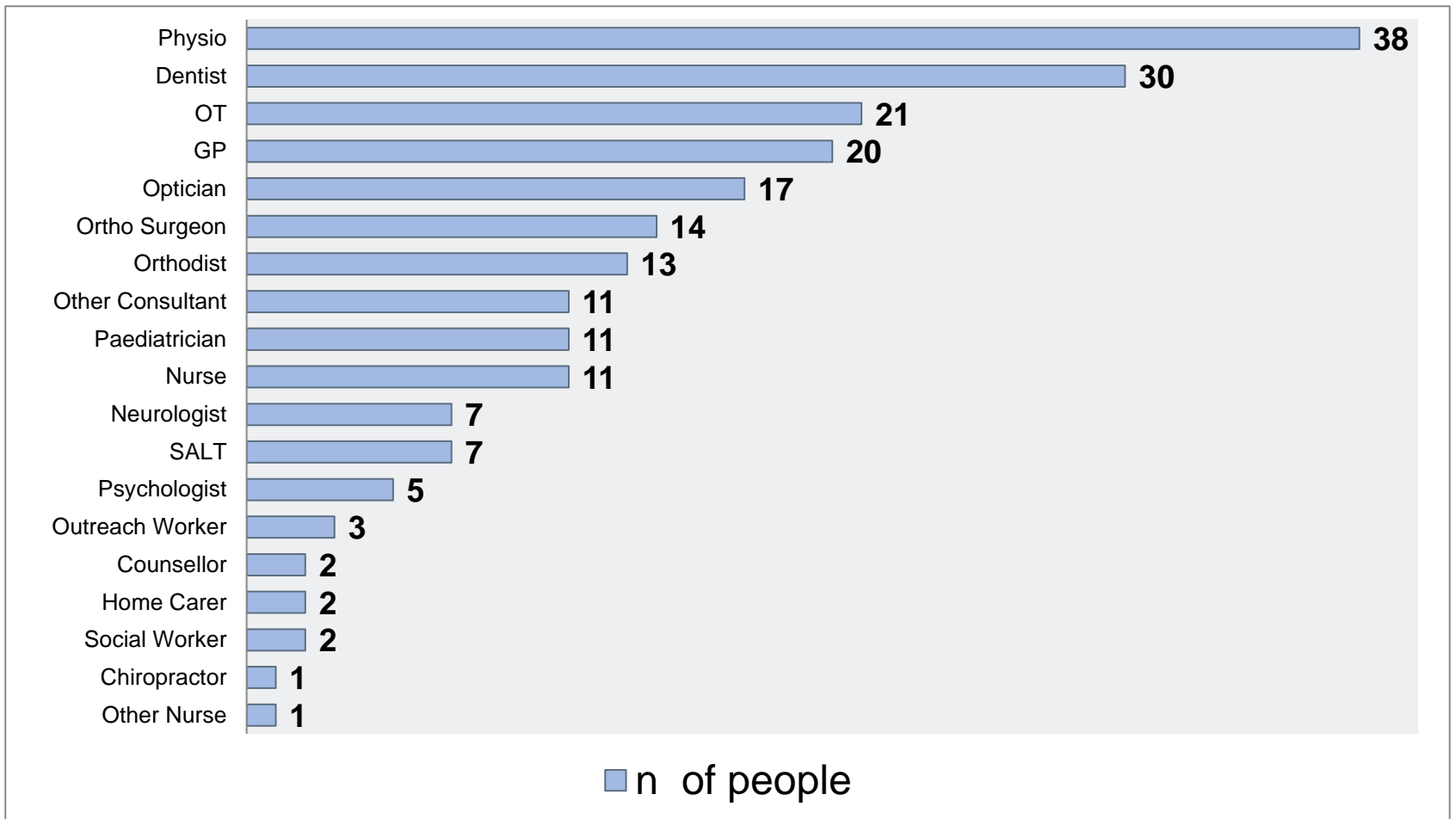
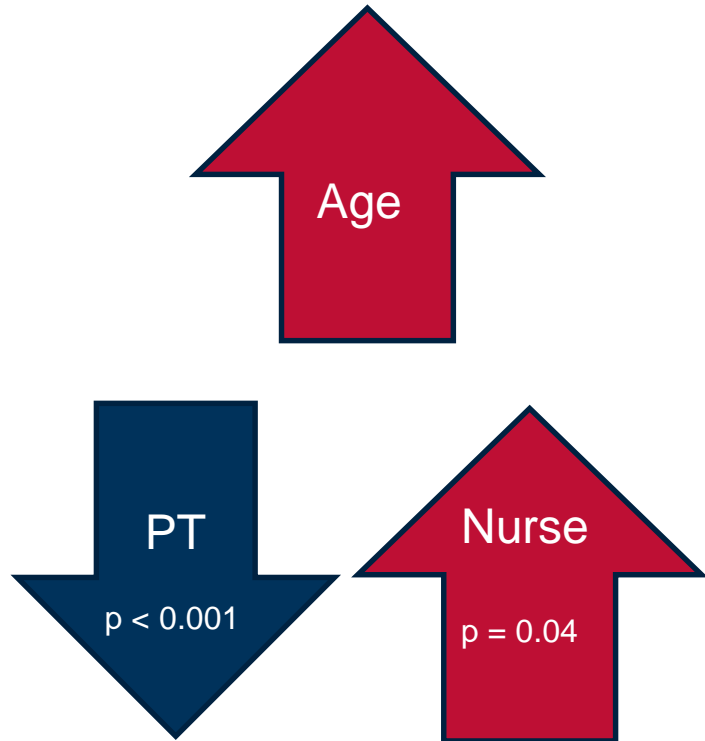


Figure 2 Breakdown of the number of participants with at least one visit to each health care professional over the previous 3 months

Associations



- Participants in **GMFCS level III** reported **higher number of visits to a physiotherapist and to a paediatrician** ($p < 0.001$ and $p = 0.03$, respectively), whereas the numbers of visits to an **occupational therapist and to a nurse were higher for those classified as GMFCS level II** ($p = 0.02$ and $p = 0.03$, respectively, when compared to those classified as GMFCS level I, regardless of age and gender.
- **Girls also attended a neurologist more frequently than males** (RR 7.4, 95% CI 1.2 to 45.4, $p = 0.03$), regardless of age and GMFCS level.
- There were **no associations** for age, gender or GMFCS level with the number of visits to an orthotist, a speech and language therapist, a psychologist, a counsellor, an optician, an orthopaedic surgeon or a general practitioner.

Discussion and Conclusion



- Young people with CP often ***experience a myriad of co-morbidities*** in addition to their CP diagnosis including epilepsy, respiratory complications and a range musculoskeletal pathologies (Pruitt *et al.*, 2009). Therefore, the ***need for specialist medical care for people with CP*** remains high throughout their lifespan.
- The findings from this study could inform the future provision and delivery of services for young people with CP in England, with ***physiotherapists, occupational therapists and dentists*** among the most highly frequented professions.
- The study highlights that the ***frequency of attendance*** to certain health care professionals varies depending on the ***severity of motor impairment (GMFCS level), age and gender***, which could assist parents, young people with CP and their health care professionals.
- An understanding of existing health service utilisation patterns and how it may relate to physical characteristics of young people with CP is pertinent to order to identify gaps in health care, ***to organise and manage current service provision and assist in future service planning*** and ultimately to deliver high quality care, for young people with CP.

Study organisation

Research Team		
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Study organisation

Sponsored by Brunel University London

Lead R&D department is Royal Free London NHS Foundation Trust

Supported by grant from



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