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Predicting the prevalence of cerebral palsy by severity level in children aged 3-15 years across England and Wales by 2020

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ABSTRACT

AIM: To estimate the number of children living with cerebral palsy (CP) in England & Wales in 2013 by severity and to extrapolate this figure to 2020.

METHOD: Data from the North of England Collaborative Cerebral Palsy Survey for births during 1991-2000 were restricted to individuals aged ≥3 years to estimate the prevalence of CP and to calculate 15-year survival by severity according to the number of severe impairments and lifestyle assessment score. The number of 3-15-year olds with CP of different severity in England & Wales was estimated in 2013 and 2019 using actual and nationally projected births.

RESULTS: Cumulative survival estimates up to age 16 years in children with CP differ significantly by severity ranging between 97-100% for children with non-severe CP and between 64-67% for those with most severe CP. By the end of 2013, the estimated number of children aged 3-15 years living with CP in England & Wales will be about 20,500 rising to approximately 22,100 by 2020, a 7.5% increase.

INTERPRETATION: The number of children living with CP in England & Wales will increase by 2020 due to an increasing population. This will have significant implications for health and social care service planning.

Short title (up to six words): predicted prevalence of CP by severity

What this paper adds?

- 15-year survival rates in children with CP differ significantly by severity being the lowest (between 64-67%) for those with most severe CP.
- We estimate that by 2020, there will be approximately 22,100 children aged 3-15 years living with CP in England & Wales, around two thirds of them with moderate or severe CP.
- There will be a 7.5% estimated increase in the total number of 3-15 year-old children living with CP in England & Wales by 2020 which should be taken into consideration when planning health and social care services.

Keywords: cerebral palsy prevalence, severity, survival, projected estimates, North of England Collaborative Cerebral Palsy Survey (NECCPS)

ABBREVIATIONS

CI  Confidence interval
CP  Cerebral palsy
HR  Hazard Ratio
LAS  Lifestyle Assessment Score
NECCPS  North of England Collaborative Cerebral Palsy Survey
ONS  Office for National Statistics
SCPE  Surveillance of Cerebral Palsy in Europe
The improvement of health, wellbeing and quality of life of all children in the UK is a public health priority, as reflected by recent government documents, including the Children and Families Act 2014 (http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted). Disabled children and those who have special educational needs, in particular, require an effective system of identification and monitoring in each region in order to allocate appropriate resources to support health and social care service planning. However, there is limited data available on the number of disabled children by region and limited understanding of their met and unmet needs, especially by specific medical condition.

Cerebral palsy (CP) is a common cause of childhood disability. During the last three decades, the overall prevalence of CP has remained relatively stable over time and across countries, ranging between 2 and 3.5 per 1000 live births.2-7 Children with CP have a much higher mortality rate compared to children without CP, which is mostly attributed to children with severe impairments.7-10 Evidence regarding improvement in CP survival over the last three decades is inconsistent, with increasing survival in some countries10 but not in others.8,9,11

Children with CP, particularly those with one or more severe impairments (motor, sensorial and/or intellectual) and/or associated conditions, have specific health and social care needs (e.g. spinal/orthopaedic surgery, need for mobility aids, respiratory support, physiotherapy, speech and language therapy, occupational therapy, medications, social workers) and often special education needs which differ depending on the type and severity of impairments. Therefore, in order to inform the planning of health and social care services and to assign the appropriate resources, it is important to estimate the number of children with CP of different severity for each region. Although in England, the Family Resources Survey annually estimates the population disability prevalence, including children, it does not provide estimates by medical condition.12

The aim of this study is to estimate the number of children living with CP in England & Wales in 2013 by severity and to extrapolate this figure to 2020 to provide evidence for health and social care planning.
METHOD

Study birth population
Data for cases of CP occurring in births between 1 January 1991 and 31 December 2000 were extracted from the prospective population-based survey of CP, the North of England Collaborative Cerebral Palsy Survey (NECCPS), in December 2015. The North of England is a geographically defined area (comprising counties of North Cumbria, Northumberland, Tyne & Wear, Durham and Darlington, and Teesside) with a stable population of almost three million and approximately 32,000 births/year, characterised by a relatively low percentage of minority ethnic groups [about 5% in 2011, Office for National Statistics (ONS) data].

NECCPS prospectively recorded infants with CP born to mothers resident in the Northern Region from 1991 (data collection ceased on 31st March 2016). Details of case ascertainment and data notification are described elsewhere\(^6\) and in Box 1.

For this analysis, cases due to a known post-neonatal insult were excluded resulting in cases with congenital CP only. All analyses were restricted to children with CP aged ≥3 years to acknowledge that deaths due to CP prior to this age were likely to be underreported,\(^8\) and because the severity information for these young children was mostly missing.

Classification and Definitions
NECCPS uses the Little Club definition of CP, updated by Bax,\(^13\) and, as a member of the Surveillance of Cerebral Palsy in Europe (SCPE) collaboration, follows the SCPE inclusion criteria\(^14\) (Box 1).

CP severity used for the survival analysis was classified using two types of measurements: 1) the number of severe impairments (a) lower limb, b) upper limb, c) intellectual, d) vision and e) hearing impairments); 2) a measure of impact of disability on the child and family, the lifestyle assessment questionnaire, a specific NECCPS severity measure. We used binary categories ‘severe’ and ‘not severe’ to classify impairment variables recorded at age five years. The impairment was defined as severe if the child: a) was unable to walk without aids; b) was unable to self-dress (e.g. to put on a T shirt); c) had severe or profound intellectual disability (IQ <50); d) was blind or had no useful vision; e) had profound or severe loss of hearing (> 70db).\(^6,15\)

The lifestyle assessment questionnaire covers six dimensions: physical independence, mobility, clinical burden, schooling, economic burden, and social integration, from which a global lifestyle assessment score (LAS) is derived.\(^16\) The LAS is expressed as a percentage, with a maximally disadvantaged child scoring 100%. We defined children with LAS<30% as having mild impairment, LAS=30-69% as moderate and LAS≥70% as severe impairment as defined in previous research.\(^6\) A typical child with a LAS of <30% completes most but not all self-help activities alone, attends mainstream school with some assistance and has minimal additional needs; whereas a typical child with a ≥70% score undertakes only a few self-help activities, requires specialised education and health and social care resulting in substantial economic and social burden for society and the family. Children who died before the LAS was measured were included in the most severe group (≥70%).

Statistical analysis
The number of live births for England & Wales by region and year of delivery for 1998-2013 was obtained from the ONS published data (e.g. for 2013 ‘Child Mortality Statistics, 2013’\(^17\))
as were projected births for 2014-2016. The number of children that reached age 3 years old between 2001-2019 was estimated by applying the national survival rates to the number of live births by region conditional to the year of birth (supplementary Figure I). As the number of deaths was available for the age groups <1 (85% of all deaths at <5 years) and 1-4 years only, we assumed that the percentage of deaths in children aged 1-2 and 3-4 years was equal (50%). For example, there were 635,549 children born in England and Wales in 1998, of whom we estimated 631,446 (99.4%) would reach age 3 in 2001.

The average prevalence of CP in the 3-year olds delivered during 1991-2000 in the North of England (NECCPS data) was calculated per 1000 3-year old children. Trends in CP prevalence over time were examined using Poisson regression adjusted for year of birth and severity. As there was no evidence of any temporal trends (data not shown), we used the average prevalence in the North of England (for those who turned 3 years old during 1994-2003) to estimate the number of children with CP who reached 3 years old between 2001-2019, in each region.

Kaplan-Meier survival probability for two-year survivors with CP (NECCPS data) was calculated up to the 16th birthday according to CP severity (by number of severe impairments and by LAS) and the survival curves were plotted. Differences in survival between severity groups were assessed using the log-rank test. Cox regression, with year as a continuous explanatory variable, was performed to examine linear trends in survival of those who reached age 3 during 1994-2003. To calculate the number of 3-15 year olds living with CP by 2014 and by 2020, we multiplied Kaplan Meier survival probabilities by the estimated number of children with CP who reached age 3 between 2001-2013 and between 2007-2019, overall and by severity. For example, to calculate the number of individuals alive by 2014, we used the 15 year survival rate for cases born during 1998-2002, the 10 year survival rate for cases born during 2003-2007 etc.

SPSS 21.0 (IBM Corporation, NY, USA) was used for the survival analysis and GraphPad Prism v 5.01 was used to plot the survival curves. Poisson regression was performed using STATA 14.1 (Statacorp, College Station, TX, USA). P<0.05 was considered statistically significant.

Ethics approval
For this study we used anonymised data of children recorded on the NECCPS. The NECCPS has ethics permission, which includes permission to analyse anonymised data. Parents give permission for their child’s name to be on the database and reports of analysis of anonymised data to be undertaken. Parents know what data are held about their child and contribute to the NECCPS data by completing a questionnaire.

RESULTS

Out of an estimated 339,009 children born during 1991-2000 in the North of England and who reached their third birthday between 1994-2003, there were 875 children with congenital CP registered in the NECCPS, giving an average CP prevalence in 3-year olds of 2.58 (95% CI 2.41-2.76) per 1000.

Table I shows the number of deaths in children aged 3-15 years old and the cumulative survival percentage in children with CP in different severity groups using two severity measurements (NECCPS data). Children with the most severe CP, i.e. with ≥3 severe impairments and with LAS≥70%, constituted a similar proportion of children, 16.6% and
19.4\% respectively (Fisher exact test of proportions, \( p=0.14 \)). The mortality rates up to the first 16 years of life were the highest in these groups of children.

The survival curves of children with CP by severity who were alive at age three years are presented in Figure 1. The 15-year survival percentages for children with no or one severe impairment or with LAS<70\% ranged between 97-100\%. The 15-year survival percentages for children with severe CP were the lowest at about 63.5\% in children with ≥3 severe impairments and 66.5\% for those with LAS≥70\% (Fig 1 and Table I), all much lower than for those with less severe CP (log-rank Mantel-Cox test \( p<0.0001 \)). Survival did not alter significantly over the study period, overall (Hazard ratio [HR]=0.95, 95\% CI 0.87-1.03; \( p=0.22 \)) or after adjustment for severity (HR=0.98, 95\% CI 0.89-1.07; \( p=0.61 \)).

Table II shows the total estimated number of 3-15 year-old children living with CP in England & Wales and by English region by 2014, the estimated number of children aged 3-15 years with at least one severe impairment (44.7\% of all 3-15 year-olds with CP in England & Wales), with moderate or severe CP (LAS≥30%, 65.7\%) and with severe CP (LAS≥70%, 15.3\%). Supplementary Table I shows the estimated prevalence of CP by severity in children aged 3-15 years in England & Wales by 2020 (per 1000 children aged 3-15 years). By 2014, 1509 children with CP in England & Wales (7.3\% of all aged 3-15 years), 661 (7.2\%) of children with at least one severe impairment, 982 (7.3\%) of children with LAS≥30\% and 210 (6.7\%) of children with LAS≥70\% were estimated to have approached the age of 16 years, when transition from child to adult services begins for many children.

By the beginning of 2020, we estimate there will be 22,077 children aged 3-15 years living with CP in England & Wales, a 7.5\% increase compared to 2013 (Table II). Nearly half of these children (\( n=9,869, 44.7\% \)) will have at least one severe impairment, 65.6\% (\( n=14,493 \)) will have moderate or severe CP (LAS≥30\%) and 15.3\% (\( n=3,375 \)) severe CP (LAS≥70\%). In England & Wales, 666 children with at least one severe impairment, 988 children with moderate or severe CP (LAS≥30\%) and 212 children with severe CP (LAS≥70\%) will be approaching 16 years of age by 2020.

**DISCUSSION**

To our knowledge, this is the first study that reports the estimated number of children with CP aged 3-15 years in England & Wales and extrapolates this data to predict numbers by 2020. Using population-based register data in the North of England, we found that 15-year survival in children with CP differed significantly by severity, ranging between 97-100\% for children with non-severe CP and between 64-67\% for those with severe CP irrespective of severity measurement. By 2020, we estimate there will be approximately 22,100 children aged 3-15 years living with CP in England & Wales, around two thirds of them with moderate or severe CP, a group of children who need access to specialised health and social care services. The information on the number of children with CP reaching 16 years of age is important for planning transition of these children to adult health care services.

Our findings on the CP prevalence and survival of children with CP of different severity are consistent with previously reported differences by severity in both children and adults.\(^{3,5,8-10,20}\) The novel aspect of the study are the predicted CP population prevalence rates and the estimated number of children with CP of various severity in England & Wales by 2020.

Our study benefits from the inclusion of population-based data from a well-established prospective CP register, NECCPS, in a well-defined geographical area. A major strength of the NECCPS is that it is based on a longstanding collaboration of local clinicians from all 15
geographical districts in the region. High case ascertainment is ensured as cases were notified from multiple sources via the regional network of interested clinicians, and data records were held at the Regional Maternity Survey Office on a single database linked to other regional registers. We deliberately restricted our data collection to a single register, acknowledging the advantages of consistent inclusion criteria and unique variables collected by the NECCPS which capture the impact of CP on the child and family, the lifestyle assessment questionnaire. We used two measures of CP severity, including LAS, and found very similar survival between these measures, which supports the robustness of our survival estimates. We used ONS projected births, which are based on fertility, mortality and immigration rates, to more reliably estimate the number of children with CP. Additionally, we accounted for changes in survival over time by using 15 year survival relating to children born during 1998-2002 and 10 year survival for children born between 2003-2007 etc.

However, our study has some limitations. We applied the North of England CP prevalence and survival rates to estimate the number of children living with CP in different regions in England & Wales assuming a stable CP prevalence over time and equal survival trends across regions, although regional differences have been reported.\(^8\) However, the stable children disability rate in the UK over the last few years\(^12\) and the relative stability of CP rates from the early 1990s, in particular for term births, and across countries\(^9,6,21\) in addition to lack of evidence in relation to improvement in the survival over time.\(^8,9,11\) suggest that an error in estimation of the number of children with CP resulting from temporal changes would be marginal. We restricted our survival analysis to CP cases delivered during 1991-2000 as firstly, we would not have achieved a sufficiently long follow up period for the 15-year survival if we used more recent data, and secondly, for 2001-2010, there was an apparent under-ascertainment of CP cases to the NECCPS, which would have resulted in an underestimation of CP prevalence. Although this reduced the number of cases included in the survival analysis, it ensured that the data used were based on high completeness of case ascertainment. The NECCPS system of death ascertainment warranted that all deaths of children in our cohort living in the region were identified up to 2014. Deaths that occurred among children who were not flagged with the National Health Services Central Register for England (born in 2000) and moved out of region might have been missed, but this under-ascertainment likely applies to very few cases. Another limitation was a relatively high percentage (nearly 20%) of cases with missing severity information based on the lifestyle assessment questionnaire compared to 6% in the severity measurement based on the number of severe impairments. In fact, only 5% (n=47) of survivors at two full years have missing severity information based on both measurements. Other cases with missing LAS have the number of impairments recorded which gives a good indication of severity in this group (41% with no severe impairment, 17% with one, 6% with two and 9% with ≥3 severe impairments).

Although a focus of this study is congenital CP, children with post-neonatally acquired CP, who account for about 5-10% of all CP cases,\(^7,22\) will have similar needs that need to be taken into account when planning services and resources.

Our predictions can be used to estimate the costs associated with specialised health and social care services utilised by children with CP. This is of particular importance in light of current cuts in health and social care services due to austerity policies. While an estimation of costs was beyond the scope of this study, we conducted a review of literature published over the last two decades that estimated the economic costs of CP. We found that there was no universally agreed approach to medical and social care cost estimation of a life-
long condition such as CP. The identified studies, most based outside Europe, used different approaches and varying types of estimated costs which resulted in a large variation in care costs estimates for individuals. The two European studies identified (a Dutch cost-of-illness study for intractable spastic CP in children\textsuperscript{23} and a Danish study quantifying lifetime costs of CP\textsuperscript{24}) were in agreement that the largest cost component was non-medical cost during childhood. Additionally, we found no published studies in the UK that estimated the economic costs of care for children with CP. However, health and social care annual costs for young adults (aged 18-25 years) with CP in the UK were estimated to be £7,900 (2005 prices) per person.\textsuperscript{25} When costs for formal (paid) personal assistance were included, the annual costs per person were estimated to be almost twice as high (£14,500) resulting in 74.3 million and 136.6 million total annual health and social care costs respectively.\textsuperscript{25}

**CONCLUSION**

The study estimates that by 2020, the predicted number of children aged 3-15 years living with CP in England & Wales will be about 22,100, a 7.5% increase compared to 2013. 45% of these children will have at least one severe impairment and two thirds will have moderate or severe CP. This information is important for health and social care service planning.

**ACKNOWLEDGEMENTS**

We thank the parents of the children with cerebral palsy for their involvement and interest in the NECCPS and all the regional collaborators who supported and participated in the NECCPS data collection. We are grateful to Professor Allan Colver for his advice and his comments on an earlier draft. We thank Jane Hutton for her earlier work on related analyses, including linkage to dates of death from the National Health Services Central Register (now NHS digital); MRC grant G9900630 contributed some funds for linkage. The study was funded by the Newlife Foundation for Disabled Children (SG/15-16/02). The NECCPS was funded by the Public Health England. The funder had no role in study design or conduct, data collection, data analysis, data interpretation, or in the preparation, review, approval, or submission of the manuscript.

The authors have stated that they had no interests that might be perceived as posing a conflict or bias.
REFERENCES


**Box 1.** Definition of cerebral palsy (CP), inclusion criteria according to the Surveillance of Cerebral Palsy in Europe (SCPE) collaboration and detail on case and death ascertainment in the North of England Collaborative Cerebral Palsy Survey (NECCPS)

**Definition:** NECCPS uses the Little Club definition of CP, updated by Bax,\(^{13}\) ("a disorder of posture and movement due to a defect or lesion in the immature brain") and complies with the SCPE consensus definition with the following key elements: cerebral palsy is a group of disorders—i.e., it is an umbrella term; it is permanent but not unchanging; it involves a disorder of movement, posture, or both, and of motor function; it is caused by a non-progressive interference, lesion, or abnormality in the developing or immature brain. CP is classified according to the agreement of SCPE: spastic CP (unilateral or bilateral), dyskinetic and ataxic.

**Inclusion criteria:** born to mothers resident in the North of England during 1991-2000, cases with congenital CP, i.e. not associated with a known post-neonatal insult, only included.

**Case and death ascertainment:** Cases were notified to the NECCPS by District Convenors, that is consultant community paediatricians, who coordinated services for such children and received information about children needing services from other paediatricians, paediatric neurologists, physiotherapists, speech therapists and the regional child development centre. The convenor completed a notification form. Further details were forwarded to the survey when the child reached 5 years of age to confirm the diagnosis and provide details of associated impairments. Further, parents were invited to return the lifestyle assessment questionnaire which recorded the impact of the CP on the child and family.\(^6\) Data records were maintained and held at the Regional Maternity Survey Office on a single database linked through the mother’s details to prospective Perinatal Mortality Survey and Northern Congenital Abnormality Survey.

Every case of CP mentioned on a child death certificate and every case mentioned as co-morbidity on a late notification of a congenital anomaly is ascertained by the survey.\(^6\) Local child deaths (up to 18 years) were matched with the NECCPS records both from local data collection and annually from the ONS. In addition, up to 2014, a list of children on the register aged <16 years (with consent for contact), has annually been submitted to the National Strategic Tracing Service (NSTS) batch tracing service to identify any deaths from summary care record system before inviting families for the NECCPS study days. In addition, for deliveries during 1991-1999, the persons on the register were flagged with the National Health Services Central Register for England and notifications of deaths were sent to the approved researcher up to 2010 inclusive.
**Table I:** Survival up to age 16 years in children with cerebral palsy (CP) aged ≥3 years by severity using two severity measures (number of severe impairments and lifestyle assessment score), North of England, 1991-2000 births

<table>
<thead>
<tr>
<th>Severity measurement/ Age (years)</th>
<th>Number of deaths and cumulative survival percentage of children with CP – n deaths (% surviving)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3-5</td>
</tr>
<tr>
<td>By number of severe impairments</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1 (99.8)</td>
</tr>
<tr>
<td>One</td>
<td>1 (99.4)</td>
</tr>
<tr>
<td>Two</td>
<td>0 (100.0)</td>
</tr>
<tr>
<td>Three and more</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>19a (86.9%)</td>
</tr>
<tr>
<td>Missing</td>
<td>0a</td>
</tr>
<tr>
<td>By lifestyle assessment score (LAS)</td>
<td></td>
</tr>
<tr>
<td>&lt;30%</td>
<td>0 (100.0)</td>
</tr>
<tr>
<td>30-69%</td>
<td>1 (99.8)</td>
</tr>
<tr>
<td>≥70%</td>
<td>20a (88.2)</td>
</tr>
<tr>
<td>missing</td>
<td>0a</td>
</tr>
<tr>
<td>Total</td>
<td>21</td>
</tr>
</tbody>
</table>

*Those with missing severity data who died aged 3-5 years (n=9) were included in the most severe category (with ≥3 severe impairments or LAS≥70%); the group with ≥3 severe impairments contained 127 children with both severe walking and intellectual disability (inability to walk without aids and IQ<50) and at least one other severe impairment, eight children with severe walking disability and two other severe impairments (upper limb and/or vision or hearing) but not severe intellectual disability, and one child with severe intellectual disability and severe upper limb and vision impairments, but not severe walking disability.
Table II: Estimated number of children with cerebral palsy (CP) aged 3-15 years – total and for different severity categories – for England & Wales and by English region by 2014 and by 2020

<table>
<thead>
<tr>
<th>Children aged 3-15</th>
<th>England</th>
<th>Wales</th>
<th>England &amp; Wales</th>
<th>North East</th>
<th>North West</th>
<th>Yorkshire and the Humber</th>
<th>East Midlands</th>
<th>West Midlands</th>
<th>East</th>
<th>London</th>
<th>South East</th>
<th>South West</th>
</tr>
</thead>
<tbody>
<tr>
<td>by 2014</td>
<td>7980713</td>
<td>426156</td>
<td>8406870</td>
<td>365758</td>
<td>1056524</td>
<td>786177</td>
<td>637841</td>
<td>855211</td>
<td>847621</td>
<td>1493418</td>
<td>1242611</td>
<td>695553</td>
</tr>
<tr>
<td>by 2020</td>
<td>8598921</td>
<td>445104</td>
<td>9044025</td>
<td>383064</td>
<td>1120477</td>
<td>840366</td>
<td>687838</td>
<td>915796</td>
<td>915155</td>
<td>1658234</td>
<td>1326849</td>
<td>751243</td>
</tr>
</tbody>
</table>

Estimated children with CP aged 3-15 years\(^b\)

| by 2014            | 19494   | 1041  | 20535           | 893        | 2580     | 1920                    | 1558         | 2089         | 2070 | 3650   | 3035        | 1699      |
| by 2020            | 20991   | 1086  | 22077           | 935        | 2735     | 2051                    | 1679         | 2235         | 2234 | 4049   | 3239        | 1834      |

Estimated children with CP with \(\geq 1\) severe impairment\(^c\)

| by 2014            | 8720    | 465   | 9186            | 399        | 1154     | 859                     | 697          | 934          | 926  | 1633   | 1357        | 760       |
| by 2020            | 9384    | 485   | 9869            | 418        | 1222     | 917                     | 751          | 999          | 999  | 1811   | 1448        | 820       |

Estimated children with moderate or severe CP (LAS\(\geq 30\%\))

| by 2014            | 12802   | 683   | 13485           | 586        | 1694     | 1261                    | 1023         | 1372         | 1360 | 2397   | 1993        | 1116      |
| by 2020            | 13780   | 713   | 14493           | 614        | 1795     | 1346                    | 1102         | 1467         | 1467 | 2659   | 2126        | 1204      |

Estimated children with severe CP (LAS\(\geq 70\%\))

| by 2014            | 2990    | 159   | 3149            | 137        | 395      | 295                     | 239          | 320          | 318  | 561    | 465         | 261       |
| by 2020            | 3209    | 166   | 3375            | 143        | 418      | 313                     | 257          | 342          | 342  | 620    | 495         | 281       |

\(^a\)The number of children aged 3-15 years by 2014 and by 2020 was estimated for deliveries during 1998-2010 and 2004-2016 respectively using ONS data on live births and survival for children aged 0-2 years. \(^b\)Estimated using the percentage of children with CP of different severity (for children aged 3-15 years) and North of England survival rates up to age 16, by severity. \(^c\)Lower limb, upper limb, intellectual, vision and hearing impairments are included; cases with missing severity data (6.4%) are not included in this estimation. LAS=lifestyle assessment score.
FIGURE LEGENDS

Figure 1: 15-year survival of children with cerebral palsy aged ≥3 years (censored at 16 years) by a) number of severe impairments, b) lifestyle assessment score (LAS)

Figure footnote: a) Those who died aged 3-5 years (n=9) were included in the most severe category (with ≥3 severe impairments, 16.6% of all two-year survivors with CP). Number of severe impairments: none (n=406, 2 deaths between 3-15 years), one (n=178, 2 deaths); two (n=90, 3 deaths), ≥3 (n=145, 53 deaths, including 9 aged 3-5 years with missing severity information), missing (n=56, 5 deaths at 6-15 years).
b) LAS<30% (mild – n=112, no deaths between 3-15 years), LAS=30-69% (moderate – n=420, 6 deaths) and LAS≥70% (severe – n=170 (19.4%), 57 deaths, including 9 deaths aged 3-5 years with missing severity data), missing (n=173, 2 deaths at 11-15 years).

Supplementary Figure 1: The number of children surviving to age 3 years in England & Wales born during 1998-2020*
*for 1998-2013 the calculation is based on the actual number of live births and the survival estimates (obtained from the Office for National Statistics (ONS) published tables), for the years 2014 and beyond the ONS projected births were used.
Figure 1

(a) Cumulative probability of surviving for different levels of severity:
- 1 severe impairment
- 2 severe impairments
- 3+ severe impairments
- Missing severity

(b) Cumulative probability of surviving for different LAS data:
- LAS < 30%
- LAS 30-69%
- LAS > 70%
- Missing LAS data
Supplementary Figure 1: The number of children surviving to age 3 years in England & Wales born during 1998-2016*
**Supplementary Table I:** Estimated prevalence of cerebral palsy by severity in children aged 3-15 years in England & Wales by 2020 (per 1000 children aged 3-15 years)

<table>
<thead>
<tr>
<th>Severity measurement</th>
<th>Estimated children with cerebral palsy aged 3-15 years by 2020</th>
<th>Cerebral palsy prevalence in children 3-15 years*(per 1000) (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>By number of severe impairments</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>10794</td>
<td>1.19 (1.17-1.22)</td>
</tr>
<tr>
<td>One</td>
<td>4702</td>
<td>0.52 (0.51-0.54)</td>
</tr>
<tr>
<td>Two</td>
<td>2351</td>
<td>0.26 (0.25-0.27)</td>
</tr>
<tr>
<td>Three and more</td>
<td>2817</td>
<td>0.31 (0.30-0.32)</td>
</tr>
<tr>
<td>Missing</td>
<td>1413</td>
<td>0.16 (0.15-0.16)</td>
</tr>
<tr>
<td>By lifestyle assessment score (LAS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30%</td>
<td>2988</td>
<td>0.33 (0.32-0.34)</td>
</tr>
<tr>
<td>30-69%</td>
<td>11118</td>
<td>1.23 (1.21-1.25)</td>
</tr>
<tr>
<td>≥70%</td>
<td>3375</td>
<td>0.37 (0.36-0.39)</td>
</tr>
<tr>
<td>missing</td>
<td>4596</td>
<td>0.51 (0.49-0.52)</td>
</tr>
<tr>
<td>Total</td>
<td>22077</td>
<td>2.44 (2.41-2.47)</td>
</tr>
</tbody>
</table>

*Estimated using the predicted number of children with CP by severity category and the population of children aged 3-15 years in England & Wales by 2020 (n=9,044,025, Table II).