

The National Cerebral Palsy Register

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In Southern Ireland Cerebral Palsy (CP) Registers had, in the past, been established in the Eastern (Counties Dublin, Meath, Kildare), Western (Counties Galway, Mayo, Roscommon) and Southern (Counties Cork, Kerry) Regions, which recorded CP cases arising in 61.5% of total national births. Currently only the Eastern Region Register remains active, and therefore information on epidemiological trends in recorded CP cases are now confined to that geographical area only.

Based on 59,796 births per annum (CSO, 2019) with a CP rate of 1.77 per 1000 births it is estimated that nationally there should be approximately 110 new cases per year.¹ Recognising the need for reliable national CP prevalence data, a feasibility study is now being undertaken to look at the establishment of a National Cerebral Palsy Register to monitor prevalence of CP cases, to include the identification of trends in aetiological factors of importance and those causes that are preventable. The development of a complete national dataset will facilitate the planning of appropriate rehabilitation and health services for affected children and permit Ireland to benchmark ourselves with other jurisdictions.

Cerebral palsy (CP) describes a group of disorders of the development of movement and posture attributed to non-progressive disturbances that occur in the developing infant or foetal brain.² The clinical manifestations are associated with distinct heterogeneity and the associated comorbidities of CP present significant challenges for individuals and families. The epidemiology of CP is changing as a result of improved neonatal care which has increased the survival chances of low birth weight and premature babies who are at particular risk. Early research into aetiology attributed peri-natal factors as the primary cause of CP, with little recognition of other causes. However, many now believe that peri-natal causes do not account for as many cases of CP as was previously believed leading to a shift in understanding about true causes.³

A Register is a collection of information on individuals who share common characteristics in a defined population. Registries are particularly suited to monitoring outcomes of care where there is a known variation and where poor performance results in high cost.⁴ A successful national register is dependent on close collaboration with key stakeholders such as Paediatricians, Neonatologists, Orthopaedic Surgeons, Maternity Hospitals, the HSE, Department of Health, and providers of services for children with physical disability. To address some of issues described above, it is important that mechanisms are developed that will facilitate research into the origins and management of CP here in the Republic of Ireland. We believe that complete national data will provide more accurate and valid surveillance trends and will provide an indispensable resource for research, free from the biases of other ascertainment methods.

The establishment of a National CP Register would be in keeping with the government's plan to develop a system for efficient electronic exchange of health information and increase the interoperability of all health data to improve care. In Ireland, the number of patient registries is growing which are increasingly being used to inform clinical and policy decision making and support health economic assessment. The most established of these is the Cancer Registry which was established in 1991 with a national mandate to collect data and now contains more than 500,000 registrants.⁵ More than 90% of people with Cystic Fibrosis are contained on a register, allowing for an efficient mechanism to keep relevant records on CF patients nationally and monitor and assess a growing range of treatments that patients are on.⁶

Our understanding of the global prevalence of CP has been shaped by the existence of many successful registers internationally from countries such as Australia, Sweden and the United Kingdom, including Northern Ireland. The most recent report from the Australian Cerebral Palsy Register (ACPR, 2018) finds that rates of CP in Australia are decreasing across all cohorts examined. Pre/peri-natally acquired CP rates declined from 2.1 (1995-1997) to 1.4 (2010-2012) children per 1000 live births. The report also finds a reduction in the number children with moderate to severe Gross Motor Function (GMFCS) levels 3-5, as well as significantly larger numbers of children who do not have visual impairments and epilepsy.⁷ Continued research must continue in order to ascertain that results are reflective of a true downward trend.

In Europe the Surveillance of Cerebral Palsy Network (SCPE) comprises a central database of CP registers using agreed standards, definitions and classifications. Data is available on more than 21,000 children with CP. The central database allows meaningful analysis and eliminates the challenges associated with interpretation of data when registers do not share the same harmonized methods and are dealing with small numbers. A recent large scale study, using the data from 26 population registers across Europe, confirmed previous reports, in that there is an overall reduction in prevalence of CP in Europe from 1.90 to 1.77 per 1000 live births in the 1980-2003 period.¹ In 2016 the SCPE database became part of the European Commission's Joint Research Centre to allow it to be utilised beyond epidemiological research as an evidence based resource for policy makers.

Critical developments in neonatal practice have significantly affected mortality, however effects on impairments are less obvious. Twenty percent of extremely premature babies (22-25 weeks) had a severe disability in 2006, which had remained constant since 1995. For term children the introduction of hypothermic treatment saw a marked decrease in mortality for those who suffered a hypoxic episode as well as a reduction in CP.¹

In developing a National Cerebral Palsy Register it is proposed to draw on and develop the expertise of the existing Eastern Region Register and utilise the experience of the staff who were involved in the Western and Southern Registers. A variety of consent models are currently being explored. Multiple and overlapping sources of ascertainment will be used. Prospective cases will be identified through both direct contact with professionals and agencies and through the use of a report card sent monthly to service professionals. Notified cases will remain unconfirmed until validated at age 5 and will be stored anonymously. Specific inclusion and exclusion criteria will be used. The dataset will be modelled on that agreed by the European Surveillance Network of Cerebral Palsy (SCPE) where formal agreements are already in place with the Eastern Register. As the Register develops additional fields may be incorporated that may be useful from a national perspective that take account of research requirements and service planning. The Register will be managed by a Registry Co-ordinator who will report to an Advisory Committee. Together they will identify a suitable storage location for the data and will ensure that confidentiality and data quality are maintained. Information will be provided to service planners and a scientific report will be produced annually.

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