Letters to the editor

'Comparison of survival in cerebral palsy between countries.'

SIR–The authors of the paper 'Life expectancy among people with cerebral palsy in Western Australia'[1] (see pages 508–15, this issue), kindly allowed us use of their database in order to compare with the large Californian database.[2,3]

We begin our comparison at age 5 years because measurements of intellectual level and severity of cerebral palsy (CP) in Western Australia are updated only until that age. Overall survival rate in the Western Australian population is 93% compared with 83% in California. This large disparity is not, however, due to differences in care in the two regions. It arises because the Californian data include nearly all the more severely affected individuals but comparatively fewer mild instances whereas the Western Australian database includes everyone with CP (most of whom are only mildly affected).

For a valid comparison, we stratified the population into four intellectual levels (IQ<20; 20–34; 25–49; 50–69) and three severities of motor dysfunction (mild, moderate,and severe), creating 12 groups.

When just one factor (severity or IQ) was controlled, the gap in survival rates narrowed considerably. When both were controlled, the survival curves became strikingly similar. Figure 1 illustrates two cases: severe impairment with IQ<20 and with IQ in the range 20–34.

Data from the UK study by Hutton and coworkers[4] of the 'three severe disabilities' group was compared to the Californian database in the same way and found to be remarkably similar.

To our knowledge, this is the first controlled comparison of survival in CP between countries.

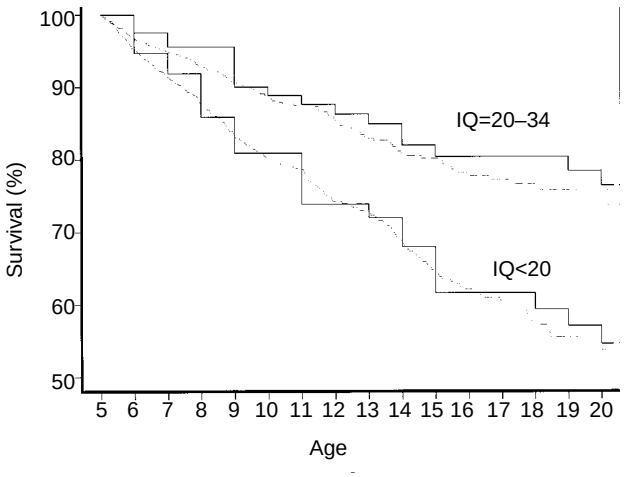

Figure 1: *Comparison of Western Australia (WA) and US survival curves for people with severe CP. All 12 pairs of curves either show similarity or have too few deaths to make comparisons meaningful. In no comparison was there a statistically significant difference; smallest p value=0.23. ——, data from WA (IQ 20–34, n=126; IQ<20, n=76); -----, data from US (IQ 20–34, n=828; IQ<20 n=974).*

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'Disability information improves reliability of cerebral palsy classification'

SIR – We were pleased to read the carefully detailed process by which the Surveillance of Cerebral Palsy in Europe (SCPE) collaborative network is standardizing the definition of CP across eight European countries.[1] Cerebral palsy (CP) suffers from a lack of precision in diagnosis and reporting due to the term's inconsistent use for a range of mild to severe motor abnormalities in children who are thought to have brain injuries. The authors identify four processes that result in differential detection of CP in the network's 14 geographically-based registries: definition and exclusion–inclusion criteria, case ascertainment, interobserver error, and method of classification and recording. Among these, the underlying impediment to accurate comparisons of CP prevalence over time and place is lack of a standard definition.

We have found that functional criteria are very important for the description of CP in a standardized form. But criteria for disability are not included in the common rules imposed by the network for a designation of CP. Of the five key elements specified, none require information as to age-appropriate activity limitations. By age 3 years, the lowest age of registration, major motor development milestones can be assessed and evidence for disability in walking, running, climbing stairs, jumping, dressing, feeding, and speech articulation should be perceptible and meaningful. The hierarchical classification scheme for subtypes of CP also does not use criteria for disability, although the authors acknowledge that disability information could help exclude ambiguous mild cases when estimating prevalence, and state encouragingly that work on functional loss is still ongoing.

Our research group has found that without evidence of disabling conditions, CP had poor reliability of classification across international cohorts. We analyzed neurological findings from three population-based cohorts of very-preterm babies born in Canada, the US, and The Netherlands in the late 1970s through to the mid 1980s. Up to five pediatricians with expertise in diagnosing CP reviewed 33–51 case records (omitting the CP diagnosis) from weighted random samples of children in each cohort