Looking at CP register data, Meehan et al. recently described the main reasons and circumstances for hospital admissions for children with cerebral palsy. They noted that these can be particularly costly. Based on their previous experience, DMCN readers emphasize the need for validation when using this potentially fruitful approach.

Sir,

We congratulate Meehan et al. on their informative study of hospital service use by children with cerebral palsy (CP). Linking disease registers with routinely collected health data, as the authors have done, is a useful source of data for population research. Linkage with a criterion standard population register can also be an efficient way to validate case definitions derived from routinely collected data alone. With this in mind, we believe the authors may be able to provide further results from their study, which would help researchers to interpret a hospital-recorded diagnosis of CP.

We know of several population studies of CP based on hospital and outpatient records, but validation studies have been rare. A recent Norwegian validation reported 98% sensitivity and 86% positive predictive value (PPV) of a CP diagnosis in the Norwegian Patient Register (NPR) relative to the Cerebral Palsy Register of Norway. Meehan et al.’s finding that almost 10% of their CP cohort had no linked hospital admissions indicates that the sensitivity of case ascertainment using Australian hospital data is no more than 90% and may compare with the crude estimate of 80% sensitivity reported in a Swedish study.

It would be particularly useful to know the number of true positive and false negative diagnoses, which would give the sensitivity of a hospital diagnosis-based case definition. True positives can be defined as the people in the CP register who had one or more hospital record in the period from 2007 to 2014. As the start and length of follow up differed according to each individual’s year of birth, it would be informative to know how the linkage rate varied by birth cohort within the register.

Finally, it would also be helpful to know how the pattern of motor symptom topography as described by specific five- and six-character ICD-10 codes matches with information recorded on the register.

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