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Primary, secondary care and mortality data-linked to identify the prevalence of cerebral palsy in children and young people

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Introduction

Evaluations of healthcare utilisation for children and young people (CYP) with chronic conditions, are increasingly relying upon routinely collected healthcare data to estimate healthcare burden and inform national policy and practice. However, chronic conditions are not consistently or accurately recorded making it difficult to conduct valid epidemiological analyses.

Objectives and Approach

We explored routinely collected healthcare datasets of 2,122,914 CYP in the English Clinical Practice Research Dataset (CPRD) and 1,636,252 CYP in the Welsh Secure Anonymous Information Linkage (SAIL) databank to identify patients with CP (an exemplar of a chronic neurodisability) from diagnosis coding (G80-83.3). Linked primary care, hospital admission outpatient and mortality data were searched from birth and populations of CYP aged 0-25 years between 2004 and 2014 with and without CP were identified. We detected the ascertainment sources and compared the results from CPRD and SAIL. In a sample of cases G80-83 codes were validated against clinical records.

Results

England: Some 7,500 cases of CP were identified (period prevalence: 3.5 per 1000 CYP). Of those, 36.6% were identified from hospital admissions; 20.6% from GP data, 42.0% were in both datasets with 0.8% from outpatient/ONS mortality data.

Wales: Some 5,400 cases of CP were identified (period prevalence: 3.3 per 1000 CYP). Of those, 38.6% were identified from hospital admissions, 25.3% from GP data, 36.0% were in both datasets, and 0.1% from mortality/outpatient datasets.

729/877(83.1%) cases coded as G80-83 in secondary care case notes were validated cases of CP leaving 16.9% that were incorrectly coded. Approximately 70% of G80 cases were recorded as G80.8-9 (CP other/unspecified). Roughly 30%

of cases were only coded as CP on one occasion within the primary and secondary care datasets.

Conclusion/Implications

Similar proportions of CP cases were identified in the two datasets giving similar period prevalences. Inconsistent and incorrect coding will affect the accuracy of these figures and precludes any analysis by disease type/severity. Improved coding of chronic conditions is needed before accurate healthcare analysis of routine data can be undertaken.

