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Swansea University
Prifysgol Abertawe

Validating coding for a chronic condition (Cerebral Palsy) in routinely collected hospital admissions data

Carter, B[1], Jones, H[1], Bethell, J[1], Kemp, A[1], and Wang, T[2]

[1]Cardiff University

[2]Swansea University

Introduction

Data-linkage provides an opportunity to evaluate healthcare utilisation of patients with chronic health conditions. However the consistency and accuracy of recording chronic conditions in routinely collected healthcare data is unclear and we aim to explore this in children and young people (CYP) with a cerebral palsy (CP).

Objectives and Approach

The study aims to validate CP case identification in routinely collected data by data-linking cases from The Northern Ireland Cerebral Palsy Register (NICPR) born 1981-2011 with routinely collected hospital admission data and cross-referencing cases between the two datasets. CP cases were identified in the administrative data using ICD-10 codes G80 (cerebral palsy), G81 (hemiplegia), G82 (paraplegia and tetraplegia) and G83.0-83.3 (diplegia and monoplegias).

Results

There were 1,693 cases in the NICPR cohort and 1,733 cases of CP identified in the hospital admissions data, 915 of which were on the NICPR giving a positive predictive value for identifying a CP case within routinely collected data of 52.8%. Specificity was high (99.8%) however sensitivity was low (54.1%).

1,157 (68.3%) patients on the NICPR had at least one hospital admission. 914 (79.0 %) cases were coded at some time point with G80-83.3 (829 (71.7%) G80, 328 (28.3%) G81-83.3). NICPR cases had a total 11,844 hospital admissions and a CP code was recorded during 6,397 (54.0%).

The type of CP was recorded in NICPR for 1,673 (98.8%) cases whereas in the hospital admissions, data the majority (70.6%) were coded as other/unspecified CP (G80.8-9).

Conclusion/Implications

This study adds to understanding of CP coding practices within routinely collected hospital data, further supporting claims that coding of CP within such datasets is poor. Coding must be accurate and consistent if data are to be meaningful, comparable and useful to inform health outcome reviews and patient care.