

Secondary care provision for children and young people with Cerebral palsy: A data-linkage study

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Introduction

Data on children with cerebral palsies are often held in registries, but these contain limited information with varying levels of follow-up. Here we show how record-linkage with healthcare datasets has enabled longitudinal follow-up of these children to understand how they use secondary care health services.

with a recent study in Australia. Thus, further demonstrating that linkage between CP registers and routinely collected healthcare may be useful for health services research and informing healthcare delivery.

Objectives and Approach

Our primary aim was to explore healthcare utilisation for children and young people (CYP) with CP aged 0-25 years between 2004 and 2014 by severity, measured by recorded Gross Motor Function Classification System (GMFCS) level. This was achieved by linking Northern Ireland Cerebral Palsy Register (NICPR) data to routinely collected secondary care data. Comparison was made to the population of CYP who were not on the NICPR i.e. non CP cases.

Results

There were 1,693 cases in the NICPR cohort born 1981-2011. Of those, 286 (16.9%) were GMFCS 1, 662 (39.1%) GMFCS 2, 277 (16.4%) GMFCS 3, 105 (6.2%) GMFCS 4 and 342 (20.2%) were GMFCS 5 (21 (1.2%) missing).

NICPR cases had 11,844 hospital admissions and 19,750 outpatient appointments during the study period accounting for 1.7% of both inpatient and outpatient attendances. Those with severe CP were more likely to have an inpatient admission and had longer stays in hospital than those with less severe CP and those without CP. 592/948 (62.4%) patients with GMFCS 1&2 had an admission compared to 345/447 (77.2%) of GMFCS 4&5 cases. The proportion of elective to emergency admissions was 72.4% versus 53.7% for non CP.

Conclusion/Implications

This study adds to understanding of service utilisation for those with CP in the UK, and provides comparable figures

