A STRATEGY TO IDENTIFY YOUNG CHILDREN WITH DEVELOPMENTAL DISABILITIES VIA PRIMARY CARE RECORDS

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Background

Electronic health records use clinical codes to classify disease and conditions, not disability (how impairment affects human function). Codes for the degree of disability are not routinely recorded alongside the diagnosis, unless part of the diagnostic code e.g. profound learning disability. Existing strategies identify conditions associated with disability, prioritising either identifying every person with possible or highly probable disability to limit type I (false negative) misclassification error. In high income countries, 1–4% of children have developmental disabilities. They can be diagnosed before the age of five but, in practice, developmental delay is often diagnosed and the disabling condition (e.g. autism spectrum disorders or cerebral palsy) diagnosed when the child is older. Diagnoses of both delay/generalised developmental disorders and a disabling condition diagnosis could indicate disability severity. Is a sensitive or specific strategy or a combination of both necessary to obtain a realistic estimate of developmental disability prevalence in preschool children?

This study aimed to develop and compare strategies to identify children with possible and probable developmental disabilities diagnosed before the age of five in primary care data.

Methods Two case ascertainment strategies were developed and the primary care records of children in the Born in Bradford (BiB) cohort study (from birth to their fifth birthday) searched: 1) to identify children with conditions associated with substantial developmental disability (autism spectrum disorders, Down syndrome and cerebral palsy and moderate-profound learning disability); and 2) to identify children with indicators of developmental disability (developmental delay, generalised developmental disorders, mild and unknown severity learning disability). The combined UK prevalence of the disabling conditions is 417 per 10,000 children below age 18. The prevalence in the study sample (n=9,727) was 85 per 10,000 (n=47 autism spectrum disorders, n=24 Down syndrome, n=12 cerebral palsy). None had moderate-profound learning disability. Half also had disability indicators (53%, n=44). The prevalence of disability indicators was 450 per 10,000 (n=438). Of those with only indicators (n=394), 75.9% had a single indicator. The most common indicators in both the condition and indicator groups were speech delay, developmental delay and developmental language delay.

Conclusion Using only disabling condition clinical codes for case ascertainment via primary care data is likely to greatly underestimate disability prevalence in children under the age of five. Where independent disability verification is not possible, the number of disability indicators may reflect disability severity.

HOW CAN THE RECENT STALLING OF LIFE EXPECTANCY GAINS IN SCOTLAND BE BEST EXPLAINED?


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Background Annual gains in life expectancy in Scotland have been slower in recent years than in the previous two decades for males and females. Similar slowdowns or even reversals have been observed in England, Wales, Northern Ireland and the USA. This contribution explores the contribution of specific causes of death to the changes in mortality by age and cause for two time periods: 2000–2 to 2012–14 and 2012–14 to 2015–17.

Methods Life expectancy at birth was calculated from death and population counts available from National Records of Scotland (NRS), disaggregated by five year age categories and by ICD-10 underlying cause of death. Arriaga’s method of life expectancy decomposition was applied to produce estimates of the contribution of different age groups and underlying causes of death to life expectancy at birth in each of the two periods.

Results Life expectancy trends deteriorated after 2012–14 and life expectancy subsequently fell. The worsening trend involved increased inequalities as it was more profound with increasing area deprivation. Almost all age groups saw a worsening of trends in the later time periods and this was also seen across almost all causes of death. In particular, the previously observed rapid improvements in circulatory causes which benefited those aged 55–84 years most, more than halved. There were also absolute increases in mortality rates for those aged 35–49 years due in large part to increases in drug-related deaths; and amongst those aged 90+ years due to increased mortality from dementia/Alzheimer’s.