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Prevalence three ways: Comparison of linked data from a patient register and electronic health records with allowance for linkage error

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Background with Rationale

Patient registers and electronic health records are both valuable resources for disease surveillance but can be limited by variation in data quality over time. Variation may stem from changes in data collection methods, in the accuracy or completeness of clinical information, or in the quality of patient identifiers and the linkage that relies on these.

Main Aim

By linking the National Down Syndrome Cytogenetic Register (NDSCR) to Hospital Episode Statistics for England (HES), we aimed to assess the quality of each and establish a consistent approach for analysis of trends in prevalence of Down's syndrome among live births in England.

Methods/Approach

Probabilistic record linkage of NDSCR to HES for the period 1998–2013, supported by linkage of babies to mothers within HES. Comparison of prevalence estimates in England using NDSCR only, HES data only, and linked data. Capture-recapture analysis and quantitative bias analysis were used to account for potential errors, including false positive diagnostic codes, unrecorded diagnoses, and linkage error.

Results

Analyses of single-source data indicated increasing live birth prevalence of Down's syndrome, particularly steep in analysis of HES. Linked data indicated a contrastingly stable prevalence of 12.3 cases per 10,000 live births, with a plausible range of 11.6–12.7 cases per 10,000 live births allowing for potential errors.

Conclusion

Case ascertainment in NDSCR improved slightly over time, creating a picture of slowly increasing prevalence. The emerging epidemic suggested by HES primarily reflects improving linkage within HES (assignment of unique patient identifiers to hospital episodes). Administrative data are valuable but trends should be interpreted with caution, and with assessment of data quality over time. Linked data with quantitative bias analysis can provide more robust estimation and, in this case, reassurance that prevalence of Down's syndrome is not increasing. Routine linkage of administrative and register data can enhance the value of each.

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