Using routine point-of-care data for research: the East london multiple sclerosis cohort.

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Background:

Few geographically-linked datasets of people with multiple sclerosis (MS) exist in the UK. The development of these datasets enriched with clinical information would aid in testing etiological hypotheses, comparing disease progression between treatment regimes, and recruiting clinical trial participants. The population in East London (defined here as The City, Hackney, Tower Hamlets, and Newham) is of particular interest because of its ethnic mix, which is reflected by its population with MS.

Methods:

Identifying cases: Based on existing outpatient clinic lists at The Royal London Hospital, a list of MS patients was created on 'Cerner Millennium Software' (CRS). MS patients that were matched to the PCTs of Tower Hamlets, Newham, and City & Hackney formed our East London MS Cohort.

Phase 1 of coding clinical data (ongoing): Scanned clinical letters are manually searched to code key variables on each patient's CRS hospital record: MS course, year of onset, first symptoms, and whether on disease-modifying treatment.

Phase 2 of coding clinical data (ongoing): When patients attend outpatient clinics, they are given questionnaires asking for further MS-related information. Completed questionnaires combined with updates from consulting clinicians are used to code further variables on patients' CRS hospital records.

Preparing data for analysis: Coded clinical data of MS patients are extracted from CRS hospital records using the CRS 'Explorer Menu'. This data is then anonymised in the secure network, before analysis with Stata statistical software.

Results:

1,144 MS patients attending the Royal London outpatients department have been identified. 451 of these patients make up our East London MS Cohort. They account for 60% of the count of MS patients identified by GP records.

The mean age of the cohort is 48 and there is a 2.4:1 female:male ratio. 62% are White, 16% Black, 9% Asian, 6% Other, and 7% Unknown. This shows an over-representation of White MS patients relative to the area's population, hence based on GP counts crude prevalence figures per 100,00 are 145 for White, 78 for Black, 28 for South Asian, and 18 for Other (92 overall).

Currently, data coding of all MS patients using the outpatient service is in progress, and the majority of our variables of interest have been coded for about 10% of patients.

Conclusion:

The demographic characteristics of the White MS patients in our cohort are very similar to those recently described in another UK-based geographically-linked MS cohort of 620 patients in Wales which was 97% White (J Neurol, Neurosurg & Psychiatry, 80(4): 386–391). They described a mean age of 51, a female:male ratio of 2.4:1, and a prevalence of 146 per 100,000.

However, what is unique to our cohort is its ethnic diversity, allowing us to show prevalences for ethnic minorities. What is more, when data coding is complete, we will be able to conduct further epidemiological studies, including migration studies, treatment effectiveness studies, and case-control studies of risk factors.

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