

## Validating the diagnostic accuracy of membranous nephropathy in the health improvement network (THIN) database

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### Background

Membranous nephropathy (MN) is among the most common causes of nephrotic syndrome in adults worldwide. Despite this, there is currently no robust data on the epidemiology of MN in the UK population. The Health Improvement Network (THIN) is an electronic medical record database that holds longitudinal anonymised patient records for over 17 million patients and has shown to be generalisable to the UK regarding demographics and crude prevalence's of major conditions. To our knowledge, accuracy of the read codes for glomerular disease is yet to be validated. This will be the first study into MN validating the diagnostic accuracy using the THIN database.

### Methods

THIN database was interrogated for patients with MN using read codes. Two cohorts were considered: Definite cohort, defined as read codes expected to correspond to a diagnosis of MN, and Probable cohort, defined as read codes that could correspond to a diagnosis of MN. In order to confirm the diagnosis of MN, a short questionnaire was sent to the GP practice of a randomly selected cohort of patients asking if the diagnosis of MN was correct, and that the diagnosis had been confirmed by a specialist renal centre, with or without a renal biopsy.

### Results

267 patients with a record of MN were identified from the THIN database. 235 of the patients had Definite cohort read codes, with a mean age at diagnosis of 57 years. There were 155 (66.2%) male and 79 (33.8%) female patients. 32 patients were identified in the Probable cohort. GP questionnaires were sent to 71 randomly selected patients with 61 responses (85.9% response rate). This represented 23% (n=53) of the total Definite cohort and 25% (n=8) of the total Probable cohort. Of the 61 returned questionnaires, an MN diagnosis was confirmed in 96% (n=51) of patients with a definite read code and 25% (n=2) with a probable read code. Amongst the confirmed MN diagnoses in the Definite cohort, 88% (n=45) of the patients had primary MN.

### Conclusion

The THIN database is a valid data resource for studying MN in patients with a read code from the Definite cohort list. Read codes from the Probable cohort list cannot be used unless confirmed on a case by case basis such as through the GP. The results of this study will feed into a larger project with an aim to describe accurately the epidemiology of MN in the UK population, and report the incidence and prevalence of specific secondary associations of MN. Once these factors are fully understood, diagnostic and care pathways for MN can be developed.