

## Validating epilepsy diagnoses in routinely collected data

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## Introduction

Primary healthcare records are used for studies within large data repositories. One of the limitations of using these routinely collected data for epilepsy research is the possibility of including incorrectly recorded diagnoses. To our knowledge, the accuracy of UK GP diagnosis codes for epilepsy has only partially been validated.

## Objectives and Approach

We aimed to validate the accuracy of case ascertainment algorithms in identifying people with epilepsy in routinely collected Welsh healthcare data.

A reference population of 150 people with definite epilepsy and 150 people without epilepsy was ascertained from hospital records and linked to records held within the Secure Anonymised Information Linkage (SAIL) databank in Wales. We used three different algorithms to identify the reference population: a) individuals with an epilepsy diagnosis code and two consecutive AED prescription codes; b) individuals with an epilepsy diagnosis code only; c) individuals with two consecutive AED prescription codes only.

## Results

We applied the algorithms to all patients and to adults and children separately. For all patients, combining diagnosis and AED prescription codes had a sensitivity of 84% (95% ci 77–90) and specificity of 98% (95–100) in identifying people with epilepsy; diagnosis codes alone had a sensitivity of 86% (80–91) and a specificity of 97% (92–99); and AED prescription codes alone achieved a sensitivity of 92% (70–83) and a specificity of 73% (65–80). Using AED codes only was more accurate in children, achieving a sensitivity of 88% (75–95) and specificity of 98% (88–100). This can be explained by the widespread use of AEDs for indications other than epilepsy in

adults, which is not the case for children.

## Conclusion/Implications

GP epilepsy diagnosis and AED prescription codes can be used to identify people with epilepsy using anonymised healthcare records in Wales. In children using AED prescription codes alone is an accurate way to identify epilepsy cases. These results are generalizable to other studies that use UK primary care records.

