

## Headache and migraine data in Wales

### What we set out to do

In 2016, The Migraine Trust undertook a data analysis on the use of hospital services for people with International Classification of Disease Codes Tenth Revision (ICD10) codes relating to headache and headache plus in Wales.

The purpose of the project was to analyse and assess the disease impact of headache and migraine and to produce a case for change to act as leverage for Welsh health boards to address headache and migraine locally. The project was supported by an advisory group of leading UK headache specialists and patient representatives.

The project faced significant difficulties in gathering meaningful data to meet the set objectives. This was in the most part due to the limitations of the national data analysed. As a consequence The Migraine Trust was unable to produce a final report, however we have prepared the following briefing paper which provides a summary of our findings and concludes with a set of recommendations.

### Data sets reviewed

*Patient Episode Database for Wales (PEDW) – NHS Wales Informatics Service*

The Patient Episode Database for Wales was implemented in April 1991. It contains all inpatient and day case activity undertaken in NHS Wales plus data on Welsh residents treated in English hospital trusts. Individual records are submitted to PEDW on the basis of a patient's consultant episode. Information about the diagnosis for which a patient is admitted is coded by clinical coders to standard classifications using ICD-10.

The data reviewed in this project was based on a bespoke query made to the NHS Wales Informatics Service with the following criteria set:

- Data Range: 2012/2013 to 2015/2016 (each fiscal year presented individually)
- Age Range: All ages
- Diagnosis Code (either as primary or secondary coding, ICD-10 code in brackets):
  - Migraine (G43)
  - Other headaches (G44, R51)
  - Intracranial haemorrhage (I60, I61, I62)
  - Cortical sinus thrombosis (I67, O22.5)
  - Idiopathic intracranial hypertension (G93.2)
  - Giant Cell arthritis (M31.6)
  - Cluster headache and other TAC (G44.0)

### What the data tells us

- Total consultant episodes
- Total admissions
- Total bed days
- Total elective admissions
- Total non-elective admissions
- Total zero-day admissions
- Total readmissions
- Top five co-morbid conditions (by migraine type)

### Limitations of the data

The dataset uses up to five diagnoses (one principal diagnosis and four secondary diagnoses) recorded per hospital episode using ICD-10 codes. The high prevalence of headache and migraine mean that the margin for error in this system of data collection is too large for the data to be of use. In an audit produced by the NHS Wales Informatics Service<sup>1</sup>, only five out of 19 sites audited reached the recommended accuracy of coding (90% on primary diagnosis, 80 on secondary coding).<sup>1</sup>

In addition:

There is no agreed national data on the incidence and prevalence of headache and migraine in Wales. The availability of this data would have enabled us to infer conclusions from local data on a wider scale.

There is no national source of primary care data for headache and migraine in Wales.

There is no national source of neurology outpatient data in Wales.

The nature of the data sets does not give insight into the quality of care experienced by patients or indicate the extent to which their health was improved and quality of life improved as a result of contact with the NHS service.

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Although the advisory group identified a number of local audits and areas of good practice across the country there is no national audit of headache services in Wales.

## **Conclusion**

The available national data set is not robust enough to provide the information necessary to draw meaningful conclusions about the disease impact of headache and migraine in Wales. More work must be done to establish a comprehensive method of capturing the data of headache and migraine patients in Wales to enable commissioners to understand the disease impact locally and nationally.

## **Recommendations**

- The Migraine Trust will take the findings of the data project to the Welsh Neurological Alliance.
- A comprehensive national data content audit to be undertaken, bringing together and capturing the full extent of the current available headache and migraine data in Wales from all local and national sources in one place.
- A National Headache Advisory Group of headache specialists and expert stakeholders, to be established to undertake a review of this paper and the full data content audit to identify the gaps and priorities for improvement.

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<sup>1</sup> <http://www.nwisinformationstandards.wales.nhs.uk/sitesplus/documents/299/20150116-REP-An%20Audit%20of%20NHS%20Wales%20Clinical%20Coding%20Accuracy-v1%28FINAL%29.pdf>