

Headache and migraine data in England

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 England.

The purpose of the project was to analyse and assess the disease impact of headache and migraine to produce a clear case for change to act as leverage for commissioners 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

1) Neurology Profiles, Neurology Intelligence Network – Public Health England

<http://fingertips.phe.org.uk/profile-group/mental-health/profile/neurology>

The Neurology Profiles have been published to support the work of the Neurology Intelligence Network (NIN). They aim at providing health intelligence with which to inform the provision of care and treatment of people in England who have a neurological condition.

The indicators are currently arranged into three data domains. Neurology services, epilepsy care and emergency hospital admissions for neurological conditions.

Activity data

- Data Source: Hospital Episode Statistics
 - Hospital Episode Statistics (HES) is a data warehouse containing details of all admissions, outpatient appointments and accident and emergency attendances at NHS hospitals in England. HES data covers all NHS trusts as well as privately-run providers that provide episodes of care to NHS patients.
 - HES is derived from the Secondary Uses Service (SUS). SUS is the single, comprehensive repository for healthcare data in England which enables a range of reporting and analyses to support the NHS in the delivery of healthcare services. SUS receives commissioning data sets from providers related to accident and emergency, outpatients and admitted patient care. It provides extracts of the data the providers and commissioners as well as providing a cut which gets converted to HES.
- Date Range: 2013/14
- Age Range: 20+

2) Neurology Focus Packs, Right Care – NHS England

<https://www.england.nhs.uk/rightcare/intel/cfv/data-packs/>

The NHS England Right Care Focus Packs aim to provide information on the opportunities to improve the highest spending programmes in the NHS. They present analysis on a wide range of indicators focusing on spend, activity, quality and outcomes. The indicators for the neurology packs have been chosen with advice from national clinical leads and other key stakeholders including the National Mental Health Dementia and Neurology Intelligence Network.

Activity data

- Data Source: Secondary Uses Service Extract Mart
- Data Range: 2014/2015
- Age Group: 0 – 120 (Emergency admissions are split into children (0-18) and adult (18 +))

Prescribing data

- Data Source: ePact.net
ePact.net is an application which allows authorised users at NHS organisations to electronically access prescription data
- Data Range: 2015
- Numerator Value: Net Ingredient Cost

What the data tells us

1) Neurology Profiles, NIN – Public Health England

Migraine specific measures

- Age standardised rate of emergency admissions to hospital with headaches and migraine in the primary diagnosis code position, for those aged 20+
- Age standardised rate of emergency admissions to hospital with a mention of headaches and migraine in any diagnosis code position, for those aged 20+

Other measures of interest

- Age standardised rate of new outpatient appointments (consultant led) for those aged 20+
- Percentage of new outpatient neurology consultant led appointments that were provided within the home CCG
- Percentage of follow up outpatient neurology consultant led appointments that were provided within the home CCG
- Percentage of all outpatient neurology consultant led appointments that were provided within the home CCG
- Percentage of all outpatient neurology nursing appointments that were provided within home CCG
- Percentage of follow up outpatient neurology consultant and nursing appointments that were provided within the home CCG
- Percentage of all outpatient neurology consultant and nursing appointments that were provided within the home CCG

2) Neurology Focus Packs, Right Care

Migraine specific measures

- Day case admissions per 100,000 age/sex weighted population
- Mean elective admission length of stay (not including day cases)
- Mean emergency admission length of stay
- Total spend per 1,000 age-sex weighted population
- Elective spend per 1,000 age-sex weighted population
- Emergency spend per 1,000 age-sex weighted population
- Migraine drug spend per 1,000 ASTRO-PU population
- Rizatriptan drug spend per 1,000 ASTRO-PU population
- Sumatriptan Succinate drug spend per 1,000 ASTRO-PU population

Other measures of interest

- Total inpatient neurological condition spend per 1,000 age-sex weighted population
- Elective inpatient neurological condition spend per 1,000 age-sex weighted population
- Emergency inpatient neurological condition spend per 1,000 age-sex weighted population
- Neurological procedure spend per 1,000 age-sex weighted population (by procedure)
- Percentage of population with LLTI or disability
- Percentage of population with depression
- Age standardised rate of new outpatient appointments (consultant led) for those aged 20+

Limitations of the data

The NIN and Right Care data sets offer an insight into neurology data which historically has not been available. Whilst this is a valued and welcome resource there are significant limitations in the use of the data sets to understand the disease impact of headache and migraine.

HES admitted patient care and outpatient data is generally considered to be complete and robust. However, there is a question as to the quality of the coding provided by hospitals in particular coding that wasn't the primary reason for an episode of care. As such, there is likely to be a margin of error when compared to real-world expectations. This margin of error will be accentuated when analyses includes secondary (or 'mention') diagnosis codes.

In addition:

The coding method does not distinguish between a primary headache disorder diagnosis (tension-type headache, migraine, cluster headache) and a secondary headache disorder (headache attributed to another condition or injury).

There is no national prevalence and incidence data recorded for neurology in England. The availability of this data would have otherwise enabled us to normalise audited local data to infer conclusions on a wider scale.

The data sets do not give insight into the numbers of patients that are not admitted to inpatient services and where they receive care, if at all, in the system.

The NIN and Right Care datasets do not capture data from outpatient and primary care sources. There is no national source of primary care data for headache and migraine in England.

There is no ability to link the data presented in the NIN and Right Care datasets to data sets held outside of neurology to understand the impact and presentation of patients with comorbidities within the system.

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. Both the Focus Packs and the Neurology Profile datasets are presented in formats that are difficult to read for non-experts with little context being directly given to published figures.

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 England.

Conclusion

The national datasets for neurology are richer in England than elsewhere in the UK. However, the existing data sets are inadequate to provide commissioners with a true picture and understanding of the cost of headache and migraine locally. More work must be done to establish a comprehensive method of capturing the data of headache and migraine patients in England to enable commissioners to understand the true disease impact.

Recommendations

- The Migraine Trust to take the findings of the data project to the NIN, Right Care Programme, the National Neurology Advisory Group and the 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 England 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.