Headache and migraine data in Scotland

The data project

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 Scotland.

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

Inpatient and Day Case activity data set – ISD Scotland
The Inpatient and Day Case activity data set, compiled by ISD Scotland, is a collection of data records based on discharges from non-obstetric and non-psychiatric hospitals in Scotland. Only patients treated as inpatients or day cases are included.

The data reviewed was based on a bespoke query made to ISD Scotland with the following criteria set:
- Data Range: April 2012 – March 2015
- 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 elective admissions
- Total day case admissions
- Total non-elective admissions
- Total zero-day admissions
- Total admissions
- Elective admission bed days
- Non-elective admission bed days
- Total bed days
- Elective mean length of stay
- Non-elective mean length of stay
- Overall mean length of stay
- Total readmissions
- Total elective patient count

- Total non-elective patient count
- Total patient count
- Total bed days in excess of the Healthcare Resources Group (HRG) trimpoint

Limitations of the data

The dataset uses up to six diagnoses (one principal diagnosis and five secondary diagnoses) recorded per hospital episode using the ICD-10. The coding system means that the margin for error in this system of data collection is too large for it to be of use.

Although Scotland uses the common HRGs codes for activity, it does not have the level of detailed HRG costing that exists in England. Scottish health costs are collected and published at specialty level only[i]. Scottish health boards are therefore unlikely to look at additional granular data in practice. The Scottish National Tariffs are based on the cost of patient 'spells of care within the same specialty' which often involve several rather than individual episodes of care[ii]. Headache and migraine will likely be grouped under neurology for these purposes.

In addition:There is no agreed national data on the incidence and prevalence of headache and migraine in Scotland. The availability of this data would have enabled us to infer conclusions from local data 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.

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

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

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.

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 Scotland.

Conclusion

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

Recommendations

- The Migraine Trust to take the findings of the data project to the Scottish 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 Scotland 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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[i] http://www.isdscotland.org/Health-Topics/Finance/Scottish-National-Tariff/
[ii] http://www.isdscotland.org/Health-Topics/Finance/Scottish-National-Tariff/