# Where everyone wins – five steps to support commissioning

# headache services

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# **Key points**

- Despite significant personal, social and economic burden, the needs of many headache sufferers remain unmet
- Headache is the most common presentation to secondary care neurology services
- Commissioning services around intermediate care is a cost effective intervention where all stakeholders benefit

# Background – why headache is important

The economic, social and personal burden of headache in the community is substantial.<sup>1</sup> Migraine alone affects 7.6% of males and 18.3% of females in England.<sup>2</sup> Measures of healthrelated quality of life are similar to patients with other chronic conditions such as arthritis and diabetes <sup>3</sup> and worse than those with asthma.<sup>4</sup> One in three migraine sufferers believe that their problem controls their life <sup>5</sup> and the impact extends to family and friends.<sup>6</sup>

There are also significant economic consequences. Indirect costs of migraine in the UK due to work loss have been estimated as approximately  $\pounds$ I billion a year.<sup>7</sup> Setting this in an NHS context, two studies have reported from hospital settings. A study in an NHS hospital in Hull, found that 20% of respondents experienced disabling headaches with an average of 16 migraine attacks a year. The average loss of work was two days a year. There was considerable reduced efficiency at work with an estimated annual financial cost to the Trust of over  $\pounds$ 110,000.<sup>8</sup> A study in a Liverpool NHS Hospital<sup>9</sup> found that 21% of respondents had migraine and lost 3 days of work a year.

In the U.K. the annual primary care consultation rate for headache is 4.4 per 100 patients. Although only 3% are referred to secondary care, headache is the most common cause of neurological referral<sup>10</sup>. This article offers a framework to support the commissioning of headache services and argues that intermittent care headache clinics led by a GP with a special interest in headache (GPwSI) offer important benefits to both patients and commissioners.

#### Step 1 – Headache is neurologists heart-sink - keep it away from them

Up to 30% of neurology referrals are for headache but only a small number of neurologists have a special interest in the area and many referrals are inappropriate for a secondary care setting.

There is no difference in headache impact between neurology headache referrals and patients managed in primary care but referred patients consult more frequently and have higher levels of headache related anxiety<sup>11</sup>. Apart from reassurance that no serious pathology is present, inevitably with an inappropriate brain scan (secondary care imaging rates are as high as 60%<sup>12</sup>), in many cases the needs of headache sufferers remain unmet.

#### Step 2 – Educate GPs in the management of headache

Most headaches present to primary care but the majority of headache sufferers are reluctant to seek help and when they do the condition is often poorly managed by the GP.<sup>13</sup> The majority of headaches that present to the GP do not reach a diagnostic threshold<sup>14</sup> and when a diagnosis is made, treatment is often less than ideal.

The reasons for this are not known but include a low priority for headache education. The majority of primary care presentations will be migraine where diagnosis is not challenging and management pathways are well defined. Ongoing education for GPs in the diagnosis and management of headache is an important first step. Headache GPwSI can support this development.

### Step 3 – Allow direct access by GPs to neuroradiological investigation.

Although a brain tumour can present with a number of symptoms, headache is invariably a cause for concern for both patient and doctor but there is a wide discrepancy in GP access to neuroradiological investigation to exclude this possibility.

The context in which the decision to investigate a headache is made also plays an important part. In secondary care, patients often anticipate the exclusion of secondary pathology and consultants are under pressure to make a diagnosis at the first appointment. In primary care frequent review can monitor the development of relevant features. Where GPs have direct access to neuroradiological investigation reported rates are between 1.2-5.3%<sup>15</sup> with similar diagnostic yields to hospital specialists.

Three studies have reported on the impact on secondary care referrals when GPs have access to investigations. A randomised trial reported neurology referral rates of 23% for treatment as usual or 1.3% when GPs had access to MRI, a referral reduction of over 90%;<sup>16</sup> a prospective study with CT showed a referral reduction of 86%<sup>17</sup>; a retrospectively study of MRI showed that referral was avoided in 41% of patients<sup>18</sup>.

## Step 4 – Identify a primary and secondary care headache champion

This is the weak link in any initiative. However impressive the business plan, if there is not a suitable GP to take this initiative forward and train to be a GPwSI in headache and a willing secondary care neurologist to act as mentor, a project will not succeed.

Guidelines have been developed by the Royal College of General Practitioners in consultation with other key stakeholders, defining the competencies required and governance arrangements of a GPwSI including specific guidance for headache. (www.doh.gov.uk/pricare/gp-specialinterest). However in practice, areas of this guidance may prove impractical and it may be more appropriate for alternative competency frameworks to be developed by local stakeholders that reflect local circumstances.

#### Step 5 – Develop an intermediate headache care service

The British Association for the Study of Headache has proposed that intermediate care headache clinics staffed by general practitioners with a special interest should support GP colleagues who would continue to provide first-line headache care.<sup>19</sup> This development is in line with NHS policy where the hope is that intermediate care will provide more effective and efficient service delivery in local settings.<sup>20</sup> The suitability of this model for headache care has also been recently endorsed by the Royal College of Physicians and the Association of British Neurologists<sup>21</sup>.

From an economic perspective, when an intermediate care service is proposed, there are a number of factors to be considered<sup>22</sup>. These are outlined in figure 1.

- The aim of the service change and whether the shift is acceptable to all stakeholders. For example, is the aim an addition to the services in existence, complementation, substitution or a combination of all three? Is there a danger that it will simply expose unmet need?
- What are the implications for other services that may be affected directly or indirectly? For example, the introduction of a new service may de-stabilise the delivery of secondary care services.
- What is the best increment in service development to undertake and how should the service be configured? What are the local values placed on the potential changes in outcome (clinical and non-clinical) and how do they reflect national priorities?
- Are new resources available or is disinvestment required from secondary care? If so, is this a practical option and can the released resources be identified?

Figure 1 – some economic considerations when an intermediate care service is proposed

The difficulties in obtaining a rigorous and generalisable evidence base to address these questions are well recognised.<sup>23 24</sup> Service developments will also depend on the context of the local health economy and the relationships between local stakeholders. There is only one study on the cost effectiveness of headache care delivered in an intermediate care setting.<sup>25</sup> It was found that a GPwSI headache service can satisfy patients with similar headache impact as those seen in secondary care at lower cost.

#### Conclusion

Headache causes a high level of morbidity in the population with the needs of many sufferers unmet. It is the most common cause of neurological referral and the majority of cases are inappropriate for this settling. Improving headache services around the development of intermediate care and using this as a focus for GP education is a cost effective way of delivering headache services and improving care for patients with this problem.

## Resources

i) Key general background policy and implementation papers are:

• The Clinical Standards for Neurology Services in Scotland contains a section on headache which defines standards of care for this problem.

http://www.nhshealthquality.org/nhsqis/files/LongTermConditions NeurologicalHealthSe rvices OCT09.pdf

- Implementing a scheme for general practitioners with a special interest. *Department* of *Health/Royal College of General Practitioners* April 2002. <u>http://www.gencat.cat/ics/professionals/recull/bibliografic/2007\_3/Implementing.pdf</u>
- Assessment of the clinical effectiveness, cost and viability of NHS general practitioners with a special interest service. Department of Health, <u>www.sdo.nihr.ac.uk/files/adhoc/34-34-briefing-paper.pdf</u>
- The process of planning, development and implementation of a General Practitioner with a Special Interest service in Primary Care Organisations in England.
  www.sdo.nihr.ac.uk/files/project/99-final-report.pdf

## ii) Guidelines and clinical resources

- SIGN guidelines www.sign.ac.uk/guidelines
- British Association for the Study of Headache guidelines <u>www.bash.org.uk</u>

- <u>The Exeter Headache Clinic www.exeterheadacheclinic.org.uk</u> contains patient information and advice sheets particularly for medication use which can be downloaded.
- British Association for the Study of Headache has a GPwSI group. (Contact david.kernick@nhs.net)

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