Headache Services in England

A Report of the All-Party Parliamentary Group on Primary Headache Disorders
2014
Foreword

This inquiry has highlighted the huge breadth of associated factors and complex considerations that affect the provision of high quality care and the experience of headache sufferers who do, and do not, access clinical support for headache disorders.

There are large gains to be made by treating headache appropriately for the patient, the NHS, the economy, and wider society. We have a significant way to go before the provision of services and support is sufficient to address the burden of primary headache disorders across England.

Undoubtedly the headache specialist health professionals, stakeholder charities, and organisations that exist in England have identified and adopted a range of good practice solutions and cost-effective measures to diagnose, treat, and address the burden of headache disorders. Their work is commendable but they work tirelessly in the face of a lack of recognition and respect for headache disorders, and are poorly resourced to deliver their aims. Disappointingly, steps to address this situation, recognised by the All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD) in 2010, have been slow to be implemented. As such there remains non-equivocal access to quality headache services and support for patients across England.

There must be both a strong desire to change the status quo and a clear objective to address the burden of primary headache disorders. This requires strong leadership from Government through to NHS England, Strategic Clinical Networks (SCNs), and Clinical Commissioning Groups (CCGs). Patients and their representatives must also take the platform locally to demand better provision of care. They will be instrumental in generating that motive to change and their voice must be heard and respected.

Local approaches to delivering cost-effective headache services are needed but will fail to deliver achievable outcomes in the absence of a national strategy to improve the provision for headache sufferers in England. Failure to address poor public awareness, education of health professionals, and to adequately prioritise neurology undermines the ability of the NHS to effectively commission, design, and deliver high quality, effective services.

The APPGPHD’s recommendations are intended to ensure that spending on this health area is properly targeted and measurable. They intend to address inconsistencies in quality effective care across the country and ensure that the benefits of NHS resources are maximised appropriately. Proper implementation of the recommendations will reduce the burden of headache disorders on emergency admission numbers and overstretched neurology services whilst ensuring that patients have timely access to appropriate and effective care close to home.

Jim Fitzpatrick MP
Chairman, All-Party Parliamentary Group on Primary Headache Disorders
May 2014
The All-Party Parliamentary Group on Primary Headache Disorders

The All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD) is a cross party group of MPs and members of the House of Lords who have a particular interest in primary headache disorders. The aim of the APPG is to highlight and raise awareness amongst parliamentarians of the key issues affecting sufferers of primary headache disorders, their families, carers, and health professionals working in the field.

**Inquiry Panellists**

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Baroness Masham of Ilton (Secretary of the APPGPHD)

Virendra Sharma MP

Stephen O’Brien MP

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**Enquiries**

Please direct all enquiries regarding this report and the work of the APPGPHD to advocacy@migrainetrust.org
Executive Summary

Summary

Primary headache disorders are extremely disabling and highly prevalent. They place a significant demand on NHS resources and are an enormous financial cost to the economy and wider society. The publication of The National Institute for Health and Care Excellence (NICE) Clinical Guideline and Quality Standards on Headache in 2012 and 2013 respectively, signify an encouraging step forward in the recognition of these debilitating conditions. However, significant rates of misdiagnosis and subsequent mismanagement of headache disorders remain. Patients in England have non-equivocal access to specialist headache clinics and face barriers accessing appropriate, and recommended, treatments.

The evidence examined by the inquiry revealed that poorly informed and unsupported headache patients are misusing NHS services as they desperately seek a firm diagnosis, appropriate treatment, and support. Despite the fact that the majority of headache cases can be treated in primary care, headache accounts for 33% of all new referrals to neurology. It is the most common neurological reason for A&E attendance, and A&E admissions for headache have continued to increase steadily by 12% in the last 3 years.

Witnesses stressed that greater value for money and a reduction in NHS resource wastage can be achieved by strengthening headache services at primary care level. They also highlighted the need to improve access to local specialist care. Witnesses were clear that these changes must be underpinned by a change in the status and recognition of the burden of headache disorders. To improve patient outcomes and the cost-effectiveness of services in the long-term requires a national headache strategy, greater public awareness, improved education of health professionals, and headache specific data collection and analysis across the NHS.

The NHS faces an ongoing, unprecedented challenge to reduce health budgets in England without compromising patient care. Health provision for headache services can be both improved and made more cost-effective, simultaneously saving capacity in overstretched neurology outpatient and A&E departments. The APPGPHD urges the Government, stakeholders, and organisations, as identified in this report, to act on the recommendations and address inadequate provision for headache sufferers in England.
Conclusions

Tackling the scale of the problem

The current resource allocation in the NHS for primary headache disorders is insufficient to address the burden and direct costs that headache presents. Difficulties in understanding the true cost to the NHS of headache, locally and nationally, arise from the impact that highly prevalent co-morbid conditions have on sufferers' use of resources and clinical time. The difficulty in calculating the cost, and therefore evaluating value for money, is further compounded by the lack of data to measure and compare patient outcomes nationally. The direct costs are far outweighed by the societal costs of primary headache disorders. Such indirect costs, and the cost impact of addressing the burden of headache, are seemingly overlooked by the NHS. As a result the burden of headache remains greatly under-prioritised.

The provision of headache services across the country is geographically patchy and inconsistent in quality. As such patients have unequivocal access to services and there are huge disparities in value for money between CCGs and regions. High numbers of headache disorder cases that present to secondary care and Accident and Emergency (A&E) departments present a significant cost priority to be addressed. The high presentation of avoidable headache cases at A&E is symptomatic of the low satisfaction, poor service and lack of support patients experience elsewhere in the system.

Diagnosing and Treating Headache Disorders

Patients with primary headache disorders require a firm and accurate diagnosis. The significant rate of misdiagnosis and subsequent mismanagement of headache disorders still prevalent, despite the NICE headache guideline, is unacceptable. Delays to receiving a firm and accurate diagnosis increase the cost burden on NHS resources as patients are incorrectly treated, inappropriately referred, and may develop co-morbidities such as depression and anxiety. There are significant gains to individual sufferers, the NHS and the economy in strengthening earlier identification, diagnosis, and treatment of headache disorders.

Greater Public Awareness

Headache information and education needs be offered on a societal level. Messages that focus on self-management and ensure that sufferers access appropriate clinical services need to be communicated to the public. Charities and patient groups play a key role in promoting awareness and disseminating high quality, evidence-based information on primary headache disorders. They are fundamental in raising awareness amongst patients and health professionals but lack the funds and resources to tackle the problem, given its scale.

Poor public awareness and understanding of how to access quality information and care for primary headache disorders increases the burden on the NHS, society and the sufferer. Addressing this will reduce misuse of NHS services, particularly A&E admissions.
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**Headache Education**

The level of headache education and knowledge amongst non-specialist health professionals in England is inadequate. Poor education, particularly amongst GPs, threatens to undermine the implementation of the NICE headache guideline and the quality of care received by patients. Greater GP training on headache should be prioritised as GPs are likely to see the majority of headache patients. However, initiatives to improve headache training are needed to address poor knowledge and awareness amongst all health professionals who are likely to provide clinical support to sufferers, e.g. dentists, nurses, and general neurologists.

Cost-effective headache service models and opportunities to develop high quality headache services will require interested practitioners to take on specialist roles. It is therefore necessary to increase the profile of headache from the medical professional’s perspective.

**Prioritising Headache Disorders**

Currently, headache disorders are not prioritised within the NHS. Despite their prevalence and impact, headache disorders are at the ‘bottom of the pile’ of neurological commissioning priorities. Headache needs to be better recognised as a long-term health condition. CCGs need to be supported so as to understand the benefits of improving headache services on achieving outcomes related to A&E, delivering the NHS outcome framework and reducing the demand on neurology outpatient services.

A national strategy to address the burden of primary headache disorders is needed. In the absence of this, the commissioning of cost-effective services, which meet the needs of sufferers, is unlikely to be consistently prioritised throughout the country. Headache patients and stakeholders need to make better use of opportunities within the NHS structure to raise the profile of headache, and influence services locally and nationally.

**Data Collection**

The lack of collated and analysed national data on primary headache disorders presents significant difficulties in understanding the true prevalence and impact of headache disorders on the NHS. CCGs cannot prioritise and commission the types of activities that result in the best outcomes for headache patients, and thus measure cost-effectiveness, without such data. The long overdue publication of the new neurological dataset this year marked an important step forward for the future of neurology and headache services, improving patient outcomes, and understanding commissioning priorities. Additional condition specific information is needed to understand what is happening nationally and locally in support of the new dataset.

Research and data collection needs to be integrated in any commissioning plan; without this it is impossible to improve services. Specialist health professionals and stakeholder organisations can provide crucial support to NHS England and local CCGs to support them in understanding the key data that must be captured to address headache disorders.
Headache in Primary Care

The biggest opportunities to address the burden of headache exist within primary care, since this is where the majority of cases present to. Despite the NICE headache guideline and quality standards, the provision of good quality headache care and patient satisfaction within primary care is poor. Strengthening resources to improve the provision of care at primary care level will therefore yield good value for money for commissioners.

Initiatives to provide support to headache patients outside of clinical settings will reduce the demand on busy GP surgeries. Approaches to support properly diagnosed migraine and tension-type headache patients through ongoing ‘remote’ support from primary care specialists have the potential to save CCGs money by reducing clinical appointments. Partnerships with third sector organisations to deliver this care can ensure that patient outcomes are achieved.

Until headache is prioritised and addressed at primary care level it will continue to place a great burden on resources elsewhere in the system. Greater health professional education, adequate pathways, and the inclusion of headache indicators in the Quality Outcomes Framework are needed to drive forward consistent standards of care for headache patients.

GP with Special Interest Services

Specialist GP services provide an appropriate and cost-effective approach to managing primary headache disorders. Although services will require initial investment the GP with Special Interest Model (GPwSI) model can bring about capacity savings in overstretched neurology & A&E services, provide access to local and timely support for patients and greater patient satisfaction compared to being seen in general neurology. The current provision of GPwSI services is inconsistent across the country and more funding is needed to train and support interested GPs at a local level. Despite strong support from the ‘headache community’ more research and data on piloted services will strengthen the case for commissioning intermediate headache services across the country.

Headache Pathways

There is a lack of clearly defined pathways for headache patients across CCGs and SCNs in England. This has a significant cost impact to the NHS as patients are referred to inappropriate services and lack an accurate diagnosis or appropriate treatment. In turn this has a negative impact on the quality of life of sufferers. Clearly defined headache pathways can improve patient experience, ensure timely access to appropriately defined support, and optimise patient outcomes.

The development of local headache pathways should have input from key health professionals across multiple health disciplines and must be integrated to detail the essential steps to diagnose and treat all headache disorders. Headache disorder charities and patient groups should be acknowledged and listened to as key stakeholders in the creation of these pathways.
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Escalation to Secondary Care Services

Poor management of headache disorders in primary care shifts the cost burden onto resources in A&E and neurology services. The number of incorrectly triaged cases, referred from primary to secondary care neurology services, diverts costly resources away from complicated headache and other neurological conditions which require specialist attention.

Properly resourced intermediate specialist headache services can reduce the pressure on general neurology services. This provides an opportunity to reduce the number of headache patients referred to secondary care and reduce waiting lists for patients with more complex and severe headache and other neurological conditions (such as Parkinson’s disease, multiple sclerosis and motor neurone disease).

Reducing the burden of headache on neuroimaging and neurology services will also free up capacity for other neurological conditions. The necessary pathways must also be in place for GPs to support patients with health anxieties without escalating to neurology unless appropriate. Better skilled primary care practitioners will be able to identify patients requiring referral to neurology and neuroscanning services, and adequately diagnose and support those who do not. This will improve patient confidence, reduce lengthy diagnosis, and reduce patient anxiety.

Headache Clinics

Greater funding is needed to improve access to specialist consultant led headache clinics for those patients whose conditions require it. Patients should not be prevented from accessing secondary and tertiary services due to their geographical location.

In the absence of a national strategy by NHS England to improve the provision of headache services, or a clear prioritisation from SCNs, the geographic locations of clinics are largely determined by the location of the interested consultant. Strategies to improve the provision of secondary and tertiary headache services across the country must respond to patient need. This will require national data, as well as local intelligence, to understand how to make the most cost-effective use of new secondary and tertiary clinics.

Headache Nurses

Specialist Nurses provide a key cost-effective service to address the burden of headache. However, the current level of specialist headache nurse provision is inadequate. There needs to be a sufficient number of adequately trained and well-supervised specialist headache nurses in posts across the country to meet the demand of the high cohort of headache patients. Reduced spending on nurse posts in times of austerity will only yield short-term savings and further limit the support available for headache patients. Commissioners need to look at the models of good practice that exist, and consider the wider cost implications and health improvements that specialist nurses can provide in the long-term.
Multi-disciplinary Teams

Headache Disorder patients benefit from a multi-disciplinary approach to manage commonly associated co-morbid conditions. These teams should be an essential part of tertiary headache services which treat the most complex patients. Local commissioning decisions should take into account the benefits that treating headache patients holistically can have on reducing the use of NHS resources in the long term.

Commissioning Responsibility

Commissioners and Providers require clarity on the commissioning responsibilities of specialist headache services. This is essential to identify national and local commissioning priorities, and to ensure that patients can access appropriate treatments. Owing to the current commissioning chaos, it is those patients with the most disabling forms of the condition, and who require the most specialised treatment, who will lose out. This will yield further costs to the NHS as those patients rely on other services and treatments that are ineffective for their needs.

Clear definition as to whether facial pain services sit within pain services, or entirely separately, and clarity on the pathways and commissioning responsibilities for facial pain disorders, must also be established and applied across the country.

Integrated networks

The evidence highlighted that the commissioning of high quality cost-effective services must take into account the numerous different platforms that headache patients use to access support and clinical services. It will not be beneficial to consider primary, secondary, or tertiary NHS services in isolation, since opportunities to improve the patient experience and patient outcomes exist at all levels. Integrated local headache networks provide a potential opportunity to share best practice and improve headache patient pathways. However these must be underpinned with commissioning clarity to ensure they are accountable and represent value for money.
Recommendations

1. NHS England to lead an appropriate and targeted public awareness campaign to increase understanding and awareness of primary headache disorders.

2. The Department of Health to take the lead on prioritising a headache teaching curriculum for non-specialist health professionals. Health Education England and Local Education and Training Boards to ensure that health care professionals, particularly those in primary care, are equipped with appropriate training to support headache disorder patients.

3. Headache specific indicators to be included in the CCG Outcomes Indicator Set to ensure that headache is prioritised so that commissioners and clinicians are incentivised to improve outcomes.

4. Headache patients to be supported by specialist charities and stakeholder groups to engage with Local Healthwatch and health and wellbeing boards to influence services locally.

5. Better diagnosis and treatment of headache disorders by GPs. Headache indicators to be added to the Quality Outcomes Framework (QOF) to incentivise such improvements.

6. Sufficient intermediate care headache clinics staffed by GPs with a special interest in headache to be developed within every CCG.

7. SCNs to establish clearly defined local headache pathways to ensure that patients are seen promptly and appropriately.

8. NHS England’s evolving neurological dataset to identify indicators from which meaningful headache specific data can be extrapolated. The dataset to be supported by additional headache specific intelligence, captured locally, to understand local need. CCGs to commission patient experience surveys to understand the effectiveness of local services and pathways.

9. The headache nurse specialist model to be extended to all primary and secondary care specialist headache services. Commissioners to consider the cost benefits locally of intermediate care headache clinics run by specialist headache nurses.

10. NHS England to define a national strategy for addressing the burden of headache disorders with clarity of commissioning responsibilities. SCNs to take responsibility for ensuring that this is implemented locally.