

# Headache Services in England

---

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



House of Commons  
The All-Party Parliamentary Group on Primary Headache Disorders



# Glossary of Abbreviations

---

**APPGPHD** All-Party Parliamentary Group on Primary Headache Disorders

**BNF** British National Formulary

**CCG** Clinical Commissioning Group

**GPwSI** General Practitioner with a special interest

**NICE** National Institute for Health and Care Excellence

**QOF** Quality and Outcomes Framework

**SCN** Strategic Clinical Network

# Contents

---

<b>Foreword</b>	<b>4</b>
<b>The All-Party Parliamentary Group on Primary Headache Disorders</b>	<b>5</b>
Inquiry Panellists	5
Acknowledgements	5
Enquiries	5
<b>Executive Summary</b>	<b>6</b>
Summary	6
Conclusions	7
Recommendations	10
<b>Introduction</b>	<b>13</b>
Outline of the Inquiry	13
Evidence Submissions	13
Notes on the Scope of the Inquiry	13
<b>Background</b>	<b>14</b>
Neurology Services	14
Primary Headache Disorders	14
NICE	15
Research into Primary Headache Disorders	15
<b>Understanding The Cost of Headache Disorders</b>	<b>16</b>
The Cost of Headache Disorders to the NHS	16
Emergency Admissions	16
The Social and Economic Cost of Headache Disorders	17
The Current Provision of Headache Services	18
<i>Conclusion</i>	19
<b>Diagnosis and Treatment Concerns</b>	<b>20</b>
<i>Conclusion</i>	21
<b>Underpinning Cost-Effective Headache Services</b>	<b>22</b>
Public Awareness	22
<i>Sub-Conclusion</i>	23
Education of Health Professionals	24
<i>Sub-Conclusion</i>	25
Prioritising Headache Disorders	26
Incentivising Commissioners	27
<i>Sub-Conclusion</i>	27
Data Collection	28
<i>Sub-Conclusion</i>	29

---

<b>Headache Disorders In Primary Care</b>	<b>30</b>
Facilitating Good Self-Care Outside of Clinical Settings	30
Incentivising GPs	31
<i>Conclusion</i>	32
<b>GP with a Special Interest In Headache Services</b>	<b>33</b>
<i>Conclusion</i>	35
<b>Patient Pathways</b>	<b>36</b>
<i>Conclusion</i>	37
<b>Escalation to Secondary Care Services</b>	<b>38</b>
Referrals to Neurology	38
General Neurology	38
Scanning	39
<i>Conclusion</i>	40
<b>Specialist Hospital Based Clinics</b>	<b>41</b>
<i>Conclusion</i>	42
<b>Headache Nurses</b>	<b>43</b>
<i>Conclusion</i>	43
<b>Multidisciplinary Teams for Treating Headache</b>	<b>44</b>
<i>Conclusion</i>	44
<b>Commissioning Responsibility</b>	<b>45</b>
<i>Conclusion</i>	46
<b>An Integrated Approach To Addressing The Burden Of Headache Disorders</b>	<b>47</b>
<i>Conclusion</i>	47
<b>APPGPHD Recommendations</b>	<b>48</b>
<b>Appendix 1: List of Oral and Written Evidence Submitters</b>	<b>49</b>
<b>Appendix 2: The Barriers to Accessing Treatment</b>	<b>51</b>
<b>APPENDIX 3: Case Study: A Diagnostic Headache Nurse Specialist Service</b>	<b>52</b>
<b>References</b>	<b>53</b>

# 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**

Jim Fitzpatrick MP (Chair of the APPGPHD)

Pauline Latham MP (Vice-Chair of the APPGPHD)

Baroness Masham of Ilton (Secretary of the APPGPHD)

Virendra Sharma MP

Stephen O'Brien MP

The APPGPHD would like to thank the panel members who gave their time to the inquiry and this report, and to the officers and members of the group for their continued commitment.

## **Acknowledgements**

We are indebted to the individuals and organisations that submitted written and oral evidence to the inquiry.

The APPGPHD would like to thank Headache UK and its members for their support towards the ongoing administration of the group, in particular Wendy Thomas, Chief Executive, The Migraine Trust.

We would like to thank the APPGPHD Coordinator Hannah Verghese, Advocacy and Policy Manager at The Migraine Trust, for collating the evidence and for the writing of the report.

ElectroCore LLC, eNeura and the British Association for the Study of Headache (BASH) have provided funding to The Migraine Trust for the printing of this report.

## **Enquiries**

Please direct all enquiries regarding this report and the work of the APPGPHD to [advocacy@migrainetrust.org](mailto: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 to 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.

# Executive Summary

---

## 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.

# Executive Summary

---

## **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.

# Executive Summary

---

## 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.

# Introduction

---

## Outline of the Inquiry

This inquiry was launched following the changes in the health and social care system which came into force in April 2013. The aim of the inquiry was to investigate the current delivery of headache care in order to examine whether opportunities exist to prevent spending wastage, make better use of NHS resources, and to improve the experiences of headache sufferers in England.

The APPG asked individuals and organisations with experience of primary headache disorder services in England to submit evidence to the inquiry over a 12 week period. Commissioners and providers, stakeholder organisations, and professionals working in the field were asked to comment on existing service provision and the opportunities that exist for high quality, cost-effective headache services within the new NHS system. Patients, family members and carers were invited to comment on their experiences of receiving care for primary headache disorders and for their views on how these could be improved. A number of key witnesses were invited to present oral evidence to the inquiry panel across two oral evidence sessions in the House of Commons.

## Evidence Submissions

The APPG received over 70 written evidence submissions from commissioners and providers of headache services, primary headache disorder patients, stakeholder organisations and professionals working in the field.

The APPG held two oral evidence sessions in the House of Commons to hear from key witnesses.

A full list of witnesses to the inquiry is available in Appendix I.

All references to 'written' and 'oral' evidence in the report refer to submissions made to the APPGPHD inquiry during the call for evidence. Summaries of the evidence are available at [www.headacheuk.org](http://www.headacheuk.org)

## Notes on the scope of the inquiry

The evidence highlighted the huge breadth of issues related to the provision of cost-effective headache services. This report does not, nor is it the intention of the APPGPHD, make clinical recommendations. It highlights the areas that need to be addressed in line with evidence based guidelines already in existence.

The burden of primary headache disorders is a global issue. The inquiry concentrated on NHS services in England and the report, and its' recommendations, refer to the health system in England. The APPGPHD hope that the lessons learnt from this inquiry will be of interest to the other countries within the United Kingdom, although this is beyond the scope of the inquiry.

# Background

---

## Neurology Services

England has a ratio of 1 neurologist to 117,000 of the population. This is up to 10 times lower than elsewhere in Europe.<sup>1</sup>

In 2012 The Public Accounts Committee reported that the NHS in England had failed to deliver the national service framework for long-term conditions for people with neurological conditions.<sup>2</sup> This report followed a review of neurological service in England by the National Audit Office's in 2011.<sup>3</sup> The committee recognised that neurology services were poorly coordinated and lacked national leadership. It reported that Health spending on neurological conditions increased by nearly 40 % in three years while emergency admissions have risen by 32 % in the same period, and called on the Department of Health to demonstrate how it ensures value for money for neurology patients.

Since 2012 the NHS Commissioning Board has set up SCNs covering neurology, dementia and mental health and appointed a National Clinical Director for Neurology. The first neurological minimum dataset was launched in March 2014. A second National Audit Office review of neurological services is anticipated in 2014.

## Primary Headache Disorders

Headache is a painful and disabling feature of a small number of primary headache disorders namely migraine, tension-type headache, and cluster headache.<sup>4</sup> Headache affects 90% of the population at some time. They are among the most common disorders of the nervous system and can be the cause of significant and long-term disability. 4% of adults consult a GP each year for headache or migraine.<sup>5</sup>

Tension type headache is the most common primary headache disorder and is experienced by approximately 70% of the population. This headache is described as pressure or tightness, like a band around the head, sometimes spreading into or from the neck. Episodic attacks usually last a few hours, but can persist for several days. Chronic tension-type headache is less common. It affects 1-3% of adults and is considerably more disabling.<sup>6</sup>

There are approximately 6,720,000 people living with migraine in England.<sup>7</sup> Migraine is a complex condition with a wide variety of symptoms. For many people the main feature is a painful headache. Other symptoms include disturbed vision, sensitivity to light, sound and smells, feeling sick and vomiting. It is classed by the World Health Organisation as one of the top 20 leading causes of disability amongst adults. 80% of migraine sufferers have disabling attacks that interfere with life at work, home, and socialisation.<sup>8</sup>

Cluster headache disorder is less common, affecting approximately 150,000 people in England. It is characterised by attacks of excruciatingly severe pain on one side of the head or face, typically lasting between 45 to 90 minutes. It is located mainly behind or around the eye, around the top side of the head and within the temple and forehead, although any part of the head or neck can be affected. Cluster headache is defined as episodic or chronic, which occurs in approximately 10% of cases.

---

75,000 people in England suffer from trigeminal neuralgia.<sup>9</sup> It is a facial pain condition which is categorised within headache disorders, due to its characteristics. The condition is characterised by a sudden, severe, brief, stabbing pain, often triggered by just a light touch to an area of skin, occurring in attacks lasting at the most for a few seconds and usually only on one side of the face. The frequency of attacks can vary from a few times a month to several times a day depending on the severity. Each year approximately 6,500 people in England will acquire the condition. For most sufferers the condition is progressive and can worsen over time.

There is no known cure for these primary headache disorders. Treatment options vary depending on the type, frequency and severity of the disorder as well as sufferers' individual characteristics. Treatments aim to reduce the severity and frequency of attacks, improving quality of life for the sufferer. However, 50% of headache sufferers do not seek clinical support for their symptoms.<sup>10</sup> This means that prevalence figures may be considerably understated while a large cohort of sufferers remains undiagnosed and treated.

### **The National Institute for Health and Care Excellence (NICE)**

The NICE Clinical guideline for Headache was published in 2012 and followed by the NICE quality standards for headache in 2013.<sup>11</sup> This signalled a positive step towards improving the standard and quality of care for sufferers in England. Health professionals and commissioners now have access to the best available evidence-based information on which to make their decisions.

### **Research into Primary Headache Disorders**

Historically the UK has been at the forefront of research into migraine and headache. However, a lack of public funding has resulted in a declining research base as the UK falls behind its European counterparts. The principle of improving health for the future must be rooted in research. This issue has been raised on multiple occasions by the APPGPHD, yet progress remains slow.<sup>12</sup>

# Understanding The Cost Of Headache Disorders

---

## The Cost of Headache Disorders to the NHS

The direct cost to the NHS of headache treatment is estimated at £1 billion a year.<sup>13</sup> Professor Leone Ridsdale presented evidence that the direct cost to the NHS of treating a headache patient averages at £468 p.p. per year,<sup>14</sup> spent, principally, on GP appointments and medication.

Evidence submitted to the APPGPHD inquiry highlighted the difficulties in determining with great accuracy the true cost implications of headache disorders. Direct costs calculations consider the expenses associated with diagnosis and treatment of headache patients. Witnesses to the inquiry commented on the high prevalence of co-morbid depression and anxiety disorders amongst primary headache disorder patients. There is a substantial body of evidence detailing these co-morbidities and the clinical approaches required to support them.<sup>15 16 17 18</sup> We heard that patients with such co-morbidities will inevitably rely more on NHS resources and can yield greater direct costs in terms of treatment and care. ElectroCore LLC told us that the high co-morbidity rates of headache disorders mean that the collateral direct costs of treating headache (costs associated with a consequence of the index condition or associated with a condition that is co-prevalent with the index condition, perhaps via a shared underlying mechanism) will provide a more accurate picture of the true cost implications to the NHS.

*NHS expenditure for primary headache disorders is grossly understated if only the costs of managing the primary headache are considered and are disproportionate to the actual cost in headache sufferers who often have co-prevalent conditions affecting their healthcare utilization.*

**ElectroCore LLC** (written evidence)

The evidence stressed that data on headache disorders should better capture the full costs of headache disorders to provide meaningful calculation on NHS spending from which commissioning and service delivery solutions can be drawn at national and local level.

Witnesses made repeated references to the fact that direct costs to the NHS are far outweighed by the societal costs of primary headache disorders. We heard evidence that the societal costs per headache patient per year are in the region of £2,000.<sup>19</sup> Witnesses noted that such indirect costs are, by their nature, hard to calculate. Indirect costs arise from the impact that headache has on the activities of the patient, and are typically confined to the effect on productivity. Witnesses raised concerns that improvements to headache services were likely to bring about a higher reduction in indirect costs, and as such, tend to lack commissioning priority.

Commissioners, providers, and the patient groups and charities that submitted evidence to the inquiry identified that unnecessarily high numbers of cases escalated to secondary care services, and high emergency admission rates for headache disorders signified a priority area to be addressed. The proposals to reduce spending in these areas are explored elsewhere in this report, but it was stressed by the witnesses that such savings should be invested into preventative measures at primary care level and should not be regarded as 'cost-saving measures'.

---

## Emergency Admissions

Stakeholders, commissioners, and providers stressed the importance of reducing the number of headache disorder cases presenting at A&E departments. Headache is the most common neurological reason for A&E attendance and presents significant avoidable costs to the NHS. We heard that approximately 20% of headache patients seen in neurology clinics have attended A&E in the previous 6 months, 10% of whom are admitted.<sup>20</sup> There were 19,144 finished emergency admissions for migraine and headache disorders in England in 2012/13. This is a 12% increase in admissions from 2010/11.<sup>21</sup> Within some CCG areas the increase in emergency admissions was as much as 70-80% in the 3 year period.<sup>22</sup>

### Migraine in the South West:

*Neurological Commissioning Support (NCS) South West neurological services scoping report found that:*

*There are an estimated 673,265 people living with migraine in the South West. Approximately 74,347 people have chronic migraine in the region. Migraine is in the top 10 highest non-elective admission costs for neurology for CCGs in the South West. The total admissions (primary and secondary diagnosis) for migraine have increased by 37% across the Southwest over the last three years from 1,832 in 2009/10 to 2,887 in 2011/12. The costs have also increased from £1,794,381 to £2,991,158. The most common neurological co-morbidity where migraine was the secondary diagnosis) was for headache costing £94,923.<sup>23</sup>*

*In written evidence to the inquiry, NCS concluded that the findings of the South West scoping report depict a national problem, based on their findings in other SCNs.*

Data from the Hospital Episode Statistics show that most admitted headache patients do not undergo coded procedures. Where procedures are carried out, the most common is a diagnostic imaging of the central nervous system. Emergency admissions account for over 80% of all hospital admissions for migraine and headache disorders.<sup>24</sup>

Health professionals at the oral evidence sessions explained that the high presentation of headache at A&E is symptomatic of the poor service and lack of support that patients have access to elsewhere in the NHS. Dr Rachael Kilner described the high A&E figures as ‘a cry for help’<sup>25</sup> from headache patients.

## The Social and Economic Cost of Headache Disorders

The evidence from across the spectrum of witnesses highlighted the substantial economic social and personal burden of headache disorders on the community. We heard that they can be the cause of significant disability both during and in between attacks. Around 83,000 headache patients will miss work or school every day, equal to 20 million lost days of productivity per year.<sup>26</sup>

# Understanding The Cost Of Headache Disorders

---

Headache Disorders are most prevalent amongst adults of working age and subsequently place a huge financial burden on the economy. Primary headache disorders cost the UK economy an estimated at £5-7 billion a year, mostly through loss of productivity.<sup>27</sup> Absenteeism from migraine alone costs £2.25 billion, calculated on the basis of 25 million lost days,<sup>28</sup> and is the second highest reason for short-term sickness absence amongst non manual employees.<sup>29</sup>

The evidence stressed the enormous personal costs to primary headache disorder patients as a result of pain, disability, reduced quality of life, economic inactivity and associated financial losses. Adults with headache disorders have lower quality of life scores than the general population.<sup>30</sup> We heard that misdiagnosis, incorrect treatment, and long waiting lists to see consultants exacerbate the burden of headache disorders for sufferers.

Patients who wrote to us told us that they incur additional healthcare related costs through travelling long distances to specialist headache services and accessing treatment that they were unable to access on the NHS, e.g. acupuncture, physiotherapy and Botox treatment for chronic migraine.

*Quicker and more accurate diagnosis and treatment would have saved me years of worry and stress and meant that I could have started living my life again. I may even have had my first child by now...I would also have been spared watching the stress my husband and family have been put through; not knowing what was wrong with me and the toll my condition has taken on my relationships and self-confidence. I would also have saved close to £1000 in private medical fees and wasted prescription charges.*

*Primary headache disorder sufferer (written evidence)*

Headache disorder patients and patient groups emphasised the debilitating impact of headache disorders on sufferers' well-being. They described an inability to take part in social and family lives, depression, and low self-esteem as a result of the conditions. OUCH UK told us that that suicide can sadly be the consequence of failing to diagnose and treat cluster headache properly.

## The Current Provision of Headache Services

Witnesses at the oral evidence sessions told us that the current NHS resource allocation is insufficient in relation to the scale of the problem that headache disorders present to the NHS, the economy, and society.<sup>31</sup>

We heard that there is a huge disparity between CCGs and regions with regard to the existence and standard of headache services. Specialist health professionals told us that there are a limited number of dedicated headache clinics in England, run either by neurologists with a special interest in headache or specialist GPs. Access to specialist headache services is therefore inconsistent, and varies from excellent to non-existent depending on the patient's proximity to a specialist centre and what access the primary care doctor has to seek further input.<sup>32</sup>

---

*Despite the high prevalence of recurrent headache disorders [we] would suggest that there are considerable variations across [England] in the nature, scope, organisation, quantity and quality of medical care provided for headache. At the same time there is good evidence already submitted in terms of research to suggest that optimal care is rarely achieved... We receive over 150 calls a month to our helpline suggesting that [this] is the normal experience of our members. They are often unable to secure the correct management at primary care level.*

**Migraine Action** (written evidence)

The patients who submitted evidence were unsatisfied with all or part of the services they received from the NHS. Of repeated concern were high waiting lists for secondary care services and the distances that patients were required to travel to see specialists.

*I strongly believe that more services have to be provided locally. It is a disgrace that something so common and so disabling is only treated by specialist services within hospitals in major cities. [Long distance travel to see a consultant] is both physically and financially difficult.*

**Primary headache disorder sufferer** (written evidence)

Witnesses at the oral evidence sessions concluded that the regional disparities in terms of access to good quality headache services means that value for money to the NHS varies accordingly. It was noted that the difficulties in understanding value for money were compounded by the fact that performance in neurology is not well understood due to a lack of data to measure and compare outcomes.

## **CONCLUSION**

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.

# Diagnosis and Treatment Concerns

---

Evidence from specialist health professionals indicated that for care to be effective patients must be provided with the appropriate support and treatment to control their headaches and to manage associated factors which may be exacerbating the condition.

*In any patient with headache the principles of management should be to*

- *Give the patient time to express their concerns*
- *Listen to the patient*
- *Adopt a holistic approach to care*
- *Involve the patient in the decision making process*
- *Optimise the acute treatment*
- *Minimise headache frequency*
- *Support the patient until they feel in control*

**Dr Manuela Fontebasso, GPwSI (Oral Evidence)**

Health professionals told us that appropriate treatment of headache disorders requires professional training of health professionals, accurate diagnosis, and recognition of the condition, appropriate treatment with cost-effective medications, simple lifestyle modifications, and patient education. The inquiry heard that early diagnosis and effective management prevents chronicity of primary headache disorders.

A number of witnesses noted that the treatment and management of headache disorders are compromised. This was attributed to funding and service restraints, the dearth of health professionals with a special interest in headache, poor patient pathways, and poor headache knowledge amongst non specialist health professionals. Cluster headache specialists raised strong concerns. They told us that only 20% of sufferers have been correctly diagnosed and, of these, only 50% are receiving the British National Formulary recommended treatments (see Appendix 2).

Patient groups, charities, and stakeholder groups reported concerns of significant rates of misdiagnosis and subsequent mismanagement of headache disorders in primary care.

*Correct and speedy diagnosis of cluster headache as a disorder is vital. Evidence, coupled with medication usage for cluster headache patients, suggests that less than 10% of all sufferers in England are being prescribed the correct acute medication. This is also probably the case for preventative treatment too. Consequently more than 90% of cluster headache patients are sent unnecessarily to consultants and other medical professionals. This of course extends waiting times, in some cases more than a year, and together with the possible likelihood of incorrect medication being prescribed, results in huge costs of unnecessary highly specialised treatment over an extended period of time.*

**Mike Pollock, Chairman, OUCH UK (oral evidence)**

Although the NICE headache guideline and quality standards were praised, witnesses at the first oral evidence session told us that they had seen little improvement since their publication. We also heard that patients faced barriers in accessing specific treatments and therapies referred to in the guidance.

---

## **CONCLUSION**

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.

# Underpinning Cost-Effective Headache Services

---

The evidence highlighted 4 key factors to be addressed to underpin the commissioning of high quality and cost-effective headache services:

1. Public Awareness of Primary Headache Disorders
2. Education of Health Professionals on Primary Headache Disorders
3. Prioritisation of Primary Headache Disorders
4. NHS Data Collection

## **I. Public Awareness of Primary Headache Disorders**

The evidence concluded that there is a lack of public awareness about primary headache disorders, their impact, and good headache management. There is little education on some of the most challenging conditions like medication overuse, chronic migraine, and cluster headache. Patient submissions highlighted a lack of public information and avenues for support. Consequently we heard that 23% of people rely principally on family and friends for advice about headache.<sup>33</sup> Health professionals told us that the lack of public awareness places pressure on primary care and means that that it is unlikely that the true burden of headache on society is being addressed.

The evidence highlighted 3 areas of concern as a result of poor public awareness:

- i.** A significant number of sufferers do not access primary care support for their headache disorders. Less than 50% of migraine patients consult a physician and migraine remains undiagnosed and undertreated in at least 50% of patients.<sup>34</sup> Whilst the impact of headache will not require professional support in all cases, it is important that sufferers are aware of how to access information on correct headache management. Those that do require specialist attention must be aware of and able to access appropriate services.
- ii.** A lack of public information and awareness about headache and headache self-management contributes to patients misusing services, e.g. repeated GP appointments, demands for scanning, and presenting to A&E. This can occur when patients feel they are not getting good advice or support from their GP, are unsure how to self-manage, or if they have increased anxiety concerning their headache. This places a costly demand on overstretched NHS services, and leads to poor patient experience.
- iii.** A lack of quality information and awareness can result in poor self management of headache. This occurs when sufferers do not consult a GP or do not return for follow up appointments, meaning that management and treatment cannot be adequately monitored and assessed. Medication overuse headache as a result of incorrect self-management is common and can lead to ongoing complications that place a demand on primary and secondary care services.\*

---

*The majority of adult migraineurs have never consulted their general practitioner despite high levels of disability. Of those who do consult, most only have a single consultation, and of those with headache rated as severe, only 22% present to their GP for follow up in a twelve month period, limiting opportunities for review of symptoms and appropriate management<sup>35</sup>... Many headache sufferers may be unaware that their headache has a formal diagnosis and treatment options. For example, only 53% of those with International Headache Society defined migraine consider their headaches to be migraine.<sup>36</sup> Increasing an awareness of the existence of primary headache disorders and the fact that there are effective management interventions is an important first step.*

**The British Association for the Study of Headache** (written evidence)

Witnesses were encouraged by the long-term NHS cost savings and improved burden of disease that greater public awareness could bring about.

*We must target the general public with better [headache] health awareness campaigns and increased recognition of headache disorders and general lifestyle management that would significantly improve many people's health without needing to resort to expensive therapies.*

**Dr Nicholas Silver, Consultant Neurologist** (written evidence)

We heard that migraine and headache charities already hold a wealth of information that is not accessed enough by sufferers and health professionals to inform and educate patients; they told us that they are under resourced to adequately meet the demands of the cohort of sufferers across the country, and receive no government support.

## **SUB-CONCLUSION**

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.

---

\*The International Headache Society classifies medication overuse headache as headache present on 15 days of the month or more as a result of regular overuse for more than 3 months of one or more drugs that can be taken for acute and/or symptomatic treatment of headache. Medication overuse headache is a secondary headache disorder

# Underpinning Cost-Effective Headache Services

---

## 2. Education of Health Professionals

We heard that the level of headache education and knowledge amongst non specialist health care professionals at all levels of the system is inadequate. The APPG heard that the minimum level of headache teaching in the curriculum for medical students is insufficient to address the prevalence and demand of headache on NHS services.

*Headache teaching is not on the curriculum for approximately 75% of the undergraduate medical schools in England. Only 1 in 27 include a headache question in exams. The rest of the medical schools do not appear to include any lectures on headaches. This is mainly due to the lack of headache specialists who could teach students headaches classification and pathophysiology.*

*Post-graduate training appears to be strong in teaching hospitals running a headache clinic, but a lot also depends on individual doctors wishing to take training. This varies across the country.*

**Dr Anna Andreou, Research Fellow** (written evidence)

Witnesses attributed this to the lack of headache specialists who could teach students headache classification and pathophysiology and a lack of recognition and motivation to address the burden of headache disorders by the Department of Health and the Department of Education. At the second oral evidence session witnesses stressed that the lack of prioritisation of headache in undergraduate curriculum fails to encourage graduates to specialise in the field of headache. This impedes development in this area of healthcare.

Patients told us that seeing a well informed practitioner improves their overall experience and can limit the impact headache has on their personal and working lives. However, a high number of patient submissions described experiences of poor knowledge, understanding, interest or respect for primary headache disorders amongst GPs. The evidence revealed that this was a problem across the country; levels of satisfaction varied by the understanding of the particular GP rather than the geographical location. Patients cited reduced quality of life, inability to work, misdiagnosis, lengthy diagnoses and incorrect treatments as consequences of unsatisfactory GP experiences.

*The response of the NHS practitioners has been disappointing [not a single practitioner told me that prolonged taking of this medication may lead to rebound headaches]... The lack of understanding of what I have been going through from some doctors has contributed to the feelings of alienation and hopelessness.*

**Chronic Migraine Sufferer** (written evidence)

Patients told us that in the absence of well informed primary care practitioners they relied on information from charities and patient groups to inform treatment, management, and help them to determine their own care pathway. Some noted that information gathered from charities and patient groups had guided them and their GP to take decisions on their care in the absence of existing knowledge of treatment and referral options.

Health Professionals with a special interest in headache told the inquiry that the poor education and understanding of non specialist GPs undermined the implementation of the NICE headache guideline since this remains open to professionals' interpretation.

---

The evidence stressed that improving headache education for GPs is vital since the majority, 97%, of headache cases will be treated entirely by the GP.<sup>37</sup> Therefore educating all medical students and GPs should be a priority. However, the need also stretches to health professionals from a number of disciplines including district neurologists, nurses, pharmacists, pain specialists, physiotherapists, and dentists who are likely to provide clinical support to the vast numbers of sufferers.

*Healthcare professionals do not have enough training and education on headache disorders and feel helpless when it comes to dealing with common headaches. The patient, therefore, feels passed on from pillar to post to seek appropriate advice on how they should live with the problem that controls their lives. It is estimated that only 20% of patients suffer from chronic migraine and similar percentage for cluster headache receive the right diagnosis. There is lack of undergraduate education in headache disorders and most of the post-graduate education is driven by the pharmaceutical industry.*

**Dr Fayyaz Ahmed, Consultant Neurologist** (written evidence)

We also heard that improving the training of dentists in recognising primary headache disorder symptoms will help to improve the identification and suitable referral pathways for trigeminal neuralgia and facial pain sufferers.

*Medical and dental training in this area is widely different and hence primary care practitioners will vary in their ability to diagnosis, manage and appropriately refer headache disorder patients. Some healthcare professionals, especially dentists are even reluctant to come for training as it does not improve their income. Teaching in pain and headaches is woefully inadequate at undergraduate level throughout the country. Evidence based guidelines are not followed. Education needs to start at medical and dental schools and it needs to be integrated with other training in order to prevent overload. Re-validation should ensure that continuing medical education in pain at a certain level is mandatory especially for GPs and dentists.*

**Professor Joanna Zakrzewska, Facial Pain Consultant** (oral evidence)

## **SUB-CONCLUSION**

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.

# Underpinning Cost-Effective Headache Services

---

## 3. Prioritising Headache Disorders

Historically headache disorders have not been prioritised within the NHS and the APPGPHD has explored the consequences of this under the old NHS system in previous meetings and publications.<sup>38</sup> Witnesses shared the view that progress to improve the provision of cost-effective headache services across England continues to be minimal and slow. The lack of understanding and prioritisation of the true cost and impact of headache disorders was cited as a fundamental barrier to addressing the current national inconsistencies in service provision and the commissioning of high quality cost-effective service models.

*Currently headache services do not represent good value for money. This is a similar situation to services for other neurological conditions. The problem is that CCGs typically do not understand their performance in neurology because long term neurological conditions like headache have never been a priority in the NHS. This is despite the numbers of people who have these conditions. Typically people with neurological conditions frequently access health services as a result of an emergency which escalates costs. This opinion is validated by the National Audit Office (NAO 2011)*

**Neurological Commissioning Support** (written evidence)

Witnesses welcomed the positive changes that are being implemented to enhance services for people with neurological conditions in response to the 2012 Public Accounts Committee report. Most notably the appointment of the National Clinical Director for Neurology and the establishment of a SCN for mental health, dementia and neurological conditions were expected to improve outcomes for headache patients.

Witnesses warned that there is little emphasis on headache within NHS neurology priorities. As a result CCGs were not being made to realise the benefits of investing in headache services to improve patient outcomes and free up capacity in neurology and overstretched A&E services. Evidence from commissioners and providers recognised that SCNs offer the opportunity to bring about major improvements in the way headache services are provided in England but the challenge facing them is vast.

*Within the Thames Valley region headache was a principal reason for outpatient referral and outpatient attendance, and was a major cause of disability. There was no way of measuring outpatient outcomes for headache patients, and coding for outpatients needed to be implemented as a top priority. However there was focus within CCGs on reducing emergency admissions and pressure on A&E departments... CCGs needed to be made to realise the benefits of investing in headache services which would free up emergency capacity.*

**Dr Zameel Cader, Clinical Director, Thames Valley SCN** (oral evidence)

Discussions at the oral evidence sessions highlighted that the 'voice of headache patients' is lost within the wide spectrum of competing neurology priorities and must be better represented nationally and locally. We heard from witnesses that the 'headache community' of patients, stakeholders and practitioners need to come together to influence change through local and national platforms. In particular, witnesses stressed the need for patients to come forward and demand improved, and more effective services if they are unhappy with the provision in their area.

---

*Patients should engage with their SCN in order to influence change in their locality. SCNs are committed to listening to patients... The needs of headache patients needs to be better represented; the voice of patients and third sector organisations is not coming through and is currently 'crowded out' by the needs of [other neurological] patients.*

**Dr Zameel Cader, Clinical Director, Thames Valley SCN (oral evidence)**

There was a collective agreement amongst the witnesses at both oral evidence sessions that there must be a strong motive to change the current status quo and begin prioritising headache disorders. Witnesses stressed that this requires political leadership as well as direction from the National Clinical Director for Neurology to have the greatest effect.

### **Incentivising Commissioners**

The witnesses at the oral evidence sessions warned that CCGs are failing to address the provision of headache services as their focus is aimed at reducing direct costs in times of austerity. We heard that savings made from improved headache care yielded stronger indirect cost savings and as such were being overlooked by CCGs.

In his presentation to the oral evidence session, Dr Zameel Cader noted that addressing the burden of headache and improving patient outcomes falls under Domain 2 of the NHS Outcomes Framework, 'enhancing quality of life for people with long term conditions'. He stressed that CCGs must recognise headache as a long term condition and prioritise quality improvements to services accordingly. However it was noted that, in the absence of defined headache indicators within the framework and a recognition of the burden of headache, this was a challenge\*\*.

### **SUB-CONCLUSION**

Currently, headache disorders are not prioritised within the NHS. Despite their prevalence and impact, headache disorders are at the 'bottom of the pile'<sup>39</sup> 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.

---

\*\*The NHS Outcomes Framework sets out the outcomes and corresponding indicators used to hold NHS England to account for improvements in health outcomes. It is fundamental to guiding CCGs priorities and informing the CCG Outcomes Indicator Set.

# Underpinning Cost-Effective Headache Services

---

## 4. Data Collection

Historically there has been no national dataset for neurology. Commissioners, providers and stakeholders emphasised the significant barrier that the lack of data has presented to commissioning high quality, cost-effective headache services. Evidence drew attention to the concerns from the neurological community that, unlike other condition types, national data on incidence, service provision, and patient outcomes relating to neurology has not been routinely collated, published, or analysed by the Department of Health.

*Without the necessary data to establish a baseline measure of performance in neurology it has been very difficult to understand and commission the types of activities that result in the best outcomes.*

**The Neurological Alliance<sup>40</sup>**

The APPGPHD welcomed the update that since the call for evidence closed NHS England published the first ever neurological dataset, in March 2014. This followed the recommendation in the 2012 Public Accounts Committee Report.

*The intelligence available from the comprehensive neurology dataset will enable the cost-effectiveness and cost impact of headache services to be reliably evaluated.*

*In its initial stages this 'skeleton' dataset provides top line statistics and information for which neurology services can measure performance. It will still take some time for the dataset to capture information that can meaningfully influence performance in headache services. For example, data collection must capture the multiple platforms in primary and secondary care that headache patients access support. It must record patients' functional status and disease burden on discharge from neurology or intermediate headache services to assess the effectiveness of the intervention, and it must include metrics to measure patient experience of care. Indicators in the dataset should be measurable against NICE guidelines and quality standards for improvements to be assessed over the long-term.*

*The new dataset should be supported by headache specific research to support the data, measuring patient experience and access to quality headache services. The findings should influence medical research funding and be available for research purposes. The headache community are instrumental in supporting the development of such information to support the ongoing review and monitoring of the neurological dataset as it applies to headache disorders.*

**The Migraine Trust (additional written evidence)**

Witnesses agreed that the stakeholders and charities representing specific headache disorders should contribute to the development of the dataset indicators and supporting data capture to ensure that it measures meaningful intelligence for the planning and commissioning of cost-effective headache services within the competing priorities of neurology.

---

## **SUB-CONCLUSION**

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 Disorders In Primary Care

---

Health Professionals and commissioners that wrote to us noted the importance of providing sufficient resources to strengthen the delivery of headache care at primary care level. We heard that primary care provides the first point of entry into the system for most headache patients, and for the majority this will be via their GP. We heard that 97% of headache cases are managed wholly by GPs.<sup>41</sup> Commissioners, health care providers and stakeholder organisations drew upon existing evidence to demonstrate that the majority of headache patients can, and should, be treated in primary care.<sup>42</sup> <sup>43 44</sup> Submissions to the inquiry from commissioners and providers emphasised that primary care management of headache disorder can provide the best value for money and that this is where the biggest opportunities for addressing the burden of headache on the NHS exist.

*The common headache disorders require no special investigation and are manageable with skills generally available in this setting which is more appropriate to address not only co-morbidities but the complex psychosocial factors that are often an important factor in the pathogenesis of headache.*

**The British Association for the Study of Headache, BASH** (written evidence)

Witnesses raised concerns that the diagnosis and management of headache disorders by GPs is on the whole, inadequate and inconsistent. The evidence revealed that despite the NICE headache guideline and quality standards GPs remained ill equipped, both in terms of their knowledge, interest, and adequate pathways, to confidently address many of the cases that should be managed within primary care.

Witnesses to the inquiry explained that failure by GPs to identify and address the needs of headache patients was costly and ineffective, resulting in a greater burden placed elsewhere within the system. Patients told the inquiry that this could severely impact on their experience and confidence that their symptoms were being effectively recognised and treated.

*GPs need to be more alert to migraine and its causes and less grudging about getting proper diagnosis and treatment... A recurring condition will result in numerous trips to the doctor if it isn't properly dealt with. Just being sent off with a pat on the head and a prescription which may or may not work does not acknowledge the condition or the patient's distress. [Migraine] really did ruin my life and yet I hardly had any acknowledgement of this from the medical professional... Some investment early on would save constant draining of NHS GP time*

**Primary Headache Disorder Sufferer** (written evidence)

## Facilitating Good Self-Care Outside of Clinical Settings

We heard that the provision of quality information and support for good headache self-management will improve health outcomes for patients. It may lead to a reduction in the need for repeat clinical appointments for the majority of properly diagnosed migraine and tension type headache cases. Witnesses stressed that the provision of self-management support should be provided at the earliest opportunity, this may be before sufferers reach their GP e.g. via pharmacists, media messages, charities etc.

---

We heard that pharmacists have a potentially larger role to play in facilitating good self-care amongst headache sufferers, raising awareness of primary headache disorders and medication overuse headache. Dr Brendan Davies, Consultant Neurologist, presented evidence to the inquiry that 10% of sufferers will seek advice from their pharmacists for headache disorders first.<sup>45</sup>

Commissioners, providers, and charities put forward suggestions and examples to the inquiry of effective self-management support for patients outside of clinical settings. These approaches relied on the provision of high quality information and remote communication methods from knowledgeable health professionals, such as email and phone support from GPs, and specialist nurses to reduce the number of clinical appointments.

A number of providers noted that innovative approaches that can demonstrate cost-effectiveness and a reduction in clinical appointments without compromising patient care should be welcomed and encouraged by CCGs. Some witnesses recognised that the third sector can play a valuable role in the design and delivery of these approaches, but noted that they needed support to compete as a provider.

The National Migraine Centre told us that charities with innovative models of delivery were disadvantaged from competing as a willing provider due to funding and CCG budget restraints. They reported that the NHS is funding innovative models of service developments in other health areas. However they have so far experienced reluctance to prioritise such approaches to headache from NHS England. They told us that:

*There is a lack of funding for third sector organisations to develop new models of care which would greatly assist the NHS...Our proposed 'telehealth' model has had significant interest from CCGs but budget restrictions in these areas have meant that no group has yet commissioned the model...Partnerships with third sector organisations such as The National Migraine Centre to deliver care would have benefits for the NHS in terms of value for money and quality outcomes however staff in CCGs are under considerable pressure and have no knowledge of how helpful these could be.*

*The National Migraine Centre (written evidence)*

## **Incentivising GPs**

Witnesses at the oral evidence sessions stressed that poor diagnosis and mismanagement of headache disorders at primary care level will not improve until headache becomes a priority for GPs. Despite its prevalence there are no headache indicators in the Quality and Outcomes Framework (QOF). Discussions at the first oral evidence sessions concluded that GPs should be motivated to drive forward the standard of care for headache patients.

It was agreed by witnesses that the QOF provides a good platform to drive forward consistent standards of support for headache patients in primary care. Witnesses noted that messages and incentives about headache care should focus on timely and accurate diagnosis and treatment management plans in primary care. Until such indicators are included in the QOF, a number of witnesses noted that consistent improvements in care would not be optimised.

# Headache Disorders in Primary Care

---

## **CONCLUSION**

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 a Special Interest In Headache Services

---

The GP with a Special Interest (GPwSI) model<sup>\*\*\*</sup> was heavily recommended as a cost-effective solution to improving the delivery of headache care in both the written and oral evidence submissions.

Witnesses outlined that GPwSIs provide intermediate care and supports GP colleagues who continue to provide first-line headache care.<sup>46</sup> GPwSIs can act as the first line of referral for GPs referring headache patients. Witnesses explained that specialist GPs can risk stratify headache disorder patients so that those that really need a secondary care opinion are referred appropriately. In turn they will provide support and increase the knowledge of GP colleagues in diagnosis, management and the use of scans. Local stakeholders must define pathways of care depending on local circumstances and expertise.

The benefits of this model, outlined by the Royal College of General Practitioners<sup>47</sup>, and explored in detail by health professionals at the oral evidence sessions include:

- reduced costs and unnecessary secondary care referrals, helping divert referrals to a service provided by the GPwSI or extended scope practitioners
- improved skills and facilitation of more effective management of patients in primary care, using the GPwSI's insight into general practice and their specialty to disseminate education and training
- improved clinical services for patients by reducing delays, improving access, and keeping care closer to home
- enhanced patient care by managing the condition at a specialist level, but also taking a holistic approach to co-existing multi-morbidities.

Professor Leone Ridsdale presented in-depth evidence on the need and benefits of adopting a GPwSI model for managing primary headache disorder patients. We heard that GPwSIs diagnosed migraine in patients 3 times more frequently than non-specialist GPs.<sup>43</sup> Dr Ridsdale noted that services provided by GPwSIs were, in relative terms, slightly cheaper than non-specialist neurologists. GPwSI services have been found to satisfy patients with similar headache impact as those seen in secondary care at lower cost.<sup>48</sup> Reducing A&E attendances and the demand for neuroscanning in secondary care were highlighted as attractive consequences of commissioning the model.

This was supported by witnesses at the second oral evidence session:

*Repeat GP visits from patients represents a waste of resources. An opportunity exists for GPs with a Special Interest to remove some of the burden from routine GP practices. Employing a higher number of GPwSIs could also reduce A&E attendance. Efforts should be made to build on existing headache centres in order to provide better resources for GPwSIs.*

**Professor Peter Goadsby, Professor of Neurology** (oral evidence)

---

<sup>\*\*\*</sup>A GP with a special interest in headache supplements their role as a general practitioner by providing an additional specialist headache service while still working in the community.

# GP with a Special Interest In Headache Services

---

It was clear from the submissions that the model has support from the headache community and professional groups alike. Its suitability has recently been endorsed by the Royal College of Physicians and the Association of British Neurologists.

*The [Royal College of General Practitioners] supports the [GPwSI] model proposed by The British Association for the Study of Headache whereby intermediate care headache clinics staffed by general practitioners with a special interest in headache support GP colleagues who continue to provide first-line headache care. The college also emphasises the importance of adequate training in the area of headache at an undergraduate and post graduate level.*

**The Royal College of General Practitioners** (written evidence)

Evidence from patients indicated that timely access to a local specialist was important.

*My GP referred me on [to a neurologist] very quickly. However he has not [got] the knowledge to help [me] understand what migraine is or how/why it occurs... [Access to] someone in the practice who is well informed about diagnosis and treatment option will provide a greater sense of trust that things may not be as serious as they might have otherwise thought. They also would get treatment more quickly which has to have a beneficial effect on quality of life.*

**Primary Headache Disorder Patient** (written evidence)

Some providers that wrote to us about GPwSI services had found that patients reported greater satisfaction with their treatment than those treated by non-specialist neurologists. Professor Leone Ridsdale and Dr Manuela Fontebasso both highlighted the benefits of the holistic approach that GPwSIs were able to take in improving patient experience of care in their presentations to the inquiry.

Evidence from specialist headache professionals emphasised that GPwSIs would require training and support from neurologists with a special interest in headache. The model is therefore reliant upon interested health practitioners and the availability of specialist neurologist support its delivery.

A number of the CCG representatives that wrote to us recognised that an ideal model of healthcare for primary headache disorder patients should include local access to non-consultant specialist clinics within primary care. It was encouraging to hear that the commissioning of cost-effective approaches were being explored and implemented. However witnesses warned that GPwSI models exist sporadically across the country, reiterating the regional variations in access to specialist care for patients and cost-efficiency for the NHS.

Concerns were raised by commissioners and providers regarding the ongoing funding for GPwSI services and the evidence reported that existing services were being stopped due to budget cuts. Concerns of the CCGs that GPwSI actually increased the demand were also highlighted.

A number of the witnesses noted that evidence for the model is limited but that this remained the most appropriate and cost-effective solution to addressing the burden of primary headache disorders.

---

*[T]he difficulties in obtaining a rigorous and generalisable evidence base to address these questions are well recognised.<sup>49 50</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>51</sup>... This model is likely to be attractive for headache commissioners. Approximately 30% of secondary care neurology referrals are for primary headache and the available evidence suggests that this need can be addressed more cost-effectively by general practitioners with a special interest.*

**The British Association for the Study of Headache BASH** (written evidence)

## **CONCLUSION**

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.

# Patient Pathways

---

The evidence stressed the importance of GPs' ability to refer complex cases to the appropriate services promptly. This relies on clearly defined and implemented local headache pathways. Witnesses at both oral evidence sessions noted that clearly defined pathways play a vital role in securing accurate and timely diagnosis and access to appropriate treatment. Witnesses raised concerns that such pathways were not in place across the country or were poor.

*There are no treatment pathways [for trigeminal neuralgia patients] and it is a struggle to get information from healthcare professionals. I would have been lost without TNA UK.*

**Jillie Abbott, Trigeminal Neuralgia patient** (oral evidence)

As well as poor quality care, witnesses highlighted that poor patient pathways waste NHS resources.

*A recently published review of patients attending oral surgery in Newcastle<sup>52</sup> shows that [trigeminal neuralgia] patients have been through multiple referrals including attendance at A&E and this is the same at UCLH. At UCLH 44% of patients have already been to a secondary care provider, one third are referred by dentists. Informed patients, including often patients who join a support group, will determine their own care pathway which can lead to extensive travel for the patient but potentially improved care.*

**Professor Joanna Zakrzewska, Consultant and Head of Facial Pain Unit** (written evidence)

The charities representing sufferers stressed that patients are essential in defining these pathways and their voice must be recognised. They identified that pathways will vary locally but must be guided by the NICE headache guideline and other available evidence based guidance.

We heard that well established pathways with access to the necessary resources in primary and secondary care will better support GPs to manage headache disorder patients. Some witnesses suggested a fast-tracking referral process for those in extreme pain or distress as a result of their condition. These pathways play a vital role in preventing avoidable and costly emergency admissions, inappropriate referrals and ensuring effective headache management within the SCN.

*Equity of provision needs to be established with an explicit integrated headache care pathway in place within each SCN so that both professionals and patients understand sources of referral and support.*

**Sue Thomas, Chief Executive, Neurological Commissioning Support** (written evidence)

---

## **CONCLUSION**

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.

# Escalation to Secondary Care Services

---

## Referrals to Neurology

We heard that headache accounts for 33% of all neurology referrals.<sup>53</sup> Witnesses stressed that the number of incorrectly triaged cases referred from primary to secondary care neurology services diverts costly resources away from more complicated neurological conditions requiring specialist attention.

*The symptom usually does not represent serious pathology but can on occasion do so e.g. brain tumour, this raises anxiety amongst both clinician and patients. We need to support primary care to manage this cohort of patients better rather than constructing a system that requires escalation to secondary care before appropriate interventions have been undertaken in GP practices.*

**GP & Clinical Accountable Officer for North Staffs CCG** (written evidence)

Patients told us that they found it difficult to get a referral to an appropriate service to see a consultant. They blamed a lack of communication amongst health professionals and a lack of joined up services. Patients told us that they face long waiting lists and a lack of accessible local services depending on their location in the country.

We heard that patients, unhappy with the support received from their GPs, will request referrals to see a 'specialist' for their headache disorder. Witnesses at the second oral evidence session discussed the importance of 'redefining' patients' perspective of 'specialists' in headache. They explained that patients need to be made more confident in the skills of health professionals in primary care to diagnose and manage headache disorder. This will require investment into specialist primary care services and greater GP education.

## General Neurology

Specialist health professionals and headache charities told us that education and interest among general neurology is poor and, as such, fails to deliver a cost-effective solution to improving care for headache disorder patients. 30% of patients are unhappy with the service they received in general neurology<sup>54</sup>.

We heard that because the emphasis in general neurology is typically focused on excluding serious underlying causes e.g. a brain tumour; patients are typically discharged back to their GP without suitable diagnosis or ongoing treatment plan.

Witnesses warned that this is not a cost-effective approach and does not address the ongoing and holistic needs of the headache patient. The health providers that submitted evidence told us that the emphasis should shift onto correctly diagnosing the headaches that require secondary care and on ensuring adequate primary care for those which do not. Complex cases that require specialist consultation should instead be referred to the appropriate consultant with a special interest in headache, or facial pain consultant for trigeminal neuralgia cases.

---

## Scanning

Commissioners and providers noted that the high number of headache related referrals to secondary care services for scanning presents an expensive problem to the NHS and does not present a cost-effective approach to managing the vast majority of headache disorder patients.

Evidence presented at the first oral evidence sessions echoed existing research that the major reasons patients were referred for scanning was because they reported other symptoms which they related to their headache, or because they were suffering anxiety about their headache symptoms.<sup>55</sup> Evidence from specialist headache consultants explained that the request for scanning is to rule out severe underlying causes, although less than 1 in 1000 patients consulting a GP for headache would be found to have a brain tumour.<sup>56</sup> The NICE headache guideline noted that NICE concluded that a reduction in referrals for neuroimaging scans and associated follow up appointments will lead to cost savings for commissioners. However, the inquiry heard that the demand for referrals is not reducing.

The recently published neurology dataset reported that a third of all CT scans are for inpatients with a diagnosis mention of a neurological condition with 1,104,310 imaging events (of all imaging events 3,348,650). According to the NICE Headache Costing Report the unit cost of direct access computerised tomography (CT) scan is £87 and that of a magnetic resonance imaging (MRI) scan<sup>2</sup> is £153.<sup>57</sup>

Evidence to the inquiry suggests that there is support from the headache community for training GPs and GPwSIs in the appropriate use of scans, which could lead to a reduction in secondary care referrals. We heard that Primary Care provides a suitable setting to address holistic support required for health anxiety surrounding headache. However without better support in primary care to manage both the headache and the health anxiety, witnesses told us that this is unlikely to reduce referral to secondary care.

Health professionals told us that patients' expectations need to be better managed. There should be greater public awareness amongst patients about headache to prioritise diagnosis and management plans rather than just ruling out severe underlying causes. We heard that this requires greater patient confidence in the ability of their GP to understand and manage primary headache disorders.

# Escalation to Secondary Care Services

---

## **CONCLUSION**

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.

# Specialist Hospital Based Clinics

---

We heard that there is a lack of neurologists with a special interest in headache in England. As such the provision of specialist clinics for headache disorders is inconsistent across the country resulting in unequivocal access for patients whose symptoms necessitate specialist care. The patient respondents to the inquiry who were most satisfied with their experience of secondary and tertiary services lived in close proximity to a specialist headache clinic.

There are approximately 37 consultant neurologist-led headache clinics in England which are unevenly distributed across the country. A number of witnesses raised access issues for patients living away from London.

*There is an uneven geographical spread of specialist headache clinics in England. This means that patients across the country do not have equal access to specialist advice and treatment. Due to the nature of their condition they may not be able to travel to clinics easily and this can have implications for work and finances. There are often long waiting lists to see consultants and the clinics are overstretched and cannot meet the high demand of patients. There are too few doctors specialising in headache to meet the need in England. This is attributable to too little headache education and awareness in undergraduate training, a lack of research funding and a lack of high impact journals choosing to publish papers on headache.*

**Wendy Thomas, Chief Executive, The Migraine Trust** (oral evidence)

A number of the evidence submissions stressed that more specialist centres are required to deal with refractory headache disorders, especially with the emergence of new treatments for headache disorders, which require specialist management.

*The provision of specialist headache clinics in secondary care in the UK is particularly poor. There are only a small number of clinics with an uneven geographic distribution. Few of these clinics have specialist nurse support. Tertiary care is basically the clinic at the Institute of Neurology, London. Whilst they have a good reputation, more tertiary centres should be opened to provide better geographic cover. Also, funding for tertiary treatment is difficult and long winded to obtain, further slowing patient care.*

*New secondary care headache services need to be developed with an appropriate geographic spread. These clinics will see patients previously seen in other general neurology clinics, so there will not be an expansion, just rationalisation and specialisation of services. New tertiary headache centres should be supported in strategic locations to compliment the existing London service. Two new locations should be sufficient in the Midlands and the north of England.*

**Professor Carl E Clarke, Professor of Clinical Neurology** (written evidence)

# Specialist Hospital Based Clinics

---

## **CONCLUSION**

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

---

We heard that specialist nurses can make a huge difference in reducing the burden placed on other health care professionals. Witnesses noted that specialist headache nurses provide a cost-effective solution to delivering better headache patient outcomes.

Witnesses noted concerns that, despite the evidenced clinical and cost efficacy of specialist nurses<sup>58</sup>, few general neurology or specialist headache clinics in England have specialist nurse support. At the time of writing there are only 11-13 trained headache specialist nurses in England; witnesses agreed that this figure is wholly inadequate.

We heard that headache nurses can offer high quality, patient centred, and cost-effective care to reduce the burden on neurology. Patient education is at the core of the headache specialist nurse role, equipping patients with the information and support they require to understand and manage their condition.<sup>59</sup> Follow up appointments and telephone clinics with specialist nurses offer patients individualised support to implement their treatment management plan without the need for repeated clinical appointments. Witnesses highlighted that this reduces the cost of consultant follow up appointments whilst providing the patient and their GP with the necessary support for the ongoing management of their condition after discharge.

We also received evidence that specialist nurses can be trained to safely and effectively diagnose tension-type headache and migraine and such posts can be better utilised to deliver value for money for the NHS. The inquiry heard that nurse-led diagnostic headache services can lead to substantial reductions in neurology waiting times and lead to potential reduction in A&E admissions.<sup>60 61</sup> (See Appendix 3)

## **CONCLUSION**

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.

# Multidisciplinary Teams for Treating Headache

---

The inquiry heard evidence of the benefits of multidisciplinary teams in the treatment and management of headache in both primary and secondary care. Of particular emphasis was the role that clinical psychologists and physiotherapists can play in the common co-morbidity management of headache. However, witnesses warned that these benefits remain largely untapped across the country. The evidence demonstrated that there are models of good commissioning practice throughout the country where multidisciplinary headache services are delivering positive patient outcomes.

*Physiotherapists in multi disciplinary teams have a wide scope of practice and are able to use many different facets of these for patient benefit... Nationally there are examples of individual local practices with specialised centres that include headache treatments... Variability of service provision across the UK is problematic as funding for core physiotherapy services is being withdrawn in some areas.*

**Vivienne Dascanio, Chairman, Acupuncture Association of Chartered Physiotherapists**  
(written evidence)

We heard that a multidisciplinary approach provides holistic support to the patient and it can improve patient experience whilst reducing consultant appointment time and follow-ups. Witnesses noted that multidisciplinary headache interventions require support from a GP or neurologist with a special interest in headache to ensure that the headache is appropriately managed.

For the most complex and severe headache cases, a multidisciplinary approach to address the holistic needs of headache patients was identified as a key service need. Witnesses stressed the importance of this approach in tertiary care headache services. However, we heard that clinics face pressure in terms of resource allocation and training times. Witnesses warned that the multidisciplinary approach to managing headache is unlikely to be a priority for health care commissioners

*Tertiary services must have multi-disciplinary team services. These centres must have enough time to see complex patients who often have other co-morbidities, initial assessment should be by the whole of the multi-disciplinary team and then patients can proceed to management*

**Trigeminal Neuralgia Association, TNA UK** (written evidence)

## **CONCLUSION**

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

---

We heard that the changes to the way the NHS is commissioned and delivered have resulted in a lack of clarity of commissioning responsibility for primary headache disorder services. Health professionals told us that there appears to be no clear consensus amongst CCGs of the responsibility for commissioning specialised treatments for headache disorders.

We heard of a lack of commissioning consistencies within individual SCNs for specialised treatments. Health professionals told us that there is a lack of clarity as to which services are the responsibility of CCGs and which fall under Specialised Commissioning services. Witnesses also highlighted confusion over the commissioning of facial pain services as disorders such as trigeminal neuralgia fall between headache and pain services.

The lack of a clear commissioning process and pathway for tertiary specialist headache and cranial pain disorders in England was raised as a priority area that must be addressed.

*Whilst NHS England has produced an outline scoping document for pain services there has been no mention of headache and cranial pain within this document and it solely focuses on non-cranial pain disorders. Thus a significant proportion of individuals suffering from complex or refractory headache or cranial pain disorders have no hope of accessing NHS tertiary headache services in the future without such a commissioned service being added to the NHS England future commissioning policy. By contrast patients with non-cranial pain disorders have clear commissioned services via NHS England.*

**Dr Brendan Davies, Consultant Neurologist** (additional written evidence)

Specialist Consultants that presented evidence explained that the chaos is complicated further by the varying availability of headache services in different regions. The fragmented approach to commissioning services results in non-equivocal access to treatments and services for headache disorder patients across England. It contributes to the inconsistencies in services' ability to deliver good value for money for the NHS and deliver patient outcomes.

*Until there is infrastructure of how the services may run, it is difficult for commissioners to identify a unique commissioning strategy. Hence there is chaos which is complicated further by the availability of the services in different regions.*

**Dr Fayyaz Ahmed, Consultant Neurologist** (written evidence)

*[H]eadache and cranial pain disorders, when referred to secondary care services, are commissioned largely within the remit of Neurosciences commissioning. Whilst 20% of Neurology outpatient referrals are likely to be headache related it is currently unusual for Headache commissioning to be separate scope despite it making up a 1/5 of the workload and a much lesser proportion needing highly specialised interventions e.g. Cranial Botulinum toxin for Chronic migraine (NICE TA260), Occipital nerve stimulation for refractory chronic migraine (NICE IPG 452), Single pulse transcranial pulse magnetic stimulation for acute migraine (NICE IPG 477). At present patients needing such interventions have no clear knowledge of who is responsible for this NHS service delivery.*

**Dr Brendan Davies, Consultant Neurologist** (additional written evidence)

# Commissioning Responsibility

---

## **CONCLUSION**

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.

# An Integrated Approach To Addressing The Burden Of Headache Disorders

---

Throughout the evidence submissions we heard repeatedly that resources and costs that could be 'saved' from neurology and A&E services needed to be invested into strengthening primary and intermediate care services. Witnesses told us that intermediate services would require support from well resourced specialist headache services at secondary care level.

Dr Brendan Davies proposed that local networks of clinical interest groups spanning primary secondary and tertiary care could drive forward patient outcomes locally. Such networks would need to be integrated and would be able to determine appropriate pathways and commissioning solutions based on local need and resources.

*The benefits of creating regional headache networks should be considered. These would include primary, secondary and tertiary care services, allowing for holistic solutions and avoiding the problem of patient silos. It would also allow for the sharing of best practice and clearer patient pathways.*

**Dr Brendan Davies, Consultant Neurologist** (oral evidence)

However Dr Davies noted that in the current climate of confusion regarding the commissioning of headache services such networks were unlikely to be effective. Clearly established commissioning responsibilities and headache indicators are required before such networks can be effective.

## **CONCLUSION**

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.

# APPGPHD 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.

# Appendix I: List of Oral and Written Evidence Submitters

---

## **Witnesses to the APPGPHD inquiry oral evidence sessions**

- Dr Brendan Davies, Consultant Neurologist, University Hospital of North Staffordshire
- Dr Fayyaz Ahmed, Consultant Neurologist, Hull Royal Infirmary
- Dr Giles Elrington, Consultant Neurologist, Medical Director at The National Migraine Centre
- Dr Manuela Fontebasso, GP with a Special Interest in Headache
- Dr Rachael Kilner, GP and GP with a Special Interest in Headache, South Lambeth Road Practice and Kings College Hospital
- Dr Zameel Cader, Clinical Director for the Strategic Clinical Network for the Thames Valley
- Jillie Abbott, Trigeminal Neuralgia Patient, TNA UK Trustee
- Mike Pollock, Chairman, OUCH UK
- Professor Joanna Zakrzewska, Consultant and Head of Facial Pain Unit, University of Central London Hospital NHS Foundation Trust
- Professor Leone Ridsdale, Professor of Neurology & General Practice, King's College London
- Professor Peter Goadsby, Professor of Neurology and Director of the NIHR-Wellcome Trust Clinical Research Facility, King's College London
- Vicky Probyn, Primary Headache Disorder Patient
- Wendy Thomas, Chief Executive, The Migraine Trust

## **Written Evidence Submissions to the APPGPHD Inquiry**

- 34 Patients, Carers and Family members
- 6 Clinical Commissioning Groups – evidence anonymised
- Acupuncture Association of Chartered Physiotherapists
- Dr Anna Andreou, The Migraine Trust Research Fellow, Imperial College, London
- Dr Anne-Marie Houlder, GP and Chair of the Governing Body, Stafford and Surrounds CCG

# Appendix I: List of Oral and Written Evidence Submitters

---

- Dr Crispin Fisher, GP, Leominster, Herefordshire and Primary Care Lead for Herefordshire CCG
- Dr David Hughes, GP and Clinical Accountable Officer for North Staffordshire CCG
- Dr Goska Trubshaw, GP and GP with a Special Interest in Headache & Epilepsy, Epsom Hospital and St George's Hospital London
- Dr Ingunn Bjornson, GP with a Special Interest in Headache, Cambridge Headache Clinic
- Dr Nicholas Silver, Consultant Neurologist, The Walton Centre for Neurosciences NHS Foundation Trust
- Dr Tara Renton, Professor of Oral Surgery, Kings College London
- ElectroCore LLC
- Migraine Action
- Neurological Commissioning Support
- Professor Carl E Clarke, Professor of Clinical Neurology, University of Birmingham & Sandwell and West Birmingham Hospitals NHS
- The British Acupuncture Council
- The British Association for the Study of Headache (BASH)
- The Migraine Trust
- The National Migraine Centre
- The Organisation for the Understanding of Cluster Headache OUCH UK
- The Royal College of General Practitioners
- Trigeminal Neuralgia Association (TNA UK)

# Appendix 2: The Barriers to Accessing Treatment

---

## **Additional Evidence Supplied by OUCH UK**

Sufferers of Cluster Headaches commonly experience difficulties in accessing appropriate and approved treatment from the NHS. The following examples are amongst the most frequent reported to us. Often medicines are refused on the grounds of cost. This is not related in any way to the need of the patient and raises serious ethical questions.

Sumatriptan injections are a recognised and approved treatment for the aborting of cluster headache attacks, and are recommended in The British National Formulary (BNF) 4.7.4.3. Both episodic and chronic cluster headache sufferers will during cycle use up to two subcutaneous injections a day. Many cluster headache sufferers find that their GP will only prescribe two injections at a time, often meaning that patients have no means of aborting attacks which are the most painful of the primary headache range. We cannot think of any other instances where GPs prescribe a quantity of medicine that fails to match the recommended need, purely on the grounds of cost. Complaints by sufferers about this approach often have to involve others within the NHS to support their case, but we are aware of some cluster headache sufferers who have been deleted from surgery lists on the grounds that they are 'difficult'.

The provision of ambulatory oxygen with specific flow rates is another recognised treatment. Some GPs who are not used to using O<sub>2</sub> for aborting cluster headaches will refuse to prescribe this treatment, either on the grounds of cost or through unfamiliarity with the ordering process.

The third common complaint that we hear is that GPs (with little knowledge of cluster headaches) refuse patients' requests to be referred to a neurologist, presumably on the grounds of cost. The period between individuals starting to suffer from cluster headaches and their eventual diagnosis is already far too long in England and many could start to receive treatment either to prevent or abort attacks if they were referred as soon as possible to neurologists with knowledge of the condition.

# Appendix 3: Case Study: A Diagnostic Headache Nurse Specialist Service

---

## **Written evidence submitted by Professor C E Clarke: Sandwell and West Birmingham Hospitals NHS Trust**

In Sandwell and West Birmingham Hospitals NHS Trust catchment area in the north of the West Midlands, we were swamped by headache referrals because some GPs were not sufficiently confident to diagnose or treat simple headache disorders.

In 2004, we trained an experienced neurology ward sister in the differential diagnosis of headache disorders (Clarke et al, 2005). Over 6 months, patients with non-acute headache disorders were seen by the nurse and a consultant neurologist to take a history and perform a neurological examination. Both reached independent diagnoses for patient's various headache disorders. Since serious causes of headache would be unlikely, a series of role players were included who had been trained to present with either benign or sinister headaches.

We found that consultants diagnosed 239 patients with tension-type headache (47%), migraine (39%) or other headache disorders (14%). The nurse agreed with the consultant in 92% of cases of tension-type headache, 91% of those with migraine and 61% of other diagnoses. Where the nurse did not agree with the diagnosis, most would have been referred for a consultant opinion. The nurse and the doctors misdiagnosed the same 3 of 13 role players.

We concluded that a nurse can be trained to diagnose simple headache disorders. We introduced the diagnostic headache nurse specialist service to our sub-regional neurology unit to:

1. Diagnose migraine, tension-type headache and medication overuse headache
2. Advise GPs on the treatment of these disorders
3. Collaborate with consultant neurologists in managing more complex headache disorders

Over the following 5 years, we audited our experience (Clarke et al, 2008 and 2010). The nurse saw 3,655 new patients with headache disorders with good patient satisfaction levels and no complaints from patients or GPs.

530 (14.5%) of the 3,655 patients underwent cranial imaging, but the large differences in the proportion referred for imaging by each consultant disappeared following feedback on their behaviour. The other unexpected outcome from introducing the nurse is a specialised service for patients with cluster headache, with rapid access to the nurse and thus treatment when a cluster starts.

The diagnostic headache nurse specialist service is now contracted with our CCG as an integral part of the neurology service. In the latest development of the service, we are training the nurse to administer Botulinum toxin in chronic migraine following NICE guidelines.

This headache nurse specialist model should be extended to all major headache services throughout the UK. It will reduce the time consultants need to spend with simple headache disorders and improve the quality of service for patients in terms of reduced waiting times and more rapid access to specialised treatments for cluster headache and chronic migraine.

# References

1. Association of British Neurologists, 'Local Adult Neurology Services for the Next Decade'. June 2011 [www.theabn.org](http://www.theabn.org) Accessed 23rd April 2014
2. House of Commons Committee of Public Accounts, 72nd report of Session 2010–12, Services for people with neurological conditions. Feb 2012 [www.publications.parliament.uk/pa/cm201012/cmselect/cmpubacc/1759/1759.pdf](http://www.publications.parliament.uk/pa/cm201012/cmselect/cmpubacc/1759/1759.pdf) Accessed 19th March 2014
3. National Audit Office. Services for People with Neurological Conditions. Dec 2011 [www.nao.org.uk/wp-content/uploads/2011/12/10121586.pdf](http://www.nao.org.uk/wp-content/uploads/2011/12/10121586.pdf) Accessed 19th March 2014
4. The World Health Organisation. Headache Disorders Factset No. 277. October 2012. [www.who.int/mediacentre/factsheets/fs277/en/](http://www.who.int/mediacentre/factsheets/fs277/en/) Accessed 19th March 2014
5. Latinovic, R, Gulliford M, Ridsdale L. 'Headache and migraine in primary care: consultation, prescription, and referral rates in a large population'. *Journal of Neurology Neurosurgery & Psychiatry* 2006. 77 p385–387
6. Ibid.
7. The Neurological Alliance. 'Measuring up: improving the collection of neurological data and intelligence'. April 2014 [www.neural.org.uk/store/assets/files/380/original/Final\\_-\\_Measuring\\_up\\_30\\_April\\_2014\\_.pdf](http://www.neural.org.uk/store/assets/files/380/original/Final_-_Measuring_up_30_April_2014_.pdf) Checked 21st May 2014
8. Steiner TJ. 'Lifting the burden: the global campaign to reduce the burden of headache worldwide'. *The Journal of Headache and Pain*. 2005 6(5) p373-77
9. Figure submitted by The Trigeminal Neuralgia Association in email communication to the APPGPHD. 14th March 2014.
10. Steiner TJ, Fontebasso M. 'Headache: Clinical Review'. *British Medical Journal* 2002, 325 p881-6
11. National Institute for Health and Care Excellence [www.nice.org.uk](http://www.nice.org.uk) Accessed 4th April 2014
12. Details of past meetings and publications of the APPGPHD are available at [www.headacheuk.org](http://www.headacheuk.org)
13. Ridsdale, L., Clark, C., Dowson, A., Goldstein, L., Jenkins, L., McCrone, P., Morgan, M. & Seed, P. 'How do patients referred to neurologists for headache differ from those managed in primary care?' *British Journal of General Practice* 2007, 57, 538, p388 – 395
14. Ibid.
15. Ligthart LI, Gerrits MM, Boomsma DI, Penninx BW. 'Anxiety and depression are associated with migraine and pain in general: an investigation of the interrelationships'. *Journal of Pain*. 2013 Apr; 14(4) p363-70
16. Smitherman TAI, Kolivas ED, Bailey JR. 'Panic disorder and migraine: comorbidity, mechanisms, and clinical implications'. *Headache*. 2013 Jan, 53(1) p23-45
17. Buse DC I, Silberstein SD, Manack AN, Papapetropoulos S, Lipton RB. 'Psychiatric comorbidities of episodic and chronic migraine'. *Journal of Neurology*. 2013 Aug, 260(8) p1960-9.

## References

18. Juang KDI, Wang SJ, Fuh JL, Lu SR, Su TP. 'Comorbidity of depressive and anxiety disorders in chronic daily headache and its subtypes'. *Headache*. 2000 Nov-Dec, 40(10) p818-23.
19. Ridsdale L., et al. *op cit*, p. 388 – 395
20. Gahir K, Larner A. 'Primary headache disorder in the emergency department: perspective from a general neurology outpatient clinic'. *Emergency Medical Journal*. Feb 2006, 23(2) p135–136
21. The Health and Social Care Information Centre. Hospital Episode Statistics 2010/11 2011/12 2012/13 Copyright © 2013, Re-used with the permission of the Health and Social Care Information Centre. All rights reserved." [www.hscic.gov.uk/hes](http://www.hscic.gov.uk/hes) Accessed 25th April 2014
22. House of Commons, Written Answer 181166. 9th January 2014 Jim Fitzpatrick MP [www.publications.parliament.uk/pa/cm/201314/cmhansrd/cm140109/text/140109w0001.htm](http://www.publications.parliament.uk/pa/cm/201314/cmhansrd/cm140109/text/140109w0001.htm) Accessed 25th April 2014
23. Neurological Commissioning Support, *Southwest Neurological Services Scoping report*. 2013 [www.ncssupport.org.uk/wp-content/uploads/2013/10/Southwest-SCN\\_Data-report-overview-2013.pdf](http://www.ncssupport.org.uk/wp-content/uploads/2013/10/Southwest-SCN_Data-report-overview-2013.pdf) Accessed 19th March 2014
24. The Health and Social Care Information Centre. Migraine. Copyright © 2013, Re-used with the permission of the Health and Social Care Information Centre. All rights reserved. [www.hscic.gov.uk/catalogue/PUB06348/hes-on-migr.pdf](http://www.hscic.gov.uk/catalogue/PUB06348/hes-on-migr.pdf) Accessed 19th March 2014
25. Oral evidence to the APPGPHD Inquiry, Dr Rachael Kilner, January 2014
26. Steiner TJ, Scher AI, Stewart WF, Kolodner K, Liberman J, Lipton RB. 'The prevalence and disability burden of adult migraine in England and their relationships to age, gender and ethnicity'. *Cephalalgia*. 2003 23(7) p519-27.
27. Steiner T. 'The economic cost of migraine and other headache disorders in the UK'. *Headache Disorders – not respected, not resourced. A report of the All-Party Parliamentary Group on Primary Headache Disorders*. 2010 Pages 1-3
28. Steiner T, et al. 2003 *op cit*.
29. CBI, Pfizer. *Healthy Returns. Absence and Workplace Health Survey*. 2011 [http://www.cbi.org.uk/media/955604/2011.05-healthy\\_returns\\_-\\_absence\\_and\\_workplace\\_health\\_survey\\_2011.pdf](http://www.cbi.org.uk/media/955604/2011.05-healthy_returns_-_absence_and_workplace_health_survey_2011.pdf) Accessed 21st May 2014
30. Lipton RBI, Liberman JN, Kolodner KB, Bigal ME, Dowson A, Stewart WF. 'Migraine headache disability and health-related quality-of-life: a population-based case-control study from England'. *Cephalalgia*. 2003, 23(6) p441-50
31. We received evidence that the 2003 NHS resource allocation for headache sufferers in the UK was £201 million of which £125 million was for migraine. No figures since 2003 were presented to the APPGPHD.
32. Written evidence to the APPGPHD Inquiry Dr Fayyaz Ahmed 2014
33. Thomas E, Boardman H, Ogden H, Millson D, Croft P 'Advice and care for headaches: who seeks it, who gives it?' *Cephalalgia* 2004, 24 p740–52.

- 
34. Pavone E, Banfi R, Vaiani M, Panconesi A. 'Patterns of triptans use: a study based on the records of a community pharmaceutical department'. *Cephalgia*. 2007 27(9) p1000-4
35. Thomas E, et al. *op cit*. p740-52.
36. Lipton RB, Stewart WF, Liberman JN. 'Self-awareness of migraine: interpreting the labels that headache sufferers apply to their headaches'. *Neurology*. 2002, 58 S21-S26.
37. Latinovic R et al. *op cit*.
38. APPGPHD meeting reports and publications are available at [www.headacheuk.org](http://www.headacheuk.org)
39. Oral Evidence to the APPGPHD inquiry Dr Zameel Cader, December 2013
40. The Neurological Alliance. 'Navigating Neurology Service; helping strategic clinical networks to be a success story'. 2013 [www.neural.org.uk/store/assets/files/355/original/Neurological\\_Alliance\\_navigating\\_neurology\\_services\\_September\\_2013.pdf](http://www.neural.org.uk/store/assets/files/355/original/Neurological_Alliance_navigating_neurology_services_September_2013.pdf) Accessed 21st May 2014
41. Latinovic R et al. *op cit*.
42. British Association for the Study of Headache. 'Report on the organisation of headache services'. 2002 [www.bash.org.uk](http://www.bash.org.uk)
43. The Association of British Neurologists. 'Guidelines for the care of patients with common neurological disorders in the United Kingdom'. 1993 [www.theabn.org](http://www.theabn.org) Accessed 21st May 2014
44. Ridsdale L, Kernick D. 'Improving management in primary care. Headache Disorders – not respected, not resourced'. A report of The All-Party Parliamentary Group on Primary Headache disorders. 2010 p 4-7
45. Thomas E et al. *op cit*. p740-52
46. British Association for the Study of Headache. *op. cit*.
47. Royal College of General Practitioners. 'Role of GPwSIs'. [www.rcgp.org.uk/clinical-and-research/clinical-resources/gp-with-a-special-interest-gp-wsi-accreditation.aspx](http://www.rcgp.org.uk/clinical-and-research/clinical-resources/gp-with-a-special-interest-gp-wsi-accreditation.aspx) Accessed 4th April 2014
48. Ridsdale, L., Doherty, J., McCrone, P. & Seed, P. 'A new GP with special interest headache service: observational study'. *British Journal of General Practice*. 2008, 58 (552), p478 - 483
49. O'Cathain A, Musson G, Munro J. 'Shifting services from secondary to primary care: stakeholders views of the barriers'. *Journal of Health Service Research and Policy* 1999, 4 p154-160.
50. Kernick D, Mannion R. 'Developing an evidence base for intermediate care delivered by GPs with a special interest'. *British Journal of General Practice*. 2005, 55(521) p908-909
51. Ridsdale L, Doherty J, et al. *op. cit*. p478
52. Beecroft E.V, Durham J, Thomson P. 'Retrospective examination of the healthcare 'journey' of chronic orofacial pain patients referred to oral and maxillofacial surgery'. *British Dental Journal*. March 2013. 214 (5)

## References

---

53. McCrone, P., Seed, P.T., Dowson, A. J., Clark, L.V., Goldstein, L. H., Morgan, M. & Ridsdale, L. 'Service Use and Costs for People with Headache: a UK Primary Care Study'. *Journal of Headache and Pain*. Dec 2011, 12(6) p617-623
54. Ridsdale L, Doherty J, et al. op. cit. p478
55. Ridsdale, L., Clark, et al. op. cit. p388-395
56. Hamilton W, Kernick D. 'Clinical features of primary brain tumours: a case-control study using electronic primary care records'. *British Journal General of Practice* 2007, 57 p695-699
57. NICE. Headaches Costing Report. Implementing NICE Guidance. Sept 2012 [www.nice.org.uk/nicemedia/live/13901/60877/60877.pdf](http://www.nice.org.uk/nicemedia/live/13901/60877/60877.pdf) Accessed 21st May 2014
58. Royal College of Nursing. 'Specialist nurses Changing lives, saving money'. 2010 [www.rcn.org.uk/\\_\\_data/assets/pdf\\_file/0008/302489/003581.pdf](http://www.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf) Accessed 21st May 2014
59. Bhola R, Banks V. 'The role of the UK Specialist Nurse in Headache'. 2013 [www.bash.org.uk](http://www.bash.org.uk) Accessed 21st May 2014
60. Clarke CE, Edwards J, Nicholl DJ, Sivaguru A, Davies P, Wiskin C. 'Ability of a nurse specialist to diagnose simple headache disorders compared with consultant neurologists'. *Journal of Neurology, Neurosurgery & Psychiatry*. 2005, 76 p1170-2.
61. Clarke CE, Edwards J, Nicholl DJ, Sivaguru A, Furnmston A, Davies P. 'Prospective evaluation of a nurse-led headache service in a sub-regional neurology unit'. *British Journal of Neuroscience Nursing*. 2008, 4 p74-8





House of Commons  
The All-Party Parliamentary Group on Primary Headache Disorders