# Strategic Clinical Networks

## Headache Pathway Development

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### Purpose

This paper provides an initial outline of current and legacy pathway work in the management of patients and services to people suffering with headaches.

### Version

V1

### Status

Draft

### Date

25<sup>th</sup> July 2014

### Revision History

<table>
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<tr>
<th>Version</th>
<th>Revision date</th>
<th>Summary of changes</th>
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Introduction

From the 1st April 2013, twelve Strategic Clinical Networks (SCNs) were introduced to the new NHS structures for England in April 2013. As part of the four new networks, the SCNs were tasked to improve services for people with neurological conditions. During the first year of operation each of these SCNs has invested time in reviewing evidence and speaking to stakeholders about areas of health and social care which warrant large scale change.

In April 2014, it was agreed nationally that the SCNs would initially focus on three work streams, including headache. A headache working group was established with the following objectives:

- To identify the current headache pathways
- To share best practice
- To develop and agree a common integrated care pathways adaptable for local service provision

Improving services for people with headaches has been identified as a priority by many of the SCNs and is supported by the report from the All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD) highlighting headaches¹ as one of its clinical priorities. The report summarises that:

"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

¹ 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.
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."
**Rationale for this work**

Headache is common, costly and disabling (World Health Report, WHO 2001). 4% of adults consult a GP each year for headache (Latinovic et al. 2006). Whilst tension-type headache is the most common form in the community, the most frequent headache seen in general practice is migraine. 6.7 million people are living with migraine in England (Neurological Alliance, 2014), with 80% have disabling attack interfering with work, home or socialisation (Steiner 2005).

The direct cost to the NHS is estimated at £1 billion per year (Ridsdale 2007), with GP consults and medications of £468 per patient per year. Costs may be substantially higher than estimated as headache patients have frequent co-morbidities. For example, depression is three times more common in patients with migraine than healthy people. The cost of headache to the economy in terms of lost productivity was estimated at £5 billion.

Ninety seven per cent of headache is managed in primary care (Latinovic et al: 2005) but 70% of GP consulters for headache receive no specific diagnosis (Kernick et al: 2008). It is therefore essential to ensure that the correct management is initiated by GPs to avoid ongoing disability, medication overuse, and inappropriate emergency attendance and repeat GP attendance.

This data has been replicated by several studies and independent reports from several organisations including the APPGPHD and from Neurological Commissioning Support (NCS) which a number of SCNs have already commissioned. They highlight headaches as a specific issue in relation to high admission rates, high cost and potentially avoidable co-morbidities.

The decision to review headache management across all SCNs was based on recognition that:

1. service provision is variable;
2. headache patient pathways are frequently not well delineated;
3. patient experience is poor
4. costs for headache services are high.

The benefits of having effective services to support the management of headaches include:

- Reducing emergency admissions to secondary care
- Reducing social and financial deprivation of individuals incorrectly diagnosed with headaches
- Promoting independent living and employability
- Enhancing patient choice, empowerment and self-management
- Better use of financial and other resources (4).

**This paper therefore has the following aims:**

- Provide a compendium of national policies and guidelines and local initiatives collected from SCNs across the country regarding headaches.
- Identify and begin the process of agreeing a consensus for pathways, guidelines, protocols
- Increase awareness of local projects / best practice across the country
Background

Headache is a painful and disabling feature of the primary headache disorders including migraine, tension-type, and cluster headache. Headache may also be a presenting symptom for many disease processes and is then termed as secondary headaches.

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, equating to 94 per 10,000 patients as first visits.

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.

Migraine is a complex condition with a wide variety of symptoms. For many people the main feature is a painful throbbing 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. There are approximately 6,720,000 people living with migraine in England.

There are rarer primary headache such as cluster headache. Cluster headache affects about 150,000 people in England, about the same as multiple sclerosis. It is an excruciating headache disorder, sometimes called ‘suicide headache’. Over half of patients have suicidal thoughts, with 2% admitting to actual suicide attempts (Rozen et al., 2012).

Chronic headache is presently defined as anyone experiencing 15 days or more of headache every month for at least three months. This affects up to 3% of adults and is frequently due to chronic migraine, chronic daily headache or medication overuse headache.

Patients with frequent headaches may overuse acute treatments such as codeine, paracetamol, ibuprofen or triptans. With medication overuse, the headaches can become chronic and intractable increasing the disability arising from the headache.

There are many serious conditions that will present with headaches. This includes brain haemorrhages, tumours and infections. Many patients may visit their GP or A&E because they are worried about an underlying sinister cause for their headaches. However most patients with headaches will have a primary headache disorder.

97% of headache is managed in primary care (Latinovic et al: 2005) and 3% of headache referred to secondary and tertiary centres. This 3% referral leads to >25% of neurology new out-patient load (Patterson & Esmonde: 1993). The majority of patients are seen in secondary care once by a general neurology consultant; in many cases, this referral is to exclude secondary causes such as tumours.
Emergency Admissions

Emergency admissions account for over 80% of all hospital admissions for migraine and headache disorders [ref 24]. Approximately 20% of headache patients seen in neurology clinics have attended A&E in the previous 6 months, 10% of whom are admitted [ref 20]. 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 [ref 21]. Within some CCG areas the increase in emergency admissions was as much as 70-80% in the 3 year period [ref22].

The map of England (based on the MHDN intelligence network show the emergency admissions (primary diagnosis) and (mention) by region compared to the national average.

Legend:
Dark blue lower than the national benchmark
Light blue higher than the national benchmark

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2 All-Party Parliamentary Group on Primary Headache Disorders
Local Activity

Thames Valley SCN commissioned an NCS report with the remit of identifying neurology service provision and variation across Thames Valley based on the top ten neurological conditions (activity and spend). Headaches were an integral part of this report. Some of the findings are highlighted below:

Across Thames Valley the total hospital admissions and costs for headache have increased over the past four years. In 2012/13 total costs for those with a primary diagnosis of headache across the SCN area were £2,016,691 and for those with a secondary diagnosis were £5,008,805. The total cost burden to the Thames Valley SCN area was just over £7 million.

The admissions and costs are likely to be underestimates as in many cases; patients may not be captured by coding. For example a large proportion of patients referred to ENT with sinusitis will have migraine. Similarly, many patients seen in emergency departments with stroke-like symptoms may instead be having a migraine aura.

Admission rate per 100,000 – Total elective and non-elective admissions with a primary or secondary diagnosis of Headache and Migraine 2009/10 to 2012/13 by CCG

Elective admissions may be required to carry out relevant investigations, or deliver medical or surgical interventions. Low rates of admission are not necessarily an indication of good practice although high rates may indicate inappropriate admissions. High levels of activity are also associated with close locality to a neurosciences centre (3).
Total admission costs – Total elective and non-elective admissions with a primary or secondary diagnosis of Headache and Migraine 2009/10 to 2012/13

<table>
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<th>Year</th>
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<tr>
<td>2009/10</td>
<td>£6,255,424</td>
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<tr>
<td>2010/11</td>
<td>£6,566,809</td>
</tr>
<tr>
<td>2011/12</td>
<td>£7,407,416</td>
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<tr>
<td>2012/13</td>
<td>£6,933,603</td>
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Data collected for the same period for Thames Valley PCTs also demonstrated that spells associated with emergency admissions were greater than for elective spells. It was assumed that early, accurate diagnosis and better long-term management for patients could reduce emergency spells in hospital, providing an opportunity to review allocation of resources.
Priority areas for change

The following have been identified, across the SCNs, as priority areas for change to improve the quality and safety of services for people with headache:

- Developing integrated care pathways and models of care (quality outcome 1)
- Improving diagnosis (quality outcome 2)
- Improving on-going care for those with a diagnosis of headaches to prevent presentation to Emergency Departments (EDs) (quality outcome 3)
- Reviewing the use of drugs (quality outcome 3)
- Improving self-care / self-management (quality outcome 4)

Quality Outcomes for Headache

SCNs aim to support achievement of the following outcomes ensuring delivery of a quality service:

1) Reduce variation of care and service provision
   a. Nationwide implementation of headache care pathways for best practice

2) Ensure rapid, accurate diagnosis
   a. Improve professional awareness to better diagnose headache disorders and instigate appropriate treatment
   b. Implement clinical decision tools in GP practices

3) Decreased costs within the system.
   a. Reduce medication overuse and inappropriate treatments
   b. Reduce emergency admissions
   c. Reduce unnecessary outpatient referrals and follow-ups

4) Improved patient experience
   a. Establish a network of community headache clinics
   b. Establish a nurse-led headache service to complement community and hospital clinics

All the quality outcome indicators are interlinked as shown below.

Quality Outcome 1: Reduce variation of care and service provision

The pathway of care for the diagnosis, treatment and on-going management of headaches should be supported by evidence based principles of care. Whilst the principles should be adhered to, the model of service delivery may need to be adapted to address local variation in geography, demographics and service availability.

In order to support effective care, pathways should span primary, secondary and tertiary care and include:

- A decision support tool
- A nurse specialist to provide support across the pathway
- Pathways for headaches in people with a confirmed diagnosis
- Links to pathways for people with functional disorders
- Support for the psychological well-being of people diagnosed with headaches.
Headaches should be diagnosed safely and accurately through access to appropriate specialists and specialist investigations.

A pathway of care is described within the NICE Guideline for headaches (CG150) (appendix1). A number of pathways have also been developed across the SCNs:

- Thames Valley pathway – Headache clinics in the community (appendix 2a)
- Plymouth Pathway – Headaches – modules of care (appendix 2b)
- Wessex – Decision Support Tool Pathway (appendix 2c)
- Northern – Management of acute and chronic headache pathway (appendix 2d)
- West Norfolk – Proposed headache pathway and guidelines for West Norfolk (appendix 2e)
- London SCN / Barnet – Adult Headache Pathway (appendix 2f)

As well as the developing pathways there are a number of appendices that define guidelines and protocols for headache management:

- Greater Manchester: Headache algorithm for PCTs / Notes for PCTs and Botox management (appendix 3a)
- West Norfolk: Primary Care management of headaches (appendix 3b)
- East Kent: Pathway and policies for headaches (appendix 3c)
- Greater London: Shared learning – Video training tool for GPs (Appendix 4)

The future aim of the working group is to develop consensus pathways and protocols using the above. This pathway will underpin all of the other Quality Outcomes in this paper.

Actions for SCNs:

- Collate all the headache pathways with links to others to produce one overall pathway of care
- Define / agree standards of care to support key elements of the pathway e.g. around diagnosis, treatment etc.

Quality Outcome 2: Ensuring rapid, accurate diagnosis – Decision Support Tools and Training Videos for GPs

The key clinical issues in supporting accurate diagnosis to meet NiCE quality outcome measure:

- Identifying patients with ‘red-flag’ symptoms that may indicate a sinister cause of headaches
- Establishing the type of primary headache to ensure correct treatment is instigated to prevent chronicity and disability
- Identifying risk of medication overuse to prevent chronicity and disability

GPs may need specialist support through advice and guidance services or a decision support mechanism. For example, Wessex SCN is supporting an evaluation of a “decision support mechanism” tool pilot in four practices in Hampshire (appendix 2c).

There is also a proposal to develop a training video (appendix 4) to support GPs in each locality to improve communication with a view to developing relationships and ultimately improving the timeliness of referrals. This “training video” will focus on identifying key aspects requiring enhanced shared learning (e.g. red flags, medication overuse, acute management and prevention of migraine) in the pathway (appendix 2f)

The South West SCN is potentially working with secondary care to provide referral guidance to GPs through an “advice and guidance” system for neurological conditions.
The benefits of rapid access and accurate diagnosis are:

- Improving health outcomes and quality of life as a result of prompt access to the appropriate expertise in order to obtain a diagnosis and begin treatment
- Avoiding delayed or incorrect diagnoses and subsequent risks and costs
- Reduction in emergency admissions
- Reducing the costs to the NHS of misdiagnosis, including the cost of inappropriate prescribing and medico legal costs arising from complaints and claims.

Actions for SCNs:
1. Report from Wessex, London and South West SCN on outcomes of pilot
2. Roll-out to other SCNs if evidence of benefit

Quality Outcome 3: Decreasing costs within the system

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 from complicated headache and other neurological conditions which require specialist attention.

In the report “Headache Services in England” APPG it was stated that:

“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. 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. This presents a clear basis for management of such patients outside of the emergency care setting.

Decreasing emergency admissions could be supported by:
- Developing an ED protocol based on best practice for people presenting with headaches which safely minimises admission rates i.e. for people presenting with:
- Developing access to rapid access clinics and investigations
- Ensuring better long-term management for people within primary care

Overall the outcomes for this work would be associated with:
- Decreased attendance at the ED
- Decrease in emergency admissions
- Decrease in inappropriate investigations
- Reduction in the number of patients started on medication inappropriately.

Reduce unnecessary outpatient referrals and follow-ups
3% of headache referred to secondary and tertiary centres, leading to >25% of neurology new out-patient load (Patterson & Esmonde: 1993). The majority of patients are seen in secondary care once by a general neurology consultant; in many cases, this referral is to exclude secondary causes such as tumours or to allay anxiety.

Patients may have been effectively managed in primary care without the need for an onward referral to general neurology or for imaging (see Quality Outcome 2: clinical decision support tool).

Follow-up of patients may be necessary in chronic headache patients to ensure effective treatment and avoid repeated future attendances. In other cases follow-ups may be avoided by providing appropriate community support and nurse-specialist support (see Quality Outcome 4). This provides a strong rationale a clear headache pathway (see Quality Outcome 1).

### Actions for SCNs:
- Audit of the patient journey to include:
  - Investigations
  - Attendances at A&E
  - O/P attendances

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### Quality Outcome 4: Improving patient experience

#### Providing on-going support – Community and self-management

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 unnecessary A&E admissions and outpatient referrals (Quality Outcome 3).

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.

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 headache specialists (e.g. GPwSI or headache nurse) have the potential to save CCGs money by reducing clinical appointments.

Partnerships with third sector organisations to support this care or facilitate local support networks can ensure that patient priority outcomes are achieved.

Pharmacists / Opticians can provide a key resource in managing headaches in the community. It is using innovative approaches such as these that public awareness and information can be disseminated.
Actions for SCNs:
- Identify evidence to support the effectiveness of self-management programmes
- Identify opportunities to establish patient expert groups and local patient education events
- Identify approaches to raise awareness of headache management by pharmacists and opticians
Improving effectiveness of clinical encounters

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 (see Quality Outcome 1). Integrated networks also provide the opportunity to break from the traditional hierarchical structures. Instead they promote a multidisciplinary team working approach where headache consultants, nurses, GPwSI and GPs work in partnership for the benefit of the patient.

Many headache patients can be managed by a ‘headache-aware’ GP, who will correctly diagnose and provide the appropriate treatment (Quality Outcome 2). Patients with red-flag symptoms indicating possible secondary causes should be referred to General Neurology as best practice.

Patients with rare, recurrent or refractory headaches need to be directed to the headache services which should comprise of a GPwSI, a headache nurse working in both the community and hospital, and a headache consultant neurologist. This will ensure that the clinical encounters for headache patients are effective.

GP with Special Interest Services

Specialist GP services provide an appropriate and cost-effective approach to managing primary headache disorders for the more complex patient. 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. Patients and carers routinely report the benefits of having access to a GP with Special Interest (GPwSI). 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.

Headache Specialist Nurse

Specialist nurses provide clinically and cost effective service [ref 58] but there are only 11-13 headache nurse specialists in England. There is also evidence that a nurse-led diagnostic service can lead to substantial reductions in neurology waiting times and A&E admissions [ref 60-61].

Nurses can provide patient-centred care and have a key role to provide patient education. Follow-up appointments and telephone clinics with specialist nurses can provide patients with personalised treatments without the need for outpatient consultant appointments.

Improving access to specialist nurses would provide patients with support and information, which could in turn:

- Improve the psychological well-being of people with headaches
- Decrease emergency admissions by providing timely support
- Decrease secondary care outpatient follow-up appointments.
The Thames Valley SCN is working with the Oxfordshire CCG to develop a community adult Headache Nurse and GPwSI service. There are other areas with the country such as East Kent and Devon (Exeter) that have developed such services with both quality and financial benefits

**Actions for SCNs:**
- Support the further development of GPwSI and audit to ensure value for money
- Develop innovative approaches to utilising Headache nurses to reduce the demand on neurologists within secondary care
- Work with Commissioners on developing cost benefit analyses
Appendix 1 - NiCE GUIDELINE CG 150

Headaches in Young People and Adults – CG 150

**HEADACHE OVERVIEW**

- **Person with Headache**
- **Assessment**
  - People presenting with headache
  - Evaluate people who present with headache and any of these features, and consider the need for further investigations and/or referral:
    - Worsening headache with fever.
    - New or sudden-onset headache reaching maximum intensity within 5 minutes.
    - New-onset neurological deficit.
    - New-onset cognitive dysfunction.
    - Change in personality.
    - Impaired level of consciousness.
    - Recent (typically within the past 3 months) head trauma.
    - Headache triggered by cough, valsalva (trying to breathe out with nose and mouth blocked) or sneeze.
    - Headache triggered by exercise.
    - Orthostatic headache (headache that changes with posture).
    - Symptoms suggestive of giant cell arteritis.
    - Symptoms and signs of acute narrow-angle glaucoma.
    - A substantial change in the characteristics of their headache.

**DIAGNOSIS OF HEADACHE**

- Tension type headache, migraine (with / without aura) cluster
- Menstrual related headache
- Medication overuse headache

**MANAGEMENT OF HEADACHE**

- Person diagnosed with headache disorder
- Information support for people with headache disorder
- All headache disorders
  - Tension type headaches
  - Migraine with / without aura
  - Cluster Headaches
  - Medication overuse headaches

**MANAGEMENT OF MIGRAINE WITH / WITHOUT AURA**

- Person with migraine, with / without aura
  - Acute treatment
  - Prophylactic treatment
  - Special consideration for women and girls with migraine.
Assessment

People presenting with headache

Evaluate people who present with headache and any of these features, and consider the need for further investigations and/or referral.

- Worsening headache with fever.
- Sudden-onset headache reaching maximum intensity within 5 minutes.
- New-onset neurological deficit.
- New-onset cognitive dysfunction.
- Change in personality.
- Impaired level of consciousness.
- Recent (typically within the past 3 months) head trauma.
- Headache triggered by cough, valsalva (trying to breathe out with nose and mouth blocked) or sneeze.

- Headache triggered by exercise.
- Orthostatic headache (headache that changes with posture).
- Symptoms suggestive of giant cell arteritis.
- Symptoms and signs of acute narrow-angle glaucoma.
- A substantial change in the characteristics of their headache.

For NICE guidance on referral for suspected brain or CNS tumours see referral for suspected cancer; update under development (publication date to be confirmed).

Further assessment for people presenting with new-onset headache

Consider further investigations and/or referral for people who present with new-onset headache and any of the following.

- Compromised immunity, caused, for example, by HIV or immunosuppressive drugs.
- Age under 20 years and a history of malignancy.
- A history of malignancy known to metastasise to the brain.
- Vomiting without other obvious cause.

Headache diaries

Consider using a headache diary to aid the diagnosis of primary headaches.

If a headache diary is used, ask the person to record the following for a minimum of 8 weeks.

- Frequency, duration and severity of headaches.
- Any associated symptoms.
- All prescribed and over-the-counter medications taken to relieve headaches.
- Possible precipitants.
- Relationship of headaches to menstruation.
Quality standards

The following quality statement is relevant to this part of the pathway.

Classification of headache type

Statement 1: People diagnosed with a primary headache disorder have their headache type classified as part of the diagnosis.

Statement 2: People with a primary headache disorder are given information on the risk of medication overuse headache.

Statement 3: People with tension-type headache or migraine are not referred for imaging if they do not have signs or symptoms of secondary headache.

Statement 4: People with migraine are advised to take combination therapy with a triptan and either a non-steroidal anti-inflammatory drug (NSAID) or paracetamol.

Statement 5: (placeholder). Raising public and professional awareness.

Headaches in young people and adults' NICE quality standard 42
© Source guidance
Appendix 2 – Pathways across England

Appendix 2a Thames Valley pathway – Headache clinics in the community

Headache Patient Flows

Improving Patient Self-Care

- Encouraging local patient networks
- Patient awareness days
- Signposting resources
- Web and social media
- Local fundraising
- Patient Champions
**Patient**

**GP**

- Improve headache diagnosis
- Improve treatments
- Reduce re-attendance
- Reduce medication overuse
- GP champions

**Improving First Contact**

**GPwSI**

**Clinical Decision Support Tool**

**Optimizing Onward Referrals**

**GP**

**ED**

**Clinical Decision Support Tool**

**Referral Support System**

**General Neurology**

**Headache Nurse**

**GPwSI**

**Community Service**
Appendix 2b – Plymouth Pathway

Headache Modules of Care

Peninsula Headache Website
(To coordinate, hold menus of care to help patients and referring GPs)

Headache App

To Neuropharmacist
With menu of care

To GP
With menu of care

Follow-up
Face to face or telephone (patient choice)

Consultant
If complex

National Hospital for stimulator
Battery change and ongoing maintenance (new service)

Headache Clinic (Consultant)
- Diagnosis / Investigation
- Instigate treatment menu
- Follow-up of complex patients

GPwSi in Headache

GP referral

Treatment procedures
Botox (NICE)
Nurse led
SpR Support
MDT meeting for clinical governance

Treatment procedures
GONi
Nurse led
SpR Support
MDT meeting for clinical governance

Assessment / Treatment
Psychology
- to reduce Analgesia overuse
- Manage anxiety
Nurse / Psychologist led

New Devices
Gemmacare
TMS (NICE guidance)

Governance
- Ongoing audit
- Patient satisfaction
- Botox audit
Appendix 2c – Wessex Decision Support Tool Pathway

Referral, diagnosis and management advice and guidance tool

Red Flags for serious causes of headache*

Secondary headache disorders

Primary headache disorders

Facial pain

Patient information resources for supported self-management

50% reduction in routine outpatient attendances in pilot

Two week wait (2WW)

Urgent or routine

Neurology OPA

Imaging

Abnormal scan

Neuro-imaging MDT

Refer to Neurology Triage

Advice and guidance report to GP

Report to GP

ED

Patient

Supported self-management

Red Flags+++ for emergency or acute admission*

5% follow up in OPD

GP
Appendix 2d Management of Acute and Chronic Headache Pathway – Northern SCN

Pharmacy component

Patient attends pharmacy to pick up repeat prescription for pain killers, or ask for HA advice.

Pharmacist provides additional literature and signposts according to underlying headache type.

If analgesic overuse headache possibility, provide information to patient and flag to GP.

London – developing educational resources; to include pharmacist training and patient material, inc videos.

GP component - chronic

GP is not allowed to automatically refer to neurology, but instead the pathway is to ask for advice, e.g. through advice and guidance. The link neurologist (or specialist nurse, Gpsi) can then convert to f2f consultation if required.

Logic is that once referral made, expectation is set and it is difficult to cancel this. Also, without this A&G barrier, some GPs will not be motivated to learn.

GPs identified as particularly bad at headache management to have online educational modules put on their yearly requirement or invited to sit in on neuro clinic.

A&E, MAU – Acute

Need the protocols, plus online modular training as part of periodic Dr/Nurse training requirements.
Patients seen in A&E more than once with migraine to be identified from database and receive acute HA self-management plan.

GP / A&E component – acute, recurrent

Investigations proposals

- No direct access for brain MRI for GPs
- No C spine MRIs for headache without written rationale
- Neuroimaging reported by a neuroradiologist (could be anywhere in world providing specialised)
Appendix 2e Proposed Headache Pathway and Guidelines for West Norfolk

**GP-MRI for headache – A PILOT PATHWAY & GUIDELINES**
This is an evidenced based guideline rather than a rigid protocol
*Valid 2/14 review date 2/15*

Patient 12 years or older presents with Headache

Exclude serious cause with history examination and baseline investigations
*see Red Box*

Ask the patient to use a headache diary for a minimum of 8 weeks to record
- Frequency duration and severity of headaches
- Associated symptoms
- All prescribed and OTC medications
- Possible precipitants
- Relationship of headaches to menstruation

Use headache diary to help diagnose primary headache.
Record for 8 weeks.
Try conventional treatments according with guidelines for example *in green boxes*.
While treatment is ongoing it is important that patients continue to be monitored for emergence of clues for more serious headache *see red box*

If treatment failure after several weeks then it is reasonable to consider referral for GP-MRI
It is acknowledged that in some cases scanning may aid treatment through reassurance for patients and referrer
PATHWAY - PATIENT WITH HEADACHE

Diagnosis & Assessment

RED FLAGS

HISTORICAL and EXAMINATION CLUES TO MORE SERIOUS CAUSES OF HEADACHE

ACUTE—likely to need urgent hospital admission
• SYMPTOMS AND SIGNS OF BLEED OR OTHER INTRACRANIAL CATASTROPHE
  • E.g. sudden onset severe headache or acute new neurological deficit
• SYMPTOMS AND SIGNS OF INFECTION—Meningitis, encephalitis, abeobece
  • E.g. fever, meningism, photophobia, confusion, falling conscious level, seizures

ACUTE/SUBACUTE—likely to need urgent admission or urgent specialist review
• SYMPTOMS AND SIGNS OF CRANIAL ARTERITIS
  • E.g. jaw claudication, polymyalgia, temporal artery tenderness, raised ESR
• SYMPTOMS AND SIGNS OF RAISED INTRACRANIAL PRESSURE
  • E.g. brief episodes of unocular visual loss, morning headache that clears on sitting, cough headache, papilloedema
• SYMPTOMS AND SIGNS OF PROGRESSIVE NEUROLOGICAL DEFICIT
  • Progressive limb or facial weakness, gait unsteadiness, confusion, personality change
  • New visual field defects, double vision, ptosis (including Horner’s syndrome), dysarthria or cranial nerve palsy
• SYMPTOMS AND SIGNS OF CORTICAL IRRITATION
  • Focal or generalised seizures
  • Bizarre or stereotyped sensory or visual symptoms (unless typical for migraine)
• SYMPTOMS AND SIGNS OF MENINGEAL IRRITATION (see also signs of infection above)
  • Postural headache; cough headache

PAY PARTICULAR ATTENTION IN PATIENTS:
• With new onset headache plus past history of neoplasm
• With new onset headache in older age groups
• If progressively worsening headache without other features

• DON’T FORGET THE SIMPLE QUESTIONS
  Are there clinical pointers to problems with other systems?—E.g. chest disease
• DON’T FORGET THE SIMPLE TESTS
  Blood count, ESR (>50ys) and serum biochemistry can give important clues

RED FLAG NEGATIVE

MIGRAINE — ~60% of all presentations
Migraine without aura
- Episodic disabling
  - Lasts 4-72 hours untreated
  - Unilateral or bilateral
  - Pulsating/throbbing/banging
  - Moderate/severe treasoning and/or photophobia
  - Sensitivity to light/nausea during headache
  - Exacerbation by physical activity
  - Often associated with family history

Migraine with aura
- As above and in addition, Aura can occur with or without headache lasts 5 - 60 mins prior to headache
  - Usually visual flickering lights spots/lines or loss of vision but can be sensory and/or speech symptoms
  - Different aura symptoms occur in succession.

INTERMITTENT < 15 days per month

CHRONIC > 15 days per month

> 4 hrs per day

< 4 hrs per day

Cluster headaches <1% of GP presentations

Patients with cluster headache are in severe pain and need rapid effective treatment.
15-180 minutes
MF 3:1 ratio
>20 yrs.
Smokers
Episodes last 0-12wks
1-2 x per annum, often at same time of year
Very severe, often at night
Singly unilateral
Ipsilateral conjunctival injection, rhinorrhea +/- ptosis

Tension-type headache 15% of presentations (but high population prevalence)
- Episodic
  - Bilateral
  - Pressing/tightening (not pulsating)
  - Micromoderate
  - Stress common trigger
  - Nausea not present
  - Not aggregated by physical activity
  - May occur in combination with migraine and secondary headache

This includes

Chronic Migraine
- Medication Overuse headache (MOH)
- Chronic Tension Headache
- and represents 30% of GP presentations
- MF 1:5
- MOH can occur especially over the counter analgesia.
- Can occur with other headache types.
References:
http://guidance.nice.org.uk/cg150/guidance
Clinical Knowledge Summaries http://www.cks.nhs.uk accessed 29/3/12
Migraine in primary Care Advisors (Mipca) http://mipca.org.uk/ free modules available on headaches for health professionals
SIGN guidelines. www.sign.ac.uk includes apps on headaches for smart phones
British association for the Study of headache http://www.bash.org.uk/
Royal College of General Practitioners some excellent resources including interview and fact sheet compiled by Headache Champion Dr David Kernick

Appendix 1 Information - Manage trigger factors for Tension Type Headache and Migraine when possible:
- For people with TTH triggered by stress, consider offering:
  1. Lifestyle advice about the importance of regular mealtimes, adequate hydration, avoidance of caffeine, a regular sleep pattern, and exercise.
  2. Advice on relaxation techniques, such as progressive muscular relaxation, muscular stretching, or controlled breathing techniques.
  3. Referral for cognitive behavioural therapy to teach the person to identify and challenge thoughts and beliefs that generate stress and aggravate headache.
- For people with sleep difficulties, see the PRODGY topic on insomnia
  http://prodgy.clarity.co.uk/insomnia
- For people with a sedentary lifestyle, advise regular physical exercise.

Appendix 2 - Management of Medication Overuse Headache – from CKS
http://www.cks.nhs.uk/headache_medications_overuse/management/scenario_diagnosi
s/#393230
- Explain the cause of medication-overuse headache and its prognosis.
- Refer all people with medication-overuse headache that is complicated by significant coexisting conditions, and all people who are predominantly overusing opioids.

For people not requiring referral:
- Agree a date to withdraw treatment, at a time when the person can manage withdrawal symptoms; if possible, this should be when good social support is available. For people who are working, advise that they may need to take time off work.
- Prescribe an anti-emetic to be used as required during the withdrawal, such as:
  - Domperidone tablets 10 mg to 20 mg, up to four doses in 24 hours.
  - Metoclopramide tablets 10 mg, up to three doses in 24 hours.
  - Prochlorperazine buccal tablets 3 mg to 6 mg, up to two doses in 24 hours.
- Advise the person to:
  - Withdraw abruptly.
  - Ensure adequate hydration, by drinking at least 2 litres of fluid daily during the withdrawal. Caffeinated drinks (including tea, coffee, and caffeinated carbonated drinks such as colas) should be avoided.
  - Avoid taking any acute pain treatments if possible during the withdrawal.
- Review after 7 days, or earlier if withdrawal symptoms are poorly tolerated.
  - If withdrawal symptoms are poorly tolerated, offer naproxen 250 mg to 500 mg twice daily regularly for 5–7 days (maximum of 1 g in 24 hours) for symptomatic relief, but advise restricting use to this time period.
  - If headache or withdrawal symptoms persist, review weekly for 3 weeks.
If withdrawal is successful, advise limiting symptomatic treatments to 2 days a week, or less if possible, to reduce the risk of relapse.

If withdrawal is successful, but headache persists after 3 weeks, reassess the diagnosis (see the CKS topic on Headache - assessment):
  - Refer the person if the diagnosis is uncertain, or
  - Manage the underlying headache disorder (see the CKS topics on Migraine and Headache - tension-type).

If withdrawal is unsuccessful or relapse occurs
  - Identify reasons for failure or relapse and manage these (if possible) before further attempts at withdrawal, or
  - Refer to a neurologist for assessment and further management.

Appendix 3 - MIPCA/MA Diagnostic Screening Questionnaire (DSQ)

MIPCA/MA Diagnostic Screening Questionnaire (DSQ)
(Dowson AJ et al. Headache Care 2005;2:111-8)

1. Has the pattern of your headaches been generally stable (i.e. no change or only small changes in frequency and severity) over the past few months? [Yes / No]

2. Have you had headaches for longer than 6 months? [Yes / No]

3. Are you aged between 5 and 50 years? [Yes / No]

4. Does the headache interfere to a noticeable extent with your normal daily life (work, education and social activities)? [Yes / No]

5. On average, how many days with headache do you have per month?
   [Less than 1 / 1 / 1–4 / 5–15 / 15–30 / Every day]

6. On average, how long do your headaches last, if left untreated?
   [Less than 15 minutes / 15 minutes to 1 hour / 1–2 hours / 2–4 hours / over 4 hours / My headaches are always there]

7. On average, on how many days per week do you take analgesic medications? [Less than 1 / 1 / Up to 2 / 2 or more / Every day]

8. Do changes in your senses (sight, taste, smell or touch) occur in the period immediately before the headache starts? [Yes / No]
DSQ: diagnostic algorithm

- A ‘no’ answer to Questions 1, 2 or 3 indicates the possibility of secondary (or sinister) headaches. These patients should be investigated further and do not complete the remaining questions.
- For patients who answer ‘yes’ to Questions 1–3:
  - Question 4:
    - ‘No’ = episodic tension-type headache
    - ‘Yes’ = migraine or chronic headache
  - Question 5:
    - <1; 1; 1–4 and 5–15 days = migraine
    - 15–30 days and every day = chronic headache
  - Question 6: For patients with chronic headaches only:
    - <15 minutes = investigate further
    - 15 minutes to 1 hour = possible cluster headache, investigate further
    - 1–2 and 2–4 hours = investigate further
    - Over 4 hours and my headaches are always there = chronic primary headache
  - Question 7: For patients with chronic primary headaches only:
    - <1; 1; up to 2 = chronic headache without medication overuse
    - 2 or more and every day = chronic headache with medication overuse (MOH)
  - Question 8: For patients with migraine only:
    - Yes = migraine with aura
    - No = migraine without aura
Appendix 4 Information sheet for General Practitioners concerning people who may be eligible for Botox treatment of chronic migraine.

This patient has at least 15 headaches per month and has been seen by a consultant neurologist who considers that there is a migrainous origin.

Before the patient can be referred to the hospital for Botox injections they must have had at least three prophylactic treatments from different drug groups. Each drug needs to be titrated up to the working dose and kept at that dose for at least two months.

Three out of the following five drugs:

- Nortriptyline or Amitriptyline to at least 50mg for at least two months
- Propranolol to at least 160mg for at least two months
- Pizotifen to at least 1.5mg for at least two months
- Topiramate to at least 100mg for at least two months
- Sodium Valproate to at least 1000mg for at least two months, BUT AVOID IN WOMEN OF CHILDBEARING AGE

If a patient suffers from side effects and is not able to keep taking a drug for the full duration, this still counts as one of the prophylactic treatments attempted to treat the migraines, just so long as the side effects can properly be attributed to the drug in question.

Patients will also need to keep a daily headache diary. Diary sheets with instructions on how to fill them in will have been given to the patient at the neurology clinic.

Once a patient has tried three prophylactics and still has documented headaches 15 per month, 8 of which are migrainous, they can be referred to Dr Hendrie’s migraine clinic at the QF. They will need to know in advance that the treatment consists of 31 injections around the scalp with very fine-bore needles.

Guideline compiled by the following:
- Dr. Dan Rose, Dr. Geoff Hunnam, Dr. Jonathan Graham, Consultant radiologists Queen Elizabeth Hospital Kings Lynn
- Dr. Jeremy Brown, Dr. Philip Buttery Consultant neurologists Queen Elizabeth Hospital Kings Lynn
- Dr. Keith Redhead, general practitioner West Norfolk Clinical Commissioning Group
- Gill Edcy, Debbie Craven, medicines Management team NHS Norfolk Community Pharmacists,
- Dr. Andy Dowson, Director of headache Services at Kings College Hospital London and Chairman of MIPCA (Migraine in Primary Care Advisors)
- Dr Oliver Hendrie December 2013
Appendix 2f Adult Headache Pathway and Guidelines for Barnet (London SCN)

ADULT PRESENTING WITH HEADACHE

HISTORY & EXAMINATION

It > 5 months duration serious cause unlikely

It < 6 months duration consider serious cause

Episodic Migraine

Acute Treatment
- Try early = 24 hours onset
- Analgesia: NSAID eg Nапрокен 250-500mg
- Anti-emetic eg Domperidone 50mg
- Sumatriptan 60-100mg

Prevention
- Avoid Triggers
- Metoprolol 50-200mg daily
- On Antidepressantes 10-150mg twice or 10-10mg twice

Response to treatment
- Monitor and adjust treatment
- Consider withdrawing preventative 6 months after
- Avoid increasing analgesia use

Not responding or complicating co-morbidities
- Refer to Neurology or Headache Clinic

Emergency treatment of Migraine at home
- Diclofenac 75mg IM
- Compridone 12.5mg IM
- Sumatriptan 50mg oralis

Episodic tension-Type headache

Acute Treatment
- Analgesics: NSAID mg Naproxen 250-500mg
- Avoid opioids and compound analgesics

Prevention
- Antiemetics
- Amitriptyline 15-100mg
- Nortriptyline 10-150mg

Common causes:
- Chronic migraine
- Chronic tension type headache
- Medication over-use headache

Red Flag Features
- Progressive headache
- Sudden new “worst ever” headache
- Scalp tenderness, jaw claudication
- Significant fever or systemic upset
- New altered headache in elderly
- New altered headache in Immunocompromised
- New altered headache in patient with known malignancy
- Examination abnormal:
  - Dye movements
  - Fundus – eg papilloedema
  - Pupils and palpebral reactions
  - Limb and or gait ataxia
  - Tendon reflexes/plantar

Serious Problem suspected
- Consider other acute cause
- TMJ dysfunction
- Cervicogenic headache
- Ophthalmic Neuralgia
- Sinusitis
- VAS

Yes
- Refer urgently to neurology
- If migrainous suspected refer 2 week wait

No
- Other Secondary Headache

Please address letters to Dr. Bal Athwal, Consultant Neurologist, Neurology Department, Royal Free Hospital, Pond Street, Hampstead, London NW3 2QG.
The Neurology Secretary’s office fax number is 020 7472 6020

Guidelines developed by: Dr. Asna Turner, GP, NHS Barnet Clinical Lead and Dr. Bal Athwal, Consultant Neurologist, Royal Free Hampstead NHS Trust
January 2010
Review Date: January 2012
### Headache Summary Camden Guidance

#### Migraine

**Diagnosis**
- Recurrent episode moderate or severe
- Unilateral (unilateral 30%)
- 4-/ pulsating +/- aura
- lasts 4-72 hrs
- Assoc nausea +/- vomiting, photophobia or phonophobia
- v/v FH migraine
- Triggers include – stress, depression, dietary, menstruation, exercise, altered sleep, excess different stimuli, weather change, chemical e.g. OTH/ alcohol

**Management**
- Acute: 1st line – simple analgesics – paracetamol/NSAIDs
- 2nd line – H1 agonists e.g. sumatriptan
- 3rd line – intranasal sumatriptan
- 4th line – buccal prochlorperazine
- 5th line – domperidone sups.
- Prophylaxis: 1st line – 8-blockers propranolol – 80-240mg individual doses
- 2nd line – Pindolol/ceflaxetine 25-150mg/day
- Topiramate 50-300mg/day
- Sodium Valproate – 800-1500 mg/day
- Gabapentin – 1200-2400 mg/day
- Valproatae – 75-150 mg/day

**Migraine C1 to C0 of OCCP > 20 yrs w/o aura**
- Avoid COCP and avoid cold
- Exclude MOH as complicating factor.

#### Cluster

**Diagnosis**
- Severe unilateral pain in trigeminal distribution
- Lasts 15min – 72hrs
- Cluster period 6-12wks usually same time each year
- Ipsilateral autonomic features
- Assoc restlessness
- Assoc nausea / photophobia / phonophobia and aura usually absent

**Management**
- Acute: Subcut inj. 6mg sumatriptan
- Nasal sumatriptan or 20mg triptan
- Oxygen 100% 10-12/min for 10-20mins
- Prophylaxis: Verapamil 240-900mg/day

#### Chronic Daily Headache – CDH (tension type headache)

**Diagnosis**
- Mild-moderate intensity
- Episode lasting < few hours
- Occurring > 15 days a month
- Unilateral or generalised
- Describe as pressing / tightness
- Often spreads into or arises from neck
- Lacks specific features assoc. with migraine
- No effect head movement / physical activity
- Often assoc. with stress / anxiety / depression

**Management**
- Education / identify contributing factors and confirm not MOH
- 1st prevention
- Regular exercise
- Phisio if MSK
- Lifestyle changes: Relaxation therapy, CBT, yoga, meditation to ↓ stress
- Medication: IF 2 or less days/wks try
  - Amoxicillin/paracetamol/buproxen
  - Otherwise consider Amphetamine 25-150mg/day

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Refer if therapy fails or uncertain
Appendix 3 - Protocols and Guidelines for the Management of Headaches

Appendix 3a – Greater Manchester Headache Algorithm / Notes PCT V2 March 2012 and Botox for Migraines

Greater Manchester Headache Management Pathway
March 2012 Version 2

Adult with Headache

- Emergency symptoms?
  - Yes
  - Consider urgent referral to rheumatology, ophtalmology or neurology as appropriate (for consideration of transcranial artery Doppler)
  - NO

- Giant cell arteritis?
  - Yes
  - Prednisolone 60mg o.d. immediately
  - NO

- 2WW referral (use Neurology 2WW form)
  - NO

- Bedrest?
  - Yes
  - NO

- Can you diagnose migraine or tension headache?
  - Yes
  - Prescribe acute treatments (i.e. 1 tablet/month)
  - NO

- DOX secondary causes?
  - No
  - Refer to Neurology (use Headache Referral form)
  - Yes
  - Treat as necessary
  - NO

- Suspect - Medication overuse headache (MOH)?
  - Yes
  - Stop offending medication (for 3 months if MOH)
  - NO

- Still troublesome?
  - Yes
  - No further treatment
  - NO

- Can you diagnose migraine or tension headache?
  - Yes
  - NO

- Still troublesome?
  - Yes
  - No further treatment
  - NO

Preventative and Acute Treatments

Preventative treatments
- If relevant, consider stopping combined oral contraception. Note: combined OCP is contraindicated in migraine with aura.
- Ensure not oversupplying analgesics or triptans
- Treat tension headache usually improves 2 weeks after ceasing triptans, but can take longer
- Medication overuse headache improves/resolves within 2 months of analgesic cessation
- Modify lifestyle (adequate sleep, hydration, reduce caffeine intake, trigger avoidance)
- If prophylactic necessary, try the following treatments for 6 months at the target dose before judging efficacy
- Migraine prophylaxis
  a) Propranolol 80mg p.o. if no benefit after 4 weeks, increased gradually (titrated to a maximum of 240mg a day)
  b) If ineffective or intolerable (or other contraindications): Amitriptyline 50mg p.o. increasing by 10mg a week up to 100mg or maximum tolerated below that (unlicensed, but standard practice)
  c) Don't bother with prophylaxis (weight gain, sleep, etc. benefit)
  d) If above ineffective/intolerable, try Topiramate 50mg a day increasing by 25mg every 4 weeks aiming for a target of 50mg b.d.
- Tension Type Headache prophylaxis
  - Amitriptyline 10mg p.o. increasing by 10mg a week up to 100mg or maximum tolerated below that (unlicensed, but standard practice)
Botox® for migraine at Salford Royal Foundation Trust

Botox® (Botulinum toxin type A) is licensed for the treatment of chronic migraine and provides a potentially effective strategy in addition to the other therapeutic options for the treatment of this disabling condition. It costs significantly more than existing therapies and there is concern that patients may be referred for Botox before other simpler and effective medications have been considered.

The North West Specialist Commissioners Clinical Reference Group has developed a protocol for the use of Botox in migraine across the North West Neuroscience centres. The criteria for the referral of patients with chronic migraine and migraine with medication overuse are detailed below and apply to clinicians in primary and secondary care.

Patient groups: Referral criteria

1) Chronic migraine
   a. Headaches on ≥15 days per month (a minimum of 8 must be migrainous)
   b. No analgesic overuse (<10 days per month of analgesic or triptan use)
   c. Lifestyle changes implemented as appropriate, including withdrawal of caffeine
   d. Tried three (3) of the following (unless contraindicated) and continued each for 3 months without significant benefit (unless inappropriate, as judged by the clinician):
      i. Amitriptyline or Nortriptyline: 150mg o.n. or highest tolerated below that
      ii. A Betablocker: Propranolol SR 240mg a day or max tolerated below; or Metoprolol 200mg per day or max tolerated below that
      iii. Topiramate: highest tolerated dose up to 50mg b.d.
      iv. Sodium Valproate: highest tolerated dose up to 600 - 1000mg b.d.
      v. Gabapentin highest tolerated dose up to 600-1200mg tds
      vi. Lisinopril up to 20mg o.d.
   e. Relevant co-morbidities treated optimally

2) Chronic migraine and medication overuse
   a. Headaches on ≥15 days per month (a minimum of 8 must be migrainous)
   b. Analgesic use ≥15 days per month and/or triptan or opiate use ≥10 days per month
   c. No improvement with or intolerant of Topiramate up to 50mg b.d.
      d. Failed analgesic withdrawal as an outpatient, with appropriate pharmacological support; inpatient withdrawal of medication considered or tried if felt to be appropriate or likely to be effective
      e. Considered and/or tried a scalp nerve block (occipital nerve(s)) as part of an analgesic-withdrawal regime
      f. Relevant co-morbidities treated optimally

Referrals should be directed to:
Dr Adam Zernansky, Consultant Neurologist
or
Dr Mark Kellett, Consultant Neurologist

Referrals should include a detailed history that covers the above referral criteria. Failure to document the above information will result in the return of the referral pending satisfactory completion.

If patients satisfy the above criteria they should be asked to complete a daily headache diary starting in GP, as 2 months of headache diary information will be required prior to being started on treatment. Diaries should record the number of headache or migraine days per month, GP visits, A & E visits and other hospital attendances for headache as well as the days that triptans are used. This should be continued throughout the treatment period.
Appendix 3b - Primary Care management of Headache - A Pilot Pathway and Guidelines including access to MRI

Primary Care management of Headache:
A Pilot Pathway and Guidelines including access to MRI
Authors
Dr. Keith Redhead (KR) general practitioner West Norfolk Clinical Commissioning Group, Dr. Dan Rose (DR), Dr. Geoff Hunnam (GH), Dr. Jonathan Graham (JG), Consultant radiologists Queen Elizabeth Hospital Kings Lynn. Dr. Jeremy Brown (JB), Dr. Philip C. Buttery (PB) Consultant neurologists, Queen Elizabeth Hospital Kings Lynn, Debbie Craven (DC), medicines Management team NHS Norfolk Community Pharmacists, Dr. Andy Dowson (AD) Director of headache Services at Kings College Hospital London and Chairman of MIPCA (Migraine in Primary Care Advisors), Jan Sanders (JS) Commissioning Manager West Norfolk Clinical Commissioning Group, Phil Koopowitz (PK) GP and chairman of West Norfolk Referral Management Centre, Alison Lowe (AL) Operations Manager West Norfolk Referral Management Centre
Address for correspondence k.redhead@nhs.net

Abstract
Background
A Pilot pathway and guidelines to assist primary care practitioners manage patients with headache was introduced by the West Norfolk Clinical Commissioning Group (WNCCG) after GPs had expressed a wish to have greater access to imaging.

Aim
The pathway, which included GP access to MRI, provided guidelines as to who should not be referred for scanning, but rather admitted or referred urgently i.e. “Red Flags”. It grouped the “Green flag” patients with primary headache into categories, to aid diagnosis, provide evidence based treatment plans and guidance as to which patients were eligible for GP-MRI.

Design and Setting
The pilot was preceded by an educational programme provided by the authors of the pathway. Every GP from the 23 practices in the WNCCG serving a total population of 164,500 was invited to attend.

Method
A representative from each practice, was obliged to attend the educational programme held on 4/7/12 to allow their practice to take part in the pilot. Access to GP-MRI commenced on 1/4/13.

Results
The educational meetings were highly evaluated by attending GPs. 12 months following access to GP-MRI there was a 29% reduction in headache referrals to the neurology department. 33 patients had undergone GP-MRI. Three of these patients were subsequently referred on to the neurology department.

Conclusion
The results suggest that the pathway and guidelines enabled GPs to manage chronic headache in the community, so reducing the need for referral to neurology. It also indicates that GPs were able to make responsible use of access to imaging.

Keywords
Primary care, headache guidelines, MRI access

How This Fits in
Providing GPs with a pathway and guidelines for headache, which included access to MRI scanning launched by an educational meeting, was associated in the first year with a significant reduction in neurological referrals, without a large increase in MRI requests.
Introduction

Headache is one of the most common symptoms presenting to general practitioners. In a 2 week study of general practice consultations 38% of adults complained of headache\(^1\). The annual consultation rate for headache is 4.4 per 100 patients\(^2\). It is the most common new neurological symptom presented to general practitioners\(^3,2\) and to neurologists\(^4\). Only 3% of headache consultations are referred to secondary care\(^2\).

Headache is the reason for up to a third of new neurology referrals from general practice\(^2,4,5\). In 2011-12 it was the reason for 24% of referrals from West Norfolk GPs to the department of Neurology, Queen Elizabeth Hospital, Kings Lynn. There is however a wide variation in referral rates amongst GPs\(^6\). The Royal College of physicians, in their paper Local Adult Neurology services for the next decade, stated “greater use should be made of GPs particularly for the management of headache [...]] liaising with local neurologist for training and support”\(^7\).

Headaches presenting to GPs are most commonly migraine and chronic tension headache\(^8\) and it has been suggested that most primary headache can be managed in general practice\(^9\). However, primary care health professionals find the diagnosis and classification of headache difficult, and both health care professionals and patients worry\(^10\) about serious causes such as brain tumours, despite the fact that when patients present to their GP with headache the risk of brain tumour is 0.09%\(^11\). The decision to investigate headache depends on a number of factors including therapeutic value, clinical confidence, time constraints in the consultation, availability of imaging, the GP’s approach to risk and uncertainty, reassurance of an anxious patient and medico-legal concerns\(^12,13,14\).

At a WNCCG engagement meeting held on 9/2/12 GPs expressed the desire to have better access to imaging to investigate headaches to address some of these factors. Primary care access to imaging has been shown to reduce referral rates. An open access brain CT service for patients with chronic headache in Tayside and North East Fife reduced referrals to secondary care by 86%\(^15\). The findings of a study in Nottingham suggest that a defined access pathway for imaging to investigate chronic headache can be deployed appropriately in a primary-care setting\(^16\). GPs attended an educational meeting and MRI scans were reported clearly for non-specialist referrers to aid further management.

Preliminary discussions with the local neurologists in Kings Lynn revealed their concerns that providing GPs access to MRI may lead to delay of acute diagnoses such as subarachnoid haemorrhage, arterial dissection, meningitis, giant cell arteritis. These patients needed to be admitted or referred urgently and not referred for scanning. Kernick, Headache champion Royal College of General Practitioners, proposes GPs have access to imaging unless the patient presents with associated neurological signs, when urgent neurological referral is recommended\(^17\). An additional concern was the risk of doing harm to the patient by discovering “incidental findings” on the MRI and thereby causing anxiety. Incidental findings on brain imaging may be found in 0.6-2.8% of the population\(^18,19,20\). The radiology department was concerned about the potential for a large number of MRI requests. The commissioners (WNCCG) were concerned about duplication and overspend of resources.

In keeping with the Nottingham study, the proposal was to provide all 23 practices in the West Norfolk Clinical Commissioning Group (WNCCG) (population 164,500) with access to MRI for refractory headache. This access would be linked to an educational programme and a pilot Pathway with guidelines. The neurologists and radiologists insisted that a representative from every practice attend the educational meeting, to ensure that patients were referred according to agreed criteria.
It is suggested that headache is poorly managed by GPs. Normal investigation does not eliminate the need for follow up and appropriate management. It is estimated that 60% of patients presenting to general practice with headache have migraine. Migraine remains under-recognised, under-diagnosed and under-treated in everyday clinical practice. It was therefore proposed that the pilot pathway should contain guidelines regarding diagnosis, together with evidence-based management in keeping with local prescribing guidelines. Once a representative from every practice had attended an educational session, and the CCG had ratified the project, the pilot would commence.

**Method**

A working group consisting of a general practitioner (KR), radiologists (GH, DR, and JG), and neurologists (JB and PB) met on three occasions to devise the headache pathway and guidelines (appendix). Particular emphasis was placed on the RCP paper and the work of the Nottingham group, with whom DR had been corresponding. Expert advice was provided by the Director of Headache Services at Kings College Hospital London (AD). The Community pharmacist (DC) collaborated with the WNCCG medicines management team, to ensure the pathway treatment plans were in keeping with locally agreed prescribing guidelines. Subsequently a business plan was drawn up with the commissioning manager (JS) and agreements were made regarding neurology tariffs and the costs for GP-MRI. The chairman (PK) of the West Norfolk Referral Management Centre (WNRMC) designed a GP-MRI electronic request form. The GP-MRI reporting was undertaken by general radiologists in a suitable GP-friendly fashion. Thus, when incidental findings were detected, explicit guidance would explain their relevance. Monitoring of both GP-MRI and neurology referrals was undertaken by the operations manager (AL) of the WNRMC.

A meeting was held on the 4/7/12 organised via the GP tutor. Every GP was invited and all practices were sent the proposed pathway. The evening 2 hour 15 minute meeting consisted of 5 presentations followed by questions and answers. The presentations were as follows: KR: “Why create a headache pathway” PB: “headaches which need urgent investigation”, JB: “When should a GP ask for an MRI” JG “What should a GP do with the MRI result?” AD: “Diagnosis and management of headache in primary care”. AD also provided links to the charitable website for ongoing education. A second afternoon meeting with a similar format was held on 21/3/13, to ensure that remaining practices were represented. The pilot was launched on the 1/4/13.

**Results**

The headache pathway and guidelines were launched on 4/7/12 at an educational meeting, and by electronic distribution of the pathway to all WNCCG GPs. It was originally planned that access to GP-MRI would commence shortly after this meeting. However due to contractual problems access to GP-MRI was delayed by eight months, finally launching on 1/4/13. The educational meeting was evaluated by the 39 attending GPs using a 5 point Lickert scale and the scores averaged 4.5 out of 5. All practices were represented at one or both of the educational meetings.

The results of 22/23 practices (population 163,821) who used the Choose and Book system were analysed. The annual figures represent data collected from April to end of March. There has been a reduction of headache referrals from GPs in the WNCCG from 335 in 2011/12 to 299 in 2012/13, a reduction of 11%. The launch of the pathway took place in July 2012. There was a further reduction of headache referrals to neurology to 237 in the second year of the pathway 2013/14. Access to GP-MRI became available on the 1/4/13. This represents a 29% reduction compared with the 335 referrals in 2011/12.
There has been a reduction of headache as the reason for referral to neurology as a proportion of total neurology referrals from 24% to 21% to 18% over the 3 years.

12 months after access to imaging there had been 36 referrals for GP-MRI. 2 patients failed to attend (patients offered 2 appointments). The condition of 1 patient altered after the GP-MRI had been requested and that patient underwent urgent CT scan after discussion with the radiology department. Of 33 patients who underwent GP-MRI, there was only 1 abnormal result, a possible normal pressure hydrocephalus. There were 32 normal results, which included 9 incidental findings (27%). The 9 incidental findings were:

1. cerebral atrophy
2. small vessel ischaemia
3. pineal cysts
4. type I Arnold Chiari malformation.

Three of 33 patients who underwent GP-MRI were referred on to the neurology department. One patient with possible normal pressure hydrocephalus was referred directly as a result of GP-MRI. The other 2 patients were referred for further advice on the management of their persistent headaches. They had incidental findings on their GP-MRI (cerebral atrophy and pineal cyst).

There was a wide variation in the percentage of headache referrals as a proportion of the total neurology referrals in the individual practices. In 2011/12 the variation was 8-39% in 2013/14 the variation was 3-32%.

During the same time the data shows a reduction of total referrals to neurology from 1415 on 2011/12, 1392 in 2012/13 and 1288 in 2013/14. However if the headache referrals are removed from these figures it shows the numbers of all other neurology referrals have remained similar for the 3 years 1080, 1093 and 1051.

Discussion

The desire for access to imaging for headache had been originally expressed by West Norfolk GPs themselves. The overwhelming support for this project from constituent GPs was demonstrated by their attendance at educational meetings, their evaluation of the pathway, and their willingness to participate in the pilot.

The results demonstrate a sustained reduction of referrals of patients with headache to the neurology OP department by GPs in the West Norfolk CCG, following the launch of a pathway and piloted access to GP-MRI. The reduction in referrals in the first year would seem to be solely attributable to the educational meeting and distribution of the pathway. The reduction in the second year would appear to be a combination of the pathway and access to imaging. Overall there was a 30% reduction in headache referrals to neurology, while referrals for other neurological complaints over the same period remained static. In accordance with Ridsdale, there was seen to be a wide variation in referral patterns for headache amongst this group of GPs.

After 1 year this data indicates that GPs can use the opportunity of access to imaging for headache responsibly. The concerns of the commissioners about increased cost and the concerns of the radiologists about increased demand for MRI were not realised. The concerns of the neurologists relating to the discovery incidental findings on MRI (27%) were offset by appropriate radiological reporting. This data suggests that the pathway itself, launched by 2 educational meetings, was in part the reason for referral reduction, enabling GPs to manage headache in primary care. It demonstrates the benefit for GPs by
working with neurologists for training and support, as proposed by the RCP. The overall reduction in neurological referrals suggests its cost effectiveness.

It is proposed that GPs should continue to have access to GP-MRI according to these guidelines. There is a need for continued data collection to assess whether the enablement is continued and quality of care is maintained.

Acknowledgements

Many thanks to Neil Bindemann of the Primary Care neurology Society for introducing KR to AD and for his encouragement. Dr Hilary Lazarus for her help with the manuscript.

Tables:

<table>
<thead>
<tr>
<th>Total Neurology Referrals</th>
<th>Total Headache Referrals</th>
<th>% Headache referrals against total to Neurology</th>
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<tr>
<td>2011/12</td>
<td>1415</td>
<td>335</td>
</tr>
<tr>
<td>2012/13</td>
<td>1392</td>
<td>299</td>
</tr>
<tr>
<td>2013/14</td>
<td>1288</td>
<td>237</td>
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Table 1 Total Neurology referrals headache referrals for 3 years 2011/12, 2012/13, 2013/14

<table>
<thead>
<tr>
<th>Total Headache referrals</th>
<th>Referred direct to Neurology</th>
<th>% against total headache referrals</th>
<th>Referred to Neurology Following MRI scan</th>
<th>% against total headache referrals</th>
<th>Total referrals for MRI</th>
<th>% MRI requests referred on to Neurology</th>
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<tr>
<td>2011/12</td>
<td>335</td>
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<td>77</td>
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<tr>
<td>2012/13</td>
<td>299</td>
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<td>70</td>
<td>16%</td>
<td>118</td>
<td>555</td>
</tr>
<tr>
<td>2013/14</td>
<td>237</td>
<td>98%</td>
<td>23</td>
<td>9%</td>
<td>23</td>
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Table 2 Headache referrals and number of patients referred for GP-MRI

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<tr>
<th>Practice</th>
<th>Neurology Referrals</th>
<th>Referral Reason Headaches within Neurology</th>
<th>Percentage of Headaches referrals within Neurology</th>
<th>Referral Reason Headaches within Neurology</th>
<th>Percentage of Headaches referrals within Neurology</th>
<th>Referral Reason Headaches within Neurology</th>
<th>Percentage of Headaches referrals within Neurology</th>
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<td>1382</td>
<td>237</td>
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Table 3 Headache referrals by practice, 8 practices (highlighted) made use of access to GP-MRI
References
17. Kernick D, Williams S. Should GPs have direct access to neuroradiological investigation when adults present with headache?. The British Journal of General Practice. 2011; 61 (587): 409.
Introduction

Headache is a common condition. It has a lifetime prevalence of over 90\(^1,2\); so it affects nearly all of us. Only a small proportion of patients with headaches consult their GPs; only 4.4% of all patients consult their GPs every year because of headaches\(^3\). A small minority of these patients is referred to neurologists but, because there are few neurologists, 30% of all patients referred to neurologists are for headaches.

The International Headache Society (IHS) has produced a hierarchical classification of headaches with 15 major categories of headache diagnoses with a total of about 200 headache diagnoses (see Appendix). Yet approximately 70% to 75% of patients presenting to their GP with headache do not have their headache diagnosed\(^4,5\). Similar figures apply to the USA\(^6\). Most of these undiagnosed headaches are primary headaches and between 30% and 75% are migraine and do not receive appropriate treatment. Many receive simple analgesia transforming their episodic headaches into chronic daily headaches.

Epidemiology of Headache

Headaches are broadly classified into primary headaches, headaches that are not associated with other identifiable disease and secondary headaches, headaches that are thought to be caused by other conditions. Primary headaches are more common than secondary headaches.

The International Classification of Headache Diagnosis (ICHD) has improved consistency of diagnosis and the rigor of scientific study. The prevalence rate of migraine is now very similar across the world at about 15%\(^10,6\). However the IHS recognizes that many patients with primary headache fit more than one diagnostic diagnosis. This has led to the view that many primary headaches may share similar molecular and cellular mechanisms and that many patients, with for example tension type headaches, may benefit from anti-migraine treatment.

The Primary Headaches

The most common episodic primary headaches are migraine and Tension-type headaches (TTH), with about two thirds of migraine overlapping with TTH.

Chronic daily headache (CDH) has a prevalence of about 5%. CDH once thought to be an entity in itself, is now recognized as a transformed episodic headache.

The most common cause of transformation of episodic headache to CDH is the prolonged use of analgesia. Analgesic headaches are said to have a prevalence of about 2%, but analgesia may be a significant factor in a much higher proportion of CDH.
Other primary headaches, include the Trigeminal Autonomic Cephalgias (TAC) of which the most common is cluster headaches. Although uncommon, the severity and relative intractability of these headaches may result in frequent consultations. There are a number of other primary headaches of which the prevalence is uncertain.

**The Secondary Headaches**

Fear of misdiagnosing a sinister secondary headache is the most common reason for referral to secondary care. Many of the ICHD diagnostic codes (e.g. Headache attributed to head and/or neck trauma ICDH 5) may cause headaches by triggering migraine. Many secondary headaches present with clinical features in which the headache symptom is not the most important symptom. However it is the secondary headache in which the headache may be the most prominent clinical feature that causes most diagnostic anxiety.

Kernick et al.4 studied the subsequent diagnosis of 85,679 patients diagnosed with headache. In 25% the initial diagnosis was of primary headache, 75% were “undifferentiated”.

<table>
<thead>
<tr>
<th>Subsequent diagnosis</th>
<th>Undifferentiated</th>
<th>Primary Headache</th>
</tr>
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<tbody>
<tr>
<td>Subarachnoid</td>
<td>0.14%</td>
<td>0.02%</td>
</tr>
<tr>
<td>Malignant brain tumour</td>
<td>0.15%</td>
<td>0.045%</td>
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<tr>
<td>Benign space occupying lesion</td>
<td>0.05%</td>
<td>0.009%</td>
</tr>
<tr>
<td>Temporal arteritis</td>
<td>0.66%</td>
<td>0.18%</td>
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<tr>
<td>Stroke</td>
<td>1.06%</td>
<td>0.45%</td>
</tr>
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<td>TIA</td>
<td>0.43%</td>
<td>0.25%</td>
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The conclusion of this study was that while the prevalence of undiagnosed sinister headache was low, it was high enough to merit vigilant follow up.

**A Model for Headache Management**

Headache is common with a lifetime prevalence of 90%. 4% of the population have headache more than 50% time. Patients with migraine may lose 15 days of work per year. In the population as a whole, two days of work per year are lost through headaches and the number of days of reduced function may be five times higher 26,27. Yet the diagnosis of headache is difficult; between 70% and 75% of headaches are unclassified in primary care 4,5. Patients referred to secondary care may get an accurate diagnosis but in general they do not get a follow-up appointment and in one study 12 76% patients referred to secondary care reported relief of symptoms in contrast to a GPSI service where 89% reported relief of symptoms. About 3% of patients with headaches are referred to secondary care but the only difference in these patients appears to be that they are more anxious and put more pressure on their GPs for referral11.

The challenge, therefore is to provide a diagnosis and management strategy for the 75% of patients with headache who do not receive a formal diagnosis. The prevalence of headache is simply too great for this to be managed by a small group of super-trained GPSIs.
GPs, like other doctors, cannot maintain a specialist interest in all domains of their clinical practice; some have specialist expertise in obstetrics, others in respiratory disease. One interpretation of these figures is that about 25% of GPs have an interest in headache and are confident in the differential diagnosis of headache. The challenge is to direct patients with headache to doctors who are interested in headache. This group of doctors could be a member of a “Headache Club”. There should be approximately one member of the headache club (or more) per General Practice surgery. Headache referrals could be made by other GPs within the practice or receptionists could direct patients with headaches to the appropriate doctor. Members of the club could attend regular meetings along with neurologists and GPSIs.

More difficult headaches, refractory headaches, unusual trigeminal autonomic cephalgias, and other rare headaches would best be managed by GPSIs, who have both the expertise and resources to follow them up. A neurologist with a specialist interest in headaches (NSI) could be integrated with the GPSTI team.

**Model of Care for East Kent**

**Population 750,000**

[Diagram of model of care for East Kent with secondary care, specialist service, and headache club]
Appendix 4 – Shared Learning

Neuroscience Project Description Summary V1.1

<table>
<thead>
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<th>Work stream</th>
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<td>Project Title</td>
<td>Primary and Secondary Care Pathway Improvement Project</td>
</tr>
<tr>
<td>Domain</td>
<td>Domain 2: Enhancing quality of life for people with long-term conditions</td>
</tr>
<tr>
<td>Work stream lead</td>
<td>Lionel Ginsberg</td>
</tr>
<tr>
<td>Project lead</td>
<td>Michael Oates</td>
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</table>

**Project description:**

To improve outcomes for patients and clinicians by developing shared ownership of neurological clinical pathways, underpinned by shared learning and effective communication between primary and secondary care.

Many excellent neurological educational resources already exist. Yet “neurophobia” remains prevalent among non-neurological professionals and, conversely, neurologists sometimes fail to meet or even fully understand the needs of primary care physicians and their neurological patients. This project is not intended to reinvent the wheel by providing exhaustive educational material on the broad range of neurological conditions. Instead, it will focus on the most common outpatient conditions and use selected innovative educational approaches to amplify and clarify key points in agreed management pathways.

The first condition to be tackled will be headache, one of the top ten symptoms in general practice and the commonest reason for referral to neurological clinics. Many headache pathways have been developed between primary and secondary care (example from Barnet in Appendix 2f). The project team will first agree an up-to-date pathway and identify key aspects requiring enhanced shared learning (e.g. red flags, medication overuse, acute management and prevention of migraine). These topics will then be addressed in a semi-scripted video conversation between a general practitioner and a neurologist. The product could be available as a podcast or smartphone app. The video could be viewed as a whole or segmented into individual topic areas which could then be anchored to specific points in the pathway. Further, in-depth educational resources could also be flagged at those points. In addition to linkage to the pathway itself, there are other obvious synergies for a product of this kind, e.g. to GP web-based IT systems, and to the web hub currently being developed by the Information work stream of the London Neuroscience SCN.

Depending on the success of this headache exemplar, the same approach will be rolled out sequentially to “Dizziness” and then “Transient Loss of Consciousness (TLOC)”. Taken together, these three symptom groups constitute well over 50% of referrals to neurological outpatients.
Appendix 5 - Yorkshire & Humber action plan re Headaches

Yorkshire & Humber Strategic Clinical Network & Senate

Headache work

The Y&H SCN for Neurology has identified a clinical lead Dr Ed Dunn from Leeds Teaching Hospitals to help drive the national headache agenda across the region. The SCN has identified a project lead Colin Sloane (Newly appointed Neurology QIL) to assist Dr Dunn. Dr Dunn is also a member of the Y&H SCN Neurology Clinical Expert Group, this group consists of neurology clinical leads from across the region and SCN members. The aim of this group is to drive forward large scale change and share/agree best practice regionally so will provide a forum for discussing headache related concerns and initiatives. In line with national priorities the SCN has prioritised headache management as one of its key areas for quality Improvement and has identified the following plans to help inform the overall headache programme:

1. The development of a questionnaire to identify neurology related educational needs of Junior Doctors working in A&E. Local neurologists are concerned that some Doctors in A&E are unprepared for the complexities associated with A&E and admit patients for further investigations rather than completing certain tests during the A&E consultation/assessment e.g. performing lumbar punctures in A&E. Another A&E concern is associated with patients being discharged without adequate interventions with or without an onward referral to neurology, e.g. poor headache assessments/management relaying on the neurology consultant outpatient clinic. This is also an issue for GP management in the community.

2. The SCN will undertake a scoping exercise to identify:
   - Which hospitals in Y&H provide headache clinics
   - Consultant or nurse led clinics
   - Identify any data around headache related incidence accessing A&E, LOS.
   - Best practice pathways

3. Development of an SCN Headache task and finish group to take forward this work

4. Work with the National Headache steering group and lead as required on these initiatives on behalf of the Northern SCNs.