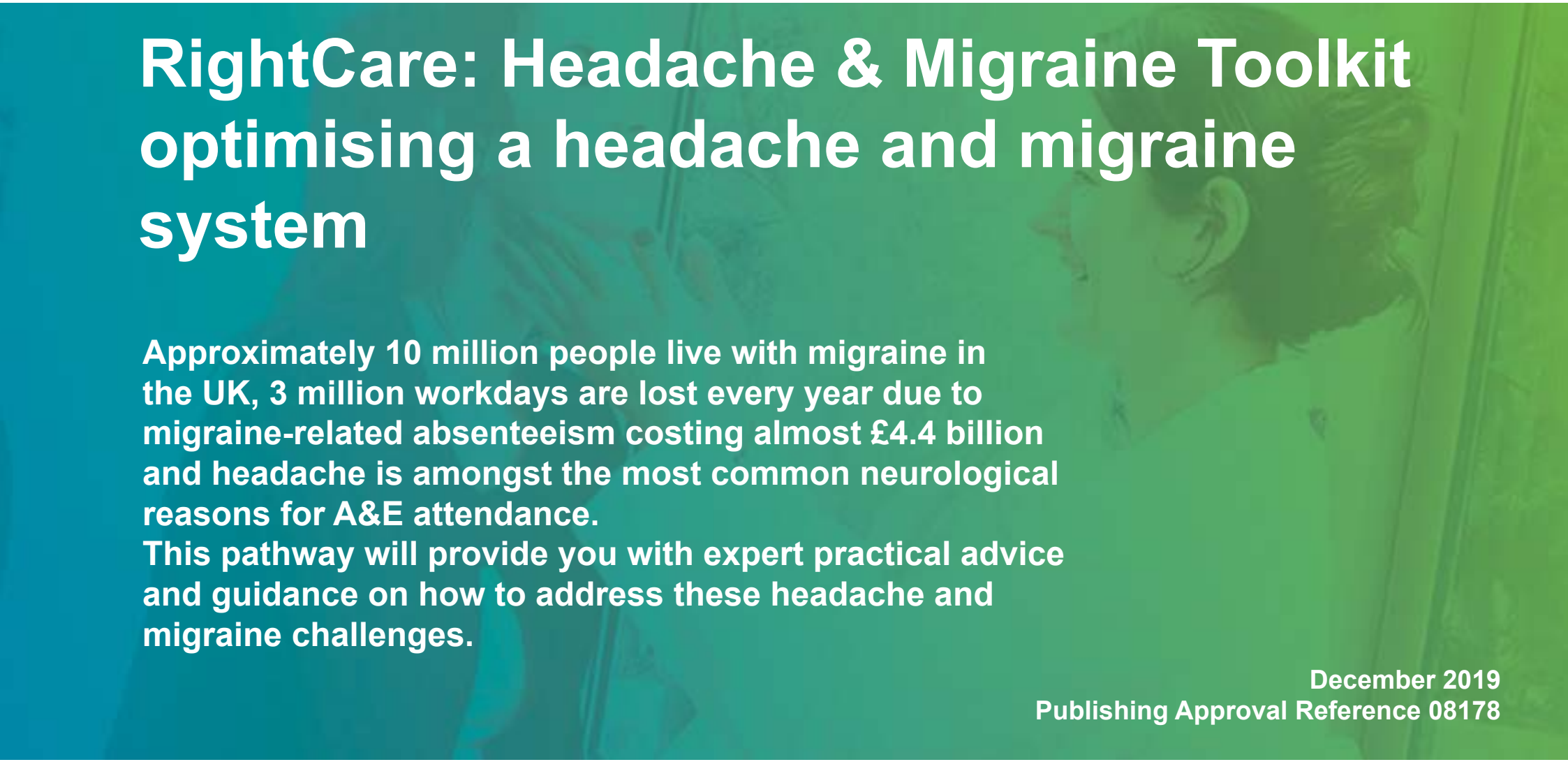
NHS RightCare

RightCare: Headache & Migraine Toolkit optimising a headache and migraine system



Approximately 10 million people live with migraine in the UK, 3 million workdays are lost every year due to migraine-related absenteeism costing almost £4.4 billion and headache is amongst the most common neurological reasons for A&E attendance.
This pathway will provide you with expert practical advice and guidance on how to address these headache and migraine challenges.

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THE NEUROLOGICAL ALLIANCE

Informed by:

NICE National Institute for Health and Care Excellence

RightCare Headache & Migraine Toolkit

This RightCare system toolkit will support systems to understand the priorities in headache and migraine care and key actions to take. It provides opportunity to assess and benchmark current systems to find opportunities for improvement. It is produced with reference to an expert group of stakeholders and is supported by NICE. Wider consultation has taken place with patient representatives, clinicians, social care organisations, professional bodies and other key stakeholders.

The National Challenges:

- Approximately 10 million people aged 15-69 live with migraine in the UK
- Migraine is the second leading cause of years lived with disability.
- 3 million workdays are lost every year in the UK to migraine-related absenteeism alone, at a cost of almost £4.4 billion.
- In the UK, the annual primary care consultation rate for headache is 4.4 per 100 registered patients, of whom, 4% are referred to secondary care for further assessment.

The National RightCare Opportunity for Improvement:

- Around £11.5m could be saved on non-elective admissions for headache and migraines if CCGs achieved the rate of their best 5 peers
- Nearly 16,500 fewer emergency admissions for headaches and migraines if CCGs achieved the rate of their best 5 peers.

Benefits to patients:

- Accurate classification and treatment will reduce unnecessary visits to both primary and secondary care.
- When headaches and migraines are better controlled, there is an improvement in quality of life issues such as improved sleep, less restriction on daily activities, attendance at work, and the overall impact on family life.

Links to other RightCare products:

RightCare has a designated neurology workstream including Focus Packs for neurology.

RightCare Headache & Migraine Toolkit

The Challenge for Commissioners

Migraine is a common and disabling primary headache disorder, and recent estimates from the Global Burden of Disease (GBD) 2016 study estimates an adult prevalence of 23.3%. However the condition is still under-diagnosed and under-treated, and public and professional understanding of the condition is poor. This leads to large numbers of patients visiting A&E or being referred into outpatient neurology services for unnecessary investigations and treatment. A large volume of these cases are primary headache disorders that could be appropriately treated and managed in a primary care setting. The increase in neurology referrals causes pressure on outpatient clinics and patient delays. There is an inevitable spill-over into unplanned (emergency) presentations to the emergency department.

The challenge for commissioners is that most headaches referred to secondary care end up with a diagnosis of migraine and/or medication overuse headache, which is best managed in the community, which is easier for patients to access and cheaper for the healthcare economy. Commissioners should have a pathway that allows people with severe or complex headache disorders, or those with concerning features, to commission a pathway that allows people with severe or complex headache disorders, to be seen in secondary care in a timely fashion whilst providing consistent support in the community for those people with migraine and other primary headache disorders who can be better managed there. Throughout this framework examples are highlighted where areas have already undertaken this work to address this challenge and improve health outcomes.

We urge all local health economies to read the British Association for the Study of Headache (BASH) guidelines which draws on the best available evidence for good practice including the NICE Clinical Guideline for Headaches (CG150) and the NICE Quality Standards for Headaches (QS42).
All commissioners should be aware of the prevalence and impact of migraine and headache disorders locally in the RightCare Focus Packs and the Neurology Intelligence Network data resources.

RightCare Toolkit: Headache & Migraine

System Improvement Priorities

Correct identification and diagnosis of headache disorders

Making appropriate referrals to secondary care

Support patients to self manage their condition after diagnosis

Long-term management of patients in primary or community care

System Improvement Priority:

Correct identification and diagnosis of headache disorders

Accurate diagnosis and appropriate management of primary headache disorders can help prevent chronicity, medication overuse headache and the impact on other physical or mental health conditions.
Therefore, classifying headache according to the presenting features will allow people with primary headache disorders to receive appropriate treatment and prevention strategies in primary care relevant to their diagnosis.
It is recognised that some people will have more than one headache disorder and therefore have more than one classification. Accurate classification and treatment has the potential to reduce referrals for unnecessary investigations and contribute to improved quality of life for people with a primary headache disorder.

Key areas for focus:

Healthcare practitioners to be supported and educated on the presenting symptoms of primary headache disorders (migraine, tension-type headache, cluster headache) and medication overuse headache (MOH).
Migraine and other headache disorders are often poorly recognised, diagnosed and subsequently managed, leading to variation in patient care, outcomes and experience.
If patient presents with an episodic, disabling headache with a normal neurological examination, it should be assumed to be migraine until evidence presents to the contrary (see slide 14 for common misinterpretation of symptoms that lead to referral). This way, more headaches will be diagnosed and treated effectively.

Guidance & Best Practice

Patients to be given a positive diagnosis of a primary headache disorder after being assessed against standardised criteria.
Both BASH and NICE guidance provide criteria that a patients symptoms can be assessed against to diagnose one of the primary headache disorders (migraine, tension-type headache, cluster headache). Where a patients symptoms are outside of these criteria (secondary headaches), referral to secondary care should be considered to rule out any other underlying pathology or other more serious conditions

Guidance & Best practice

Where a primary diagnosis cannot be made initially (and after the exclusion of secondary headaches) diagnostic decision making should be made over time by the application of a headache dairy.
There are no diagnostic tests for any of the primary headache disorders, so the use of a headache diary is an important tool in understanding the pattern of attacks. This should be undertaken over time (and once the exclusion of a more serious condition has been ruled out).

Guidance & Best practice

Actions to take

System Improvement Priority:

Correct identification and diagnosis of headache disorders

Actions to take:	
Healthcare practitioners to be supported and educated on the presenting symptoms of primary headache disorders (migraine, tension-type headache, cluster headache) and medication overuse headache (MOH).	• Have clinical champions for primary headache disorders identified within the local system, who have a role in promoting a consistent and universal awareness and understanding of primary headache disorders. • Promote and undertake learning sessions around primary headache disorders for healthcare professionals.
Patients to be given a positive diagnosis of a primary headache disorder after being assessed against standardised criteria.	• Use standardised assessment criteria to make a diagnosis of primary headache disorder (e.g. NICE diagnosis table, BASH guidelines criteria). • When a diagnosis has been made, provide an explanation of the diagnosis and reassurance that other pathology has been excluded (known as a positive diagnosis).
Where a primary diagnosis cannot be made initially (and after the exclusion of secondary headaches) diagnostic decision making should be made over time by the application of a headache dairy.	• If a primary diagnosis is not clear (but there is no concern of the presence of secondary cause for the headaches) utilise a headache diary to record frequency of attacks. • Review the headache diary in 6-8 weeks to support the diagnosis of one or more of the primary headache disorders.

Guidance and best practice examples

System Improvement Priority:

Making appropriate referrals to secondary care

Headache accounts for a large number of specialist neurology appointments, and some of these can be avoided. Unnecessary outpatient appointments waste patient's time, resulting in time off work and school, as well as causing delays in access for patients with potentially serious secondary headache disorders or other neurological conditions that require investigation urgently. So ensuring that referrals to secondary care are appropriate will benefit patients, reduce waiting times and reduce the costs associated with unnecessary attendances at outpatient clinics.

Key areas for focus:

Patients should only be referred to secondary care for further investigation if their symptoms fall outside of the standard classification of primary headache disorders.
Where a patients symptoms cannot be used to make a diagnosis of headache or migraine and the clinician has a concern that their symptoms may be reflective of a serious underlying condition, the patient should be referred onwards to secondary care for investigation. However where a patients symptoms are in line with a diagnosis of headache or migraine, they should not then still be referred to secondary care to confirm the diagnosis of a primary headache disorder for reassurance purposes

Education and awareness of healthcare practitioners of the signs of medication overuse headache, which do not require referral into secondary care.
Medication overuse headache (MOH) commonly results from chronic overuse and self-administration of analgesics to treat acute headaches. An understanding of the patients current daily medication usage should be taken in to account before referring into secondary care for further investigation. A diagnosis of MOH is usually made retrospectively and when symptoms improve after a period of time undertaking medicine withdrawal.

Consider implementation of referral support services to provide advice to healthcare professionals on the appropriateness of headache referrals to specialist outpatient neurology services.
If a healthcare professional is unsure of the necessity or appropriateness of referring a patient into secondary care for their headaches, having local initiatives in place to access a specialist (e.g. a consultant or a GPwSI), to seek advice from may help to reduce inappropriate referrals into specialist neurology outpatient clinics.

Actions to take

Guidance & Best Practice

Guidance & Best Practice

Guidance & Best Practice

System Improvement Priority:

Making appropriate referrals to secondary care

Actions to take:	
Patients should only be referred to secondary care for further investigation if their symptoms fall outside of the standard classification of primary headache disorders.	• If a patients symptoms are reflective of the features of one of the primary headache disorders, (as per NICE diagnosis table, BASH guidelines criteria), do not refer them to secondary care, unless the headache condition has not responded to a good trial of acute and preventative therapies. • Where a primary headache disorder diagnosis has been in primary or community care, do not refer the patient to neuro-imaging solely for diagnosis confirmation or reassurance purposes. • Where a secondary headache disorder is suspected (based on clinical symptoms) refer the patient to secondary care.
Education and awareness of healthcare practitioners of the signs of medication overuse headache that do not require referral into secondary care.	• Have a shared awareness and understanding of primary headache disorders across the local system. • Provide training to healthcare practitioners on the signs of medication overuse headache and common features of primary headache disorders such as migraine.
Consider implementation of referral support services to provide advice to healthcare professionals on the appropriateness of headache referrals to specialist outpatient neurology services.	• Consider implementation of a support line (e.g. email or telephone) to access specialist advice on appropriateness of a referral into secondary care.

Guidance and best practice examples

System Improvement Priority:

Supporting patients to self manage their condition after diagnosis

Well informed, educated and empowered people are better able to manage their condition long-term and on a day to day basis.

Key areas for focus:

Promote the use of headache diaries to understand personal triggers
When migraine attacks are frequent, a trigger diary may be useful in addition to an attack diary. Patients can be given a list of common triggers and record those present each day whether they have a migraine attack or not.

Guidance & Best Practice

Provide information and education to people with a primary headache disorder on the risks and signs of developing medication overuse headache.
People with migraine and other headache disorders require information relating to the risk of developing medication overuse headache - especially if they are taking triptans or opioids. High caffeine use can also impact negatively on both the frequency and severity of headaches.

Guidance & Best Practice

Utilise pharmacists to provide patient advice on MOH and appropriate use of analgesics.
Pharmacists who dispense over-the-counter or prescribed medications are well placed to advise on medication overuse headache to patients and to support them in the appropriate use of analgesics.

Guidance & Best Practice

Supporting the education of employers of the impact and effect of migraine at work.
Migraine and other headache disorders can be highly disabling and can have a significant impact on employment. Headaches and migraine may increase short term leave of absence from work, reduce capabilities (e.g. driving) or reduce quality of work in the short term, this however should not discriminate them within the workplace and employers should work with the person in respect of HR processes surrounding a known medical condition and the impact on work.

Guidance & Best Practice

Signpost people to third sector resources including local support groups or national advice lines to reduce attendance at A&E departments.
Ensure that services that are commissioned give people with a primary headache disorder information, education and support to manage their condition to reduce attendance at A&E.

Guidance & Best Practice

Actions to take

System Improvement Priority:

Supporting patients to self manage their condition after diagnosis

Actions to take:	
Promote the use of headache diaries to understand personal triggers	• Ensure that patients are given a headache diary/ template to record their frequency and personal triggers for the onset of headaches and migraine • Encourage patients to review their personal triggers to identify if any daily living activities could be changed
Provide information and education to people with a primary headache disorder on the risks and signs of developing medication overuse headache.	• Explain the risk of medication overuse headache to people who are using analgesics such as paracetamol or ibuprofen to treat their headache. • Sign post patients to local or national resources that also explain the risks and treatment options around medication overuse headache.
Utilise pharmacists to provide patient advice on MOH and appropri-ate use of analgesics.	• Utilise pharmacy public health campaigns to promote the use of pharmacists in supporting patients to manage recurrent headaches appropriately. • Undertake strategies such as making every contact count or at MUR reviews to identify if a person is over administering analgesic medication. • Provide patients with information on withdrawal of analgesics to treat medication overuse headaches.
Supporting the education of employers of the impact and effect of migraine at work.	• Encourage people with migraine to talk to their employers about their condition and provide letters of diagnosis if required.
Signpost people to third sector resources including local support groups or national advice lines to reduce attendance at A&E departments.	• Have a local directory of services and support available which enables ease of signposting or referral for people living with primary headache disorders to the services they may find useful. • Ensure that community based services and health providers have adequate training and support to signpost people to reliable and accurate information sources. • Provide people with written information or direct them to online relevant organisations such as the Migraine Trust for advice and support.

Guidance and best practice examples

System Priority Improvement:

Long-term management of patients in primary or community care

Despite the high hospital clinic burden of headache, most primary headache disorders and medication overuse headache can be appropriately diagnosed and managed within the community. Community headache clinics have the potential to provide cost effect care for the majority of the migraine and other headache disorder population by reducing the number of costly outpatient and A&E attendances.

Key areas for focus:

Undertake shared decision making (SDM) with the patient on treatment options, including prophylactic treatment.
SDM is a collaborative process through which a clinician supports a patient to reach a decision about their treatment.

Guidance & Best Practice

Personalised care plans to be agreed and in place.
Personal care and support planning is widely recognised as an essential gateway to better supporting people, and their carers . By utilising their own experience of living with migraine and other headache disorders people can develop the knowledge, skills and confidence to manage their own health, care and well-being in a partnership of equality with health service professionals. There is evidence that this may lead to better outcomes.

Guidance & Best Practice

Manage primary headache disorders in primary or community settings and prescribe medication in line with NICE guidance.
The majority of primary headache disorders can be managed in either primary or community settings, negating the attendance at outpatient clinics. Medication should be prescribed in line with NICE guidance.

Guidance & Best Practice

Refer patients to a community headache clinic or a GPwSI if they become resistant to treatment.
Where a patient has exhausted lines of therapy in line with NICE guidance, has become resistant to treatment or has extreme chronicity, referral into specialist community services may become necessary.

Guidance & Best Practice

Actions to take

System Improvement Priority:

Long-term management of patients in primary or community care

Actions to take:	
Undertake shared decision making (SDM) with the patient on treatment options, including prophylactic treatment.	• Ensure when primary headache disorder is diagnosed, that treatment options are discussed with the person to take into account their personal circumstances, goals, values and beliefs. • Discuss the use of prophylactic treatment to reduce the number of attacks in circumstances when acute therapy, used appropriately, gives inadequate symptom control.
Personalised care plans to be agreed and in place.	• After diagnosis a holistic optimal care plan should be agreed (and shared) with the patient in order to place them at the centre of their own care. • The care plan should take into account their individual needs and preferences, and account for work and lifestyle factors as well as additional health conditions and risk factors.
Manage primary headache disorders in primary or community settings and prescribe medication in line with NICE guidance.	• Understand what self-management education and services are available within the local community to support people with primary headache disorders. • Ensure that community based services and health providers have adequate training and support to be able to manage people with primary headache disorders in the community.
Refer patients to a community headache clinic or a GPwSI if they become resistant to treatment.	• Define the referral criteria and have a clear process in place to refer patients into a specialist community headache clinic.

Guidance and best practice examples

Guidance and Best Practice

This section contains all the relevant guidance, evidence and case studies aligned to each of this toolkit's system improvement priority and key areas for focus. It supports development of improvement actions when system priorities have been identified.

Common misinterpretation of headache symptoms that lead to referral

Referral concern	Pause & think before referral	Knowledge gap
“Worse in the morning” or “worse at night”	“orthostatic headache”	Typical of MOH, common in migraine
“Worse on exercise/ sex/ straining”	“headache triggered by cough, Valsalva, sneeze or exercise”	Confusing trigger with aggravated by routine physical activity
“Sudden onset”	“sudden onset headache reaching maximum intensity within 5 minutes”	Ice-pick headache presents as sudden onset and is common in migraine
“History of head trauma”	“recent (typically within the past 3 months) head trauma”	Migraine worsening is common after head injury
“Unusual Symptoms” (parasthesia, motor, cognitive difficulties)	“new onset neurological deficit” or “new onset cognitive dysfunction”	Non-visual aura, and cognitive symptoms of migraine
”Not like their usual headaches”	“a substantial change in the characteristics of their headache”	Migraine presentation evolves with age
“Not responding to treatment”		Typical of MOH & chronic migraine

Source: Richard Wood, Oxfordshire CCG, 2019

Based on data from the Oxfordshire Community Headache Clinic

Oxfordshire Headache Pathway for the Efficient Diagnostic and Management Support of Headache Disorders

Guidance	Implementation
System improvement priority: Identification and diagnosis	
Healthcare practitioners to be supported and educated on the presenting symptoms of primary headache disorders and medication overuse headache (MOH).	
BASH: National Headache Management System For Adults (2019) (pg12) NICE: • QS42 - Quality Statement 1: Classification of headache type • QS42 - Quality Statement 2: Preventing medication overuse headache • CG150 Headaches in over 12s: diagnosis and management SIGN 155: Pharmacological management of migraine	Thames Valley Strategic Clinical Network: Community Headache Pathway The Neuro Network: • Headache Pathway (adults) • Migraine – A Comprehensive Guide. Wandsworth and Merton CCGs: Primary Care Adult Headache Referral and Management Guidance Educational video's: • A brief neuro exam • Neurological examination
Patients to be given a positive diagnosis of a primary headache disorder after being assessed against standardised criteria.	
BASH: National Headache Management System For Adults (2019) (pg12) NICE: • QS42 - Quality Statement 1: Classification of headache type • CG150 recommendation 1.1, 1.2 SIGN 155: Pharmacological management of migraine	Oxfordshire Clinical Commissioning Group (2018): Oxfordshire Headache Pathway for the Efficient Diagnostic and Management Support of Headache Disorders NICE: Diagnosis poster South West Peninsula Headache Network: Referral Pathways for Headache in Adults Sunderland CCG: Northern East Adult Headache Management Guideline Thames Valley Strategic Clinical Network: Community Headache Pathway The Neuro Network: Headache Pathway (adults) Wandsworth and Merton CCGs: Primary Care Adult Headache Referral and Management Guidance

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National Challenges
Challenges for commissioners
System Improvement Priorities
Identification and diagnosis
Appropriate secondary care referrals
Self management after diagnosis
Long-term management in primary or community care
Guidance & Best Practice
Self-assessment questionnaire

Guidance	Implementation
Where a primary diagnosis cannot be made initially, diagnostic decision making should be made over time by the application of a headache diary.	
BASH: National Headache Management System For Adults (2019) NICE: CG150 recommendation 1.1.3, 1.1.4, 1.2.6 1.3.1 SIGN 155: Pharmacological management of migraine	BASH: • Headache Diary • Headache Question Information Sheet National Migraine Centre: • Migraine and headache diaries • Monthly diary template • Annual Diary Template The Migraine Trust: • Keeping a migraine diary • Migraine Diary Templates
System improvement priority: Appropriate secondary care referrals	
Patients to be given a positive diagnosis of a primary headache disorder after being assessed against standardised criteria.	
BASH: National Headache Management System For Adults (2019) (pg12) NICE: CG150 recommendation 1.1.1, 1.1.2 • QS42 - Quality statement 3: Imaging • CG150 recommendation 1.2 SIGN 155: Pharmacological management of migraine	Oxfordshire Clinical Commissioning Group (2018): Oxfordshire Headache Pathway for the Efficient Diagnostic and Management Support of Headache Disorders The Neuro Network: Migraine – A Comprehensive Guide. Information Book Wandsworth and Merton CCGs: Primary Care Adult Headache Referral and Management Guidance, Red flags advice on screening urgent conditions – advice for clinicians
Education and awareness of healthcare practitioners of the signs of medication overuse headache, which do not require referral into secondary care.	
BASH: National Headache Management System For Adults (2019) (pg33-37) NICE: • QS42 - Quality Statement 2: Preventing medication overuse headache • CG150 recommendation 1.2.7	Oxfordshire Clinical Commissioning Group (2018): Oxfordshire Headache Pathway for the Efficient Diagnostic and Management Support of Headache Disorders Thames Valley Strategic Clinical Network: Community Headache Pathway

Summary

National Challenges

Challenges for commissioners

System Improvement Priorities

Identification and diagnosis

Appropriate secondary care referrals

Self management after diagnosis

Long-term management in primary or community care

Guidance & Best Practice

Self-assessment questionnaire

Guidance	Implementation
SIGN 155: Pharmacological management of migraine	The Neuro Network: • Headache Pathway (adults) • Migraine – A Comprehensive Guide. Information Book Wandsworth and Merton CCGs: Primary Care Adult Headache Referral and Management Guidance – Wandsworth and Merton CCGs
Consider implementation of referral support services to provide advice to healthcare professionals on the appropriateness of headache referrals to specialist outpatient neurology services.	
BASH: National Headache Management System For Adults (2019) NICE: • QS42 – Headaches in over 12s • CG150 – Headaches in over 12s: diagnosis and management	The Neuro Network: Headache Pathway (adults) Sunderland Royal Hospital, Sunderland CCG: Neurology HOT Clinic service – Acute HOT neurology clinics set up to improve rapid and accurate diagnosis and appropriate investigation of patients presenting with headaches to improve patient experience, reduce the number of emergency admissions and hospital admissions. Thames Valley Strategic Clinical Network: Community Headache Pathway – Triage undertaken by neurology consultant who will also provide advice to referrers, interpret imaging reports and provide clinical oversight and support to the community clinicians Wandsworth and Merton CCGs: Primary Care Adult Headache Referral and Management Guidance – Rapid access pathways for cluster headache and serious secondary headaches

Guidance	Implementation
System improvement priority: Self management after diagnosis	
Promote the use of headache diaries to understand personal triggers (e.g. lifestyle issues).	
BASH: National Headache Management System For Adults (2019) NICE: CG150 recommendation 1.1.3, 1.1.4, 1.2.6 1.3.1 SIGN 155: Pharmacological management of migraine	BASH: • Headache Diary • Headache Question Information Sheet National Migraine Centre: • Migraine and headache diaries • Monthly diary template, Annual Diary Template The Migraine Trust: • Keeping a migraine diary • Migraine Diary Templates Migraine Trust: List of migraine triggers
Provide information and education to people with a primary headache disorder on the risks and signs of developing medication overuse headache.	
NICE: • NG102, Community pharmacies: promoting health and wellbeing • CG150 recommendation 1.3.6, 1.3.36 – 1.3.42 • QS42, Quality statement 2: Preventing medication overuse headache • CG150, Headaches in over 12s: diagnosis and management Public Health England: Local action on health inequalities: Improving health literacy to reduce health inequalities	Cumbria headache forum: Patient Educational Forum Exeter Headache Clinic: Patient Information Leaflets The Neuro Network • Headache Pathway (adults) • Migraine, a comprehensive guide Oxfordshire CCG: Community Headache Pathway, migraine prevention guidelines
Utilise pharmacists to provide patient advice on MOH and appropriate use of analgesics.	
NICE: NG102, Community pharmacies: promoting health and wellbeing National Voices: The role of pharmacy in delivering person centred care	The Migraine Trust: Community Pharmacy, explains what is it and what services it offers in the support of people with migraine

Guidance	Implementation
	The Pharmacy Network: Headache & migraine: When it all gets too much – Community pharmacists are well placed to help prevent and manage the debilitating problem that is medication overuse headache.
Supporting the education of employers of the impact and effect of migraine at work.	
The Work Foundation (2018): Society's headache: The socioeconomic impact of migraine NICE: QS42 – Quality statement 5 (placeholder): Raising public and professional awareness	The Migraine Trust: Managing migraine at work – General considerations to help you manage the impact of migraine in the workplace Employment Advocacy Toolkit – Tools and guidance for migraine sufferers, their colleagues, managers, human resource departments and occupational health professionals
Signpost people to third sector resources including local support groups or national advice lines to reduce attendance at A&E departments.	
BASH: National Headache Management System For Adults (2019) Patient Information Leaflets NICE: CG150 recommendation 1.3.5 SIGN 155: Pharmacological management of migraine	BASH: Find your local headache clinic The Migraine Trust: Information Service, Advocacy Service
System improvement priority: **Long-term management in primary or community care**	
Undertake shared decision making (SDM) with the patient on treatment options, including prophylactic treatment.	
BASH: National Headache Management System For Adults (2019) National Voices: A narrative for person centred coordinated care NHS England: • House of Care • Developing Person Centred Care • Shared decision making	The Neuro Network: • Headache Pathway (adults) • Migraine – A Comprehensive Guide. Information Book NICE Advancing Quality Alliance (AQuA): embedding shared decision making in healthcare professional practice

Summary

National Challenges

Challenges for commissioners

System Improvement Priorities

Identification and diagnosis

Appropriate secondary care referrals

Self management after diagnosis

Long-term management in primary or community care

Guidance & Best Practice

Self-assessment questionnaire

Guidance	Implementation
Undertake shared decision making (SDM) with the patient on treatment options, including prophylactic treatment.	
NICE: • Pathway, Patient experience in adult NHS services: enabling patients to actively participate in their care • CG138 Patient experience in adult NHS services: improving the experience of care for people using adult NHS services • QS15 Patient experience in adult NHS services • What is shared decision making? Public Health England: Local action on health inequalities: Improving health literacy to reduce health inequalities The Health Foundation: MAGIC: shared decision making	
Personalised care plans to be agreed and in place.	
NHS England and Coalition for Collaborative Care: Personalised care and support planning handbook	NHS England: Patient Activation & PAM FAQs Thames Valley Strategic Clinical Network: Transforming Community Neurology
Manage primary headache disorders in primary or community settings and prescribe medication in line with NICE guidance.	
NICE: • CG150, Recommendations 1.3.7 - 1.3.42 • QS42, Quality statement 4: Combined treatment for migraine	Oxfordshire Clinical Commissioning Group (2018): Oxfordshire Headache Pathway for the Efficient Diagnostic and Management Support of Headache Disorders
Refer patients to a community headache clinic or a GPwSI if they become resistant to treatment.	
Royal College of GPs: GPs with a special interest in headache Thames Valley Strategic Clinical Network: Transforming Community Neurology: What commissioners need to know	Ridsdale, Leone et al. "A new GP with special interest headache service: observational study." *The British journal of general practice : the journal of the Royal College of General Practitioners* vol. 58,552 (2008): 478-83. doi:10.3399/bjgp08X319440

Guidance	Implementation
Refer patients to a community headache clinic or a GPwSI if they become resistant to treatment.	
	Exeter Headache Clinic: Developing a General Practitioner with a Special Interest in Headache Service, support for Commissioners and Clinicians Guidance to develop a GPwSI service to improve diagnosis and management. Oxfordshire Clinical Commissioning Group (2018): Oxfordshire Headache Pathway for the Efficient Diagnostic and Management Support of Headache Disorders Thames Valley Strategic Clinical Network: Community Headache Pathway

The National Challenges: References

National challenge	Reference
Approximately. 10 million people aged 15 – 69 live with migraine in the UK	Society's Headache (The Work Foundation 2018)
Migraine is the second leading cause of years lived with disability	Global Burden of Disease (The Lancet 2016)
3 million workdays are lost every year in the UK to migraine-related absenteeism alone, at a cost of almost £4.4 billion.	Society's Headache (The Work Foundation 2018)
In the UK, the annual primary care consultation rate for headache is 4.4 per 100 registered patients, of whom 4% are referred to secondary care for further assessment	Headache and migraine in primary care: consultation, prescription, and referral rates in a large population (Latinovic et al 2006)
More information on the national challenges:	Headache Services in England (APPG on Primary Headache Disorders 2014) Facts and figures (The Migraine Trust)

Further Resources

- The Migraine Trust: www.migrainetrust.org
- Organisation for the Understanding of Cluster Headache (OUCH): www.ouchuk.org
- British Association for the Study of Headaches: www.bash.org.uk

For more information about the development of this framework please contact the Policy and Influencing team at The Migraine Trust: policy@migrainetrust.org.

Self-Assessment Questionnaire

These self-assessment questions (SAQ) are designed to help local areas (including STPs, ICSs and PCNs) gain enhanced understanding of heir headache and migraine system. The RightCare Headache and Migraine Toolkit provides a benchmark to enable understanding of the key components of a headache and migraine system. The questions should be used alongside the Toolkit to facilitate discussion and identify improvement opportunities or exemplars of good practice.

Specifically these questions are designed to:

- Assess the current existing system in place to support people living with primary headache disorders and to provide quality care for them.
- Identify any current gaps in provision and current opportunities to enhance or develop services and systems to support people living with a primary headache disorder, including working with key partners.
- Assess the progress of any system improvements over time.

Rating Key: 1 = Full met, 2 = Partially met, 3, Not met, 4= Not applicable
Grey shaded questions are no rag rated but should be used to help in gathering supplementary information

Section	Self-assessment questions	Rating (1, 2 ,3 ,4)
Identification and diagnosis	1. Do you have clinical champions for primary headache disorders identified within the local system, who have a role in promoting a consistent and universal awareness and understanding of primary headache disorders?	
	2. Do you promote and undertake learning sessions around primary headache disorders for healthcare professionals?	
	3. Do you use standardised assessment criteria to make a diagnosis of primary headache disorder (e.g. NICE diagnosis table, BASH guidelines criteria)?	
	4. When a diagnosis has been made, do you provide an explanation of the diagnosis and reassurance that other pathology has been excluded (known as a positive diagnosis)?	
	6. Is a review of the headache diary conducted after a minimum of 8 weeks to support the diagnosis of one or more of the primary headache disorders?	

Section	Self-assessment questions	Rating (1, 2 ,3 ,4)
Appropriate secondary care referrals	7. Do you take a full headache history when a patient presents with headache and migraine symptoms?	
	8. Do you assess patients for a primary headache disorder using the NICE or BASH clinical assessment criteria?	
	9. Do you ask patients to keep a headache diary to diagnose a primary headache disorder, if you are confident that the symptoms do not require a more urgent intervention?	
	10. Do you only refer patients onto neuro-imaging when you suspect a more serious underlying condition, rather than to confirm the diagnosis of a primary headache disorder?	
	11. Where a secondary headache disorder is suspected (based on clinical symptoms) is the patient referred to secondary care?	
	12. Is there a shared awareness and understanding of primary headache disorders across the local system?	
	13. Is training provided to healthcare practitioners on the signs of medication overuse headache and common features of primary headache disorders such as migraine?	
	14. Do you have a support line (e.g. email or telephone) to access specialist advice on appropriateness of a referral into secondary care?	

Section	Self-assessment questions	Rating (1, 2 ,3 ,4)
Self management after diagnosis	15. Do you provide patients with a headache diary/template to record their headaches and migraines and any triggers associated with them?	
	16. Is there a defined criteria and referral process to ensure people who need to make lifestyle adjustments are referred into the appropriate services?	
	17. Is the risk of medication overuse headache explained to people who are using analgesics such as paracetamol or ibuprofen to treat their headache?	
	18. Are patients sign-posted to local or national resources that also explain the risks and treatment options around medication overuse headache?	
	19. Do you utilise pharmacy public health campaigns to promote the use of pharmacists in supporting patients to manage recurrent headaches appropriately?	
	20. Do you undertake strategies such as making every contact count or at MUR reviews to identify if a person is over administering analgesic medication?	
	21. Are patients provided with information on withdrawal of analgesics to treat medication overuse headaches in line with NICE recommendations (1.3.36 – 1.3.38)?	
	22. Are people with migraine encouraged to talk to their employers about their condition and provide letters of diagnosis if required?	
	23. Do you have a local directory of services and support available which enables ease of signposting or referral for people living with primary headache disorders to the services they may find useful?	
	24. Do community based services and health providers have adequate training and support to signpost people to reliable and accurate information sources?	
	25. Are people provided with written information or direct them to online relevant organisations such as the Migraine Trust for advice and support?	

Section	Self-assessment questions	Rating (1, 2 ,3 ,4)
Self management after diagnosis	26. When primary headache disorder is diagnosed, are treatment options discussed with the person to take into account their personal circumstances, goals, values and beliefs?	
	27. Do you discuss acute and preventative (prophylactic) treatment with the patient in order to reduce headache frequency?	
	28. Do you prescribe prophylactic treatment alongside acute therapy, and not use it as a replacement therapy?	
	29. After diagnosis, is a holistic optimal care plan agreed (and shared) with the patient in order to place them at the centre of their own care?	
	30. Does the care plan take into account their individual needs and preferences, and account for work and lifestyle factors as well as additional health conditions and risk factors?	
	31. Do you understand what self-management education and services are available within the local community to support people with primary headache disorders?	
	32. Do community based services and health providers have adequate training and support to be able to manage people with primary headache disorders in the community?	
	33. Is there a defined referral criteria and a clear process in place to refer patients into a specialist community headache clinic?	

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- Public Health England
- The Migraine Trust

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