

Improving headache and migraine care for people of all ages:

# A tool for NHS health professionals & providers

Financial support for this project has been provided as a Quality Improvement Grant from Pfizer International LLC. Editorial control rests with The Migraine Trust and the Neurological Alliance.

the  
**migraine**  
trust



The Association of British Neurologists (ABN) has reviewed this tool and is pleased to offer a statement of approval.

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## About the tool




It can be challenging as a commissioner, provider or healthcare professional looking to improve services to be aware of sources of evidence and organisations that can inform and support improvement.

This tool identifies and directs you to the best available resources to plan, design and improve services for people of all ages affected by headache and migraine locally. It provides you with a framework to begin local service transformation, focusing on care that can be delivered in the community (particularly non-complex migraine), with the key stakeholders, partners and services in your area.

This tool has been developed with people with migraine, health professionals, service managers and Integrated Care Board (ICB) and NHS provider representatives from across England.



## How to use the tool

Use the [contents page](#) to be directed to the relevant area of the tool or work through each section in order. Clicking on the resource hyperlinks  will open a new page in your browser.

For the best experience we recommend downloading and viewing the tool in **Adobe Reader** (not on your browser).



**Adobe Acrobat Reader**



## The challenge

**H**eadache disorders represent a substantial cost to the NHS which spends an estimated £250 million per year on care for people affected by headache and £150 million per year on treating migraine. <sup>1</sup> The cost to the economy is even higher with 43 million workdays lost every year in the UK to migraine-related absenteeism alone, at a cost of almost £4.4 billion. <sup>2</sup>

Significant potential cost and capacity savings to the NHS can be achieved with better organised services. Matching best performing areas could achieve an estimated £11.5 million saved on non-elective admissions and nearly 16,500



Headache disorders **cost the NHS £250m** each year, much of it avoidable

fewer emergency admissions. <sup>3</sup> Adults diagnosed with migraine in England currently incur 81% higher direct medical costs per person per year compared to matched general population controls. <sup>4</sup>

Evidence-based and best practice headache pathways and service models that address better care of migraine directly support the goals of the NHS 10-year plan by strengthening prevention and self-management, reducing avoidable hospital attendances, outpatient waiting lists and ensuring timely, equitable access to appropriate treatment and care.

## Improving headache care as a system wide priority

**H**eadache disorders are extremely common neurological disorders affecting people of all ages. The majority of headache seen in primary care and outpatients is primary (predominantly migraine) and can be managed in the community. Although much less common, serious causes of secondary headache (such as subarachnoid haemorrhage and brain tumour) can be urgent with significant risk.

A large proportion of people affected by headache and migraine in the community struggle to access appropriate diagnosis and treatment. <sup>5</sup> <sup>6</sup> Fragmented and poorly resourced pathways can increase the complexity of patients' symptoms, worsen outcomes and disability, and widen health inequalities. This places significant avoidable pressure on urgent and emergency care, outpatient clinics and elective care waiting lists, and impacts workforce capacity and productivity across the system.



**Headache disorders affect 40% of the population** <sup>7</sup>



**Approximately 10 million people in the UK live with migraine** <sup>8</sup>



**The Global Burden of Disease study ranks migraine as one of the highest causes of disability worldwide** <sup>9</sup>

**Life expectancy, quality of life and access to quality care experience by people living with neurological conditions varies significantly according to deprivation and place of residency** <sup>10</sup>



**There is high variability in migraine-related costs across regions in England, suggesting inequities in care and access** <sup>11</sup>

## Urgent & emergency care



**1-4%** of all emergency department visits are for headache <sup>12</sup>

**Headache is the most common neurological reason** for patients attending emergency departments <sup>13</sup>

**90%** of headache presentations to the emergency department are due to primary headaches, usually migraine or tension type headache <sup>14</sup>

## Elective care & diagnostics



**Up to a third** of all new neurology outpatient appointments are for headache <sup>15</sup>

Interactions with secondary care are **2x as high** in migraine patients than in the general population <sup>16</sup>

## Primary care & community services



**Approximately 2.5 million** primary care appointments are linked to headache and migraine <sup>17</sup>

Headache is the commonest reason for **GP referrals to neurologists** <sup>18</sup>

Interactions with primary care are **1.5x higher** in migraine patients than the general population <sup>19</sup>

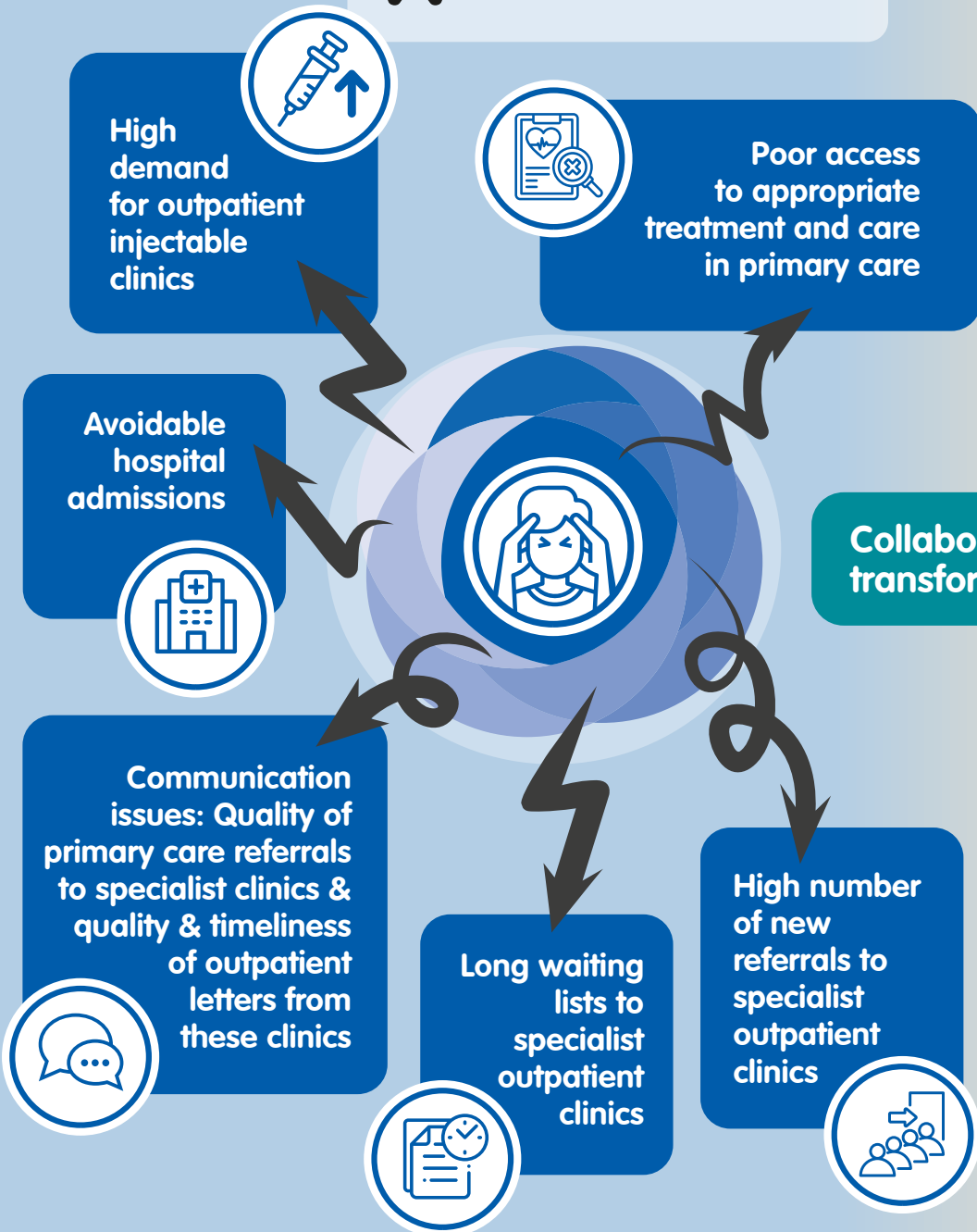
# Opportunities to improve headache care



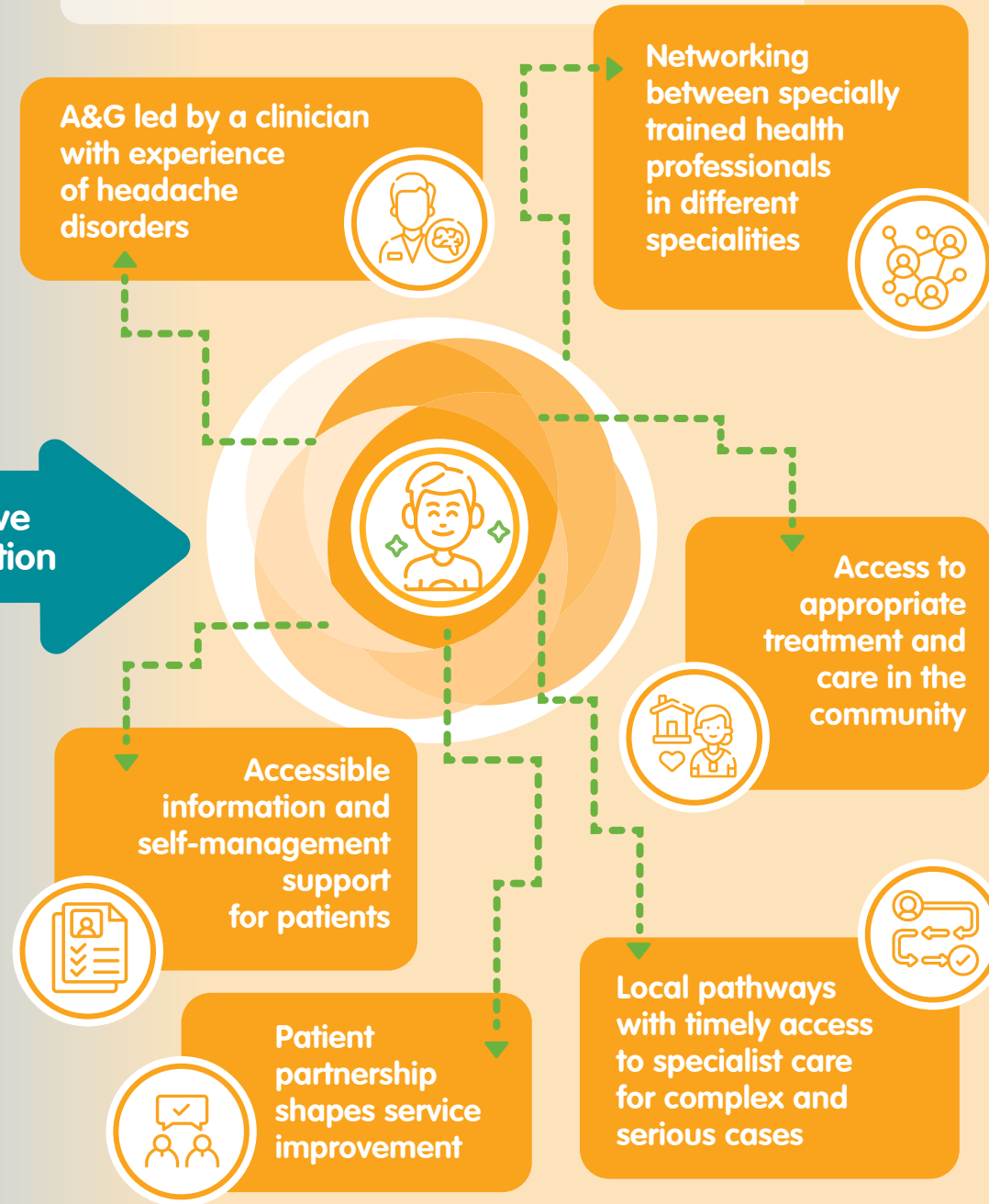
Services operating in silos to deliver headache care.



A joined up approach focusing on community based care for non-urgent headache.



Collaborative transformation



## Delivering change

Priority areas to consider for service transformation.

### Equity of access

- Implement evidence based, equitable coproduced pathways to optimise headache diagnosis and care. <sup>20</sup>
- Ensure that pathways join up NHS, local authority, and voluntary/charitable sector services, to coordinate patient journeys.
- Develop and require ICS-wide, evidence-based formulary standards to ensure equitable access to NICE-approved migraine treatments. <sup>21</sup>

### Confident and skilled multi-disciplinary workforce

- Invest in specialist and extended-role development across professions with clear headache workforce competencies .
- Create sustainable workforce plans including recruitment, retention, and skills development.
- Support and enable, through job planning , the networking of specialist clinicians and primary, secondary and community care professionals to provide learning opportunities and education to enhance primary care management and improve referrals.



Best-performing migraine care  
= **£11.5m saved and 16,500 fewer emergencies.**

### Prevention of avoidable pain and disability

- Establish advice & guidance (A&G) systems and triage, led by a clinician experienced in the management of headache disorders, to support diagnosis, treatment and management of migraine and other primary headache in primary care through the provision of succinct and patient centred A&G. <sup>22</sup>
- Promote the use of a standardised headache/migraine diary tool, which may be digital, to all patients to support healthcare providers to confirm diagnosis, identify patterns, support lifestyle modifications, assess and provide treatment, identify medication overuse.
- Increase access to community-based self-management and mental health support.
- Increase awareness and understanding of medication overuse headache in primary care to help prevent avoidable cases of analgesic overuse headache.
- Ensure networking between specially trained health professionals from different disciplines including GPs, pharmacists, neurologists, nurses, psychologists and physiotherapists in future health systems.
- Enable easy access to necessary follow up appointments in primary care for patients with headache and migraine requiring continuity of care, treatment stabilisation and to prevent worsening of disability. <sup>23</sup>

## Headache pathways that ensure treatment and care at the appropriate level for the patient

- Establish clearly defined local pathways with timely access to specialist care for complex and serious cases.
- Establish clear referral guidance and Advice & Guidance (A&G) protocols between primary, community, and specialist care to optimise access, reduce unnecessary referrals, and improve continuity of care.
- Optimise access to specialist clinics for rapid optimisation of treatment.
- Develop specialist services for children and young people.
- Establish and integrate person-centred transition pathways from paediatric to adult headache care, including community-based care. <sup>24</sup>
- Ensure neurology specialist inreach to acute wards.
- Provide rapid access to acute neurology clinics or Same Day Emergency Care pathways at all providers receiving acute medical admissions to reduce avoidable admissions. <sup>25</sup>
- Strengthen communication and partnership working with schools and educational institutions to improve holistic care for children and young people.

## Patients equipped and supported to be leaders of their care

- Work with people affected by headache and migraine and the voluntary, community and social enterprise sector (VCSE) to design, evaluate and improve services, ensuring continuous service transformation shaped by real needs and outcomes.
- Guarantee access to voluntary, community and social enterprise (VCSE) migraine support, offering tailored advice, peer support, advocacy and self-management resources that complement NHS care.
- Facilitate shared decision between patients and GPs by enabling patient involvement in A&G communications, supported by clear A&G policies, transparency and opt-in involvement for patients. <sup>26</sup>
- Provide accessible multi-channel prevention and management support options to people living with headache and migraine, including printed information, telephone support and in-person support.
- Ensure that shared decision-making and patient partnership approaches are in place that are specifically tailored to involve children and young people in decisions about their treatment and care. <sup>27</sup>

# Taking action to transform services

## Developing a local approach

Optimising headache and migraine care and reducing system inefficiencies and wastage requires different local services to work together, in partnership with patients, in a coordinated way.

Integrated approaches to service transformation should involve people affected by headache and migraine, their families and carers, clinical and operational teams, and non-clinical services such as schools and other local authority services and voluntary and community groups.

By working in partnership with these groups, services can achieve better outcomes, improve patient experience, use resources more effectively, and create safer systems.

### A coproduction approach can

- ✓ align care with real needs of the local population
- ✓ ensure workforce and system resources are directed where they have the greatest impact
- ✓ identify barriers to access to services from underserved and marginalised groups
- ✓ identify inclusion measures for implementation to improve equity across the local population

This approach should be underpinned by local referral and activity data, and national data to identify areas of high spend, system inefficiencies and, poor patient experience, and to benchmark care. National guidance and best practice models should be used to guide service transformation.

# Planning local service transformation: a system wide approach

Statutory & best practice guidance — National & local data — Coproduction

## Local communities & neighbourhoods

(Including people with lived experience of Headache & migraine)

### Key groups include:

- Patients
- Carers and family members
- CORE20Plus5 groups

### Methods:

- Coproduction and involvement
- Patient experience activities

## Planning local service transformation

## VCSE groups

Voluntary, community and social enterprise (VCSE) stakeholders can be identified via:

- ICS community partner directories
- National headache and migraine patient organisations

## Local authorities

Teams engaging with people with headache include:

- School nursing services
- Special Educational Needs and Disability (SEND)
- Social care
- Public health services
- Schools and educational institutions

## Community teams

Teams delivering headache care include:

- GP and primary care clinics
- Pharmacies
- Urgent treatment centres
- Mental health services
- Physiotherapy
- Dentists
- Opticians
- Maternity services
- NHS 111
- Ear, nose and throat services

## Hospital teams

Teams delivering headache care include:

- Neurology outpatients
- Paediatric services
- Emergency departments
- Acute wards
- Ambulance services
- Pain clinics
- Physiotherapy
- Diagnostic services
- Mental health services
- Ear, nose and throat services
- Ophthalmology

## Getting started

A checklist to take action to improve headache pathways and services with partners locally

### Identify key stakeholders

Boxes can be ticked within PDF

Map all relevant services including primary and community care, pharmacy, mental health, specialist neurology, specialist community and secondary care services, acute and emergency medicine, physiotherapy, local authority services, local voluntary and community organisations

Identify “champions” in each service that can act as pathway leads or points of contact

Establish diverse patient representatives, with the support of local voluntary and community organisations via the ICS community partner directory

Review your local integrated care strategy via your ICB and Health and Wellbeing Board website <sup>28</sup>

Utilise local strategies to identify key contacts and initiatives within the ICS

### Analyse the issue

Boxes can be ticked within PDF

Contact local data team to establish local spending and demand using national and locally collected data

Review local health equity data and guidance for neurology to identify local populations at risk of, or experiencing health inequalities

Analyse local and national patient experience data and feedback

Work with the VCSE to engage with patient representatives and communities to understand challenges and barriers to care locally

Identify local pathways and guidance in place for the diagnosis, treatment and management of headache

Use this tool to identify evidence-based recommendations and best practice guidance, pathways, service models and supporting resources

Identify the local pathways and guidance in place to support the transition from children’s to adult services for young people using health and social care services.

## Plan

Boxes can be ticked within PDF

Develop a business case for transformation, resourcing and support

Coproduce local headache pathways and service models

Establish local workforce competencies and job planning to support pathways and service models

Identify opportunities for innovative use of resources including digital solutions such as headache diaries

## Support implementation

Boxes can be ticked within PDF

Develop and utilise communication channels between community, primary and secondary care services to improve A&G processes <sup>29</sup>

Partner with primary care representatives in regional headache meeting groups to discuss A&G processes

Work with patients and communities and the VCSE to codevelop patient partnership activities to evaluate and improve pathways and services

Identify and standardise the collection of local data and evidence to support service improvement including outpatient coding

## Where to look

### NHS service transformation resources

Source	Adults	Children & young people
<a href="#">Optimising system-wide headache pathways (DRAFT)   NHS England</a>	✓	
<a href="#">Future NHS platform: Neurology Service Transformation Programme</a> (Registration with NHS email required)	✓	
<a href="#">Advice and guidance templates for Neurology   NHS GIRFT FutureNHS platform</a> (Registration with NHS email required)	✓	
<a href="#">National Neurology report   NHS GIRFT</a>	✓	
<a href="#">Headache and migraine toolkit: Optimising a headache and migraine system   NHS RightCare</a>	✓	✓ (Over 12s)

### NHS service specifications

Source	Adults	Children & young people
<a href="#">Specialised neurology services (adults) service specification   NHS England</a>	✓	
<a href="#">Paediatric Neurosciences (Neurology) services   NHS England</a>		✓

## Data and metrics

Data	Source	Data available locally	Data available nationally	Adults	Children & young people
Acute and emergency admissions for headache	<a href="#">Neurology ICB Dashboard   Neurology Service Transformation Programme</a> FutureNHS platform: Registration with NHS email required	✓	✓	✓	
Prescribing activities and changes in prescribing practices	Local prescribing database	✓		✓	✓
High cost drug prescribing activities	Blueteq	✓	✓	✓	✓
Neurology inpatient and outpatient activities	<a href="#">Neurology GIRFT   FutureNHS platform</a>	✓	✓	✓	
Local activity data: <ul style="list-style-type: none"> <li>• Diagnostic investigations</li> <li>• Referral data (community to hospital)</li> <li>• Outpatient activity</li> <li>• Inpatient admissions</li> <li>• ED attendance</li> <li>• Workforce</li> <li>• Outpatient DNAs</li> <li>• Transition data</li> <li>• Dispensing rates</li> </ul>	Trust activity data	✓		✓	✓
Health equity (neurology)	<a href="#">Neurology ICB Dashboard (health equity tab)   FutureNHS platform: Neurology Service Transformation Programme</a>	✓	✓		
Quality of care	<a href="#">National Audit of Headache Disorders   King's College London</a>			✓	
Patient experience	<a href="#">MyNeuro survey   Neurological Alliance</a>	✓	✓	✓ (condition specific)	✓ (pan-neurological)

## Clinical guidelines and quality standards

Source	Adults	Children & young people
<a href="#">QS42: Headaches in over 12s   NICE</a>	✓	✓ (over 12s)
<a href="#">CG150: Headaches in over 12s: diagnosis and management   NICE</a>	✓	✓ (over 12s)
<a href="#">Headache guideline   British Association for the Study of Headache (BASH)</a>	✓	
<a href="#">Diagnosis and management of headache in adults. SIGN clinical guideline 107   Healthcare Improvement Scotland</a>	✓	
<a href="#">NG43 Transition from children's to adults' services for young people using health or social care services   NICE</a>	✓	

## Clinical care pathways

National pathways	Adults	Children & young people
<a href="#">Optimal clinical care pathway for headache and facial pain   National Neurosciences Advisory Group</a>	✓	
<a href="#">National headache pathway   NHS Scotland</a>	✓	

Local pathway examples	Adults	Children & young people
<a href="#">Greater Manchester: Headache management guideline for adults</a>	✓	
<a href="#">Headache pathway for adults   NHS Cheshire and Merseyside, The Walton Centre NHS Foundation Trust</a>	✓	
<a href="#">North East and Cumbria Adult Headache guideline</a>	✓	
<a href="#">Oxfordshire headache pathway: triage system</a>	✓	
<a href="#">South West London Primary Care: Adult headache referral and management guidance</a>	✓	
<a href="#">Headache pathway: Clinical assessment/management tool for children   West Yorkshire Better Together</a>		✓

## Workforce planning resources

Source	Adults	Children & young people
<a href="#">Nursing competency and education framework for the management of headache disorders</a>   <a href="#">Royal College of Nursing</a>	✓	✓
<a href="#">Competency framework for GPs with an extended role</a>   <a href="#">Headache GP</a>	✓	✓
<a href="#">Job planning guidance</a>   <a href="#">Royal College of Physicians</a>	✓	
<a href="#">Job planning guidance for consultant neurologists and academic consultant neurologists</a>   <a href="#">Association of British Neurologists (ABN)</a>	✓	
<a href="#">Job Planning Guide for Consultant Paediatric Neurology</a>   <a href="#">British Paediatric Neurology Association (BPNA)</a>	✓	✓
<a href="#">UK neurology workforce report</a>   <a href="#">ABN</a>	✓	

## Health Inequality guidance and reports

Source	Adults	Children & young people
<a href="#">Improving health equity in neurology (report)</a>   <a href="#">NHS England Specialised Commissioning Neurology Service Transformation Programme</a> Future NHS platform: Registration with NHS email required	✓	
<a href="#">The migraine divide. How gender, ethnicity and social grade impact experience of migraine in the workplace, in healthcare and day to day life</a>   <a href="#">The Migraine Trust</a>	✓	

## Patient experience and policy reports

Source	Adults	Children & young people
<a href="#">Heading in the wrong direction: Challenges in migraine care and why people with migraine deserve better   The Migraine Trust</a>	✓	
<a href="#">Dismissed for too long: The impact of migraine on children and young people   The Migraine Trust</a>		
<a href="#">Act now for the 1 in 6: England findings from My Neuro survey   Neurological Alliance</a>	✓	✓
<a href="#">Insights from people with migraine on discussing and making referrals with their GPs, and the use of specialist advice and guidance: Focus group report   The Migraine Trust and the Neurological Alliance</a>	✓	

## Coproduction resources

Source	Adults	Children & young people
<a href="#">Working in partnership with people and communities: Statutory Guidance   NHS England</a>	✓	✓
<a href="#">Involving children and young people in your quality improvement journey   Royal College of Paediatrics and Child Health</a>		✓

## Guidance and resources to develop a business case

Source	Adults	Children & young people
<a href="#">Business planning for headache services   Neurology Academy</a>	✓	

## Health professionals: Learning opportunities

This information on this page is also available as a stand-alone document that can be uploaded to NHS IT systems and intranets for easy reference by health professionals. The document can be accessed and downloaded here.

### Making a diagnosis:

- [Migraine screening tool | ID migraine](#)
- [Headache and migraine guidance for health professionals \(at a glance guide\) | NHS Grampian](#)
- [Migraine Q&As for GPs by GPs \(leaflet\) | The Migraine Trust](#)



### How to use the common acute and preventer treatments:

- [Acute And Preventive Therapies In Migraine \(video\) | BASH](#)
- [Headache and migraine guidance for health professionals \(at a glance guide\) | NHS Grampian](#)



### Learn more:

- [Heads Up podcast | National Migraine Centre](#)
- [Migraine and cluster headache \(online course for GPs\) | Royal College of GPs](#)
- [Headache service transformation masterclass: Neurology Academy](#)



### Headache diaries:

- [Keeping a headache diary | The Migraine Trust](#)



### Headache and migraine management for children and young people

- [Children's Headache Training \(CHaT\) | BPNA](#)
- [Distance learning in paediatric neurology | BPNA](#)
- [Working with the school of a child with migraine \(website\) | The Migraine Trust](#)



## Health professionals:

Signposting resources with Information and support for headache and migraine patients



### Helpline

- **The Migraine Trust**  
**080 8802 0066** (Mon-Fri, 10am-4pm)

### Websites

- **The Migraine Trust:**  
[www.migrainetrust.org](http://www.migrainetrust.org)
- **OUCH UK (Cluster Headache):**  
[www.ouchuk.org](http://www.ouchuk.org)



### Information about common treatments and medication:

- [Treatment options | The Migraine Trust](#)
- [Incidental findings on MRI brain scans \(leaflet\) | BASH](#)
- [Headache types and treatment options | BASH](#)



## Information and toolkits for living with migraine in the workplace and at school:

- [Resources | The Migraine Trust](#)



## Information for children and young people:

- [Migraine in children and young people \(website\) | Migraine Trust](#)
- [Education and information support materials for schools | Ted Wrapp Trust](#)



## Mental health support

- Local NHS talking therapies service

## Headache and migraine diary templates for print:

- [Migraine diary templates are available via The Migraine Trust](#)
- [Headache diary templates are available via BASH](#)

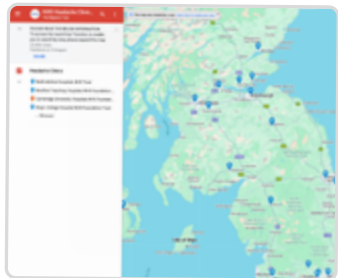


## Headache and migraine diary apps

- A number of free headache and migraine diary apps are available to use on smartphones and devices to track symptoms and triggers.



## Directory: Headache clinics, patient organisations and professional bodies



### Headache clinics:

- [NHS Headache clinics](#) | [The Migraine Trust](#)



### Professional bodies

- **British Association for the Study of Headache (BASH):** [www.bash.org.uk](http://www.bash.org.uk)
- **Association of British Neurologists (ABN):** [www.theabn.org](http://www.theabn.org)
- **British Paediatric Neurology Association (BPNA):** [www.bpna.org.uk](http://www.bpna.org.uk)
- **Royal College of Nursing |** [www.rcn.org.uk/Get-Involved/Forums/Neuroscience-Forum](http://www.rcn.org.uk/Get-Involved/Forums/Neuroscience-Forum)
- **UK Clinical Pharmacy Association Neuroscience Pharmacy Committee:** [www.ukclinicalpharmacy.org/communities/neurosciences](http://www.ukclinicalpharmacy.org/communities/neurosciences)

### National patient organisations

- **The Migraine Trust:** [www.migrainetrust.org](http://www.migrainetrust.org)
- **OUCH UK (Cluster Headache):** [www.ouchuk.org](http://www.ouchuk.org)
- **Neurological Alliance (England):** [www.neural.org.uk](http://www.neural.org.uk)
- **Brain and Spine Foundation:** [www.brainandspine.org.uk](http://www.brainandspine.org.uk)
- **The Brain Charity:** [www.thebraincharity.org.uk](http://www.thebraincharity.org.uk)
- **CSF Leak Association:** [www.csfleak.uk](http://www.csfleak.uk)
- **Idiopathic Intracranial Hypertension UK:** [www.iih.org.uk](http://www.iih.org.uk)



## Acknowledgements

This tool was developed with the support of an expert advisory group, and engagement with stakeholders through interviews and a focus group for input. Further feedback was collected at a stakeholder roundtable meeting in West Yorkshire to test the tool within an Integrated Care System (ICS) area.

The Migraine Trust and The Neurological Alliance thank all of the stakeholders that contributed to the development of the tool and to the West Yorkshire Association of Acute Trusts for co-facilitating the stakeholder roundtable. Our particular thanks to people affected by headache and migraine who took the time to take part in both the roundtable and focus group on A&G.

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The Neurological Alliance is a coalition working together to improve treatment, care and support for people affected by neurological conditions. Together we campaign to ensure people affected by neurological conditions can access high quality, joined up care and support to meet their individual needs, at every stage of their life.

**[www.neural.org.uk](http://www.neural.org.uk)**

**Email: [info@neural.org.uk](mailto:info@neural.org.uk)**

Registered by the Charity Commission for England and Wales (registration number 1039034) and a company limited by guarantee registered in England (registration number 2939840).



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The Migraine Trust is dedicated to helping people affected by migraine. We are the only UK migraine charity providing information and support, campaigning for awareness and change, and funding and promoting research.

Visit our website to subscribe to email updates and news, access migraine information and to learn more about The Migraine Trust including our support services, research and events.

**[migrainetrust.org](http://migrainetrust.org)**

**Phone Helpline 0808 802 0066**

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