



Contents

- 1 Executive summary and recommendations
- 2 Why migraine matters
- 3 Our research
- 4 The challenges and solutions facing migraine care
 - a. Empowering GPs to make an accurate and rapid diagnosis and to manage migraine
 - b. Patient-centered care at the right place
 - c. Equitable access to treatments
 - d. Improving awareness and understanding
 - e. Investment in research
 - f. Impact of Covid-19 and priorities for recovery
- 5 Conclusion
- 6 Acknowledgements
- 7 About The Migraine Trust
- 8 Appendix A
- 9 References



"My migraine has never been managed properly by the NHS. I've suffered for 13 years and they've increasingly become worse each year. I'm bed bound at least once a week. I visit my GP regularly and they send me away with a different drug to try for another year before I can be considered for another. I asked for a referral to the migraine clinic and was refused by my doctor."

Foreword

By Robert Music, CEO of The Migraine Trust

Migraine is one of the most disabling conditions in the world, affecting one in seven adults and up to one in ten children in the UK - that's 10 million people across the country. For many, the severity and frequency of their migraine attacks impacts their ability to work, socialise and care for dependents, and has a serious impact on their mental health. However, despite being so common and having such wide-ranging impacts on our population, migraine has been under-invested in, is largely absent from NHS plans or local public health strategies, receives very little funding for research, and access to specialist care is patchy and inconsistent across the country. This must change.

We hear daily through our support services at The Migraine Trust from people who have had to fight to be diagnosed correctly, who have to wait several months to see a specialist, or who are unable to access medication they are eligible for. We know that most people with migraine can and should have their condition successfully managed and treated by their GP, but the experiences of many patients who contact us show that lots of GPs are not aware of the latest treatment options and best practice, meaning people are receiving sub-standard care, and are sometimes on medication that is not working for them for many years. In fact, despite migraine and headache disorders being one of the most common topics of a GP consultation, GPs receive very limited training in managing migraine and headache disorders.

Taking action to improve migraine care will have far-reaching benefits, not only for the quality of life for the millions of people who experience migraine but also in reducing workdays lost to illness and lessening pressures on A&E departments. We know we could save many more of the 43 million workdays that are lost due to migraine illness in the UK each year and avoid most of the 16,500 emergency admissions for headaches and migraine attacks if we give people better care.

In researching this report, we spoke to patients, headache specialist GPs and key stakeholders. We compiled new information on services from NHS

Trusts and Health Boards across the UK from Freedom of Information requests and conducted opinion polling with more than 2,000 people to find out

more about attitudes and experiences. The results are clear: GP understanding of migraine care and treatment is inconsistent, access to specialist care is patchy, and the condition is trivialised and overlooked for too many people.

However, despite this I believe that this is an exciting time for migraine care. We have new NICE - and Scottish Medicines Consortium - approved migraine treatments available, with more in development. More people are speaking out about their experience of migraine, challenging the stigma and trivialisation too often associated with the condition. And there are specialist doctors, nurses and pharmacists across the country committed to providing the best possible migraine care for their patients, with some excellent examples of innovation in service delivery. We need to build on this with investment in specialist services, more headache specialist healthcare professionals and, crucially, an education drive to ensure all GPs are equipped to provide the best care and support across the country.

This report makes 16 recommendations to address the unacceptable issues in migraine diagnosis, education and care that have been overlooked for too long. Implementing these will require leadership and action by UK Governments, NHS Trusts and Health Boards, the new Integrated Care Systems in England, health education bodies, relevant Royal Colleges, frontline colleagues across the health system, and us too at The Migraine Trust. These recommendations have the potential to be transformative for the 10 million people living with migraine in the UK, and we at The Migraine Trust are committed to working with colleagues across healthcare services to make these recommendations a reality.



1. Executive summary and recommendations

Executive summary

Migraine is one of the most disabling conditions in the world.ⁱ It affects one in seven people in the UK and is ranked as the third cause of years lived with a disability.ⁱⁱ Despite this, migraine is largely absent from NHS plans or local public health strategies, receives very little funding for research, and access to specialist care is patchy and inconsistent across the country.

Improving the quality of migraine care provided in the UK will not only improve people's lives but also reduce pressures on A&E departments and secondary neurology services, alongside wider benefits to the economy and society as a result of reduced absenteeism. This report sets out the action we need from the Government, healthcare systems and other organisations to give everyone living with migraine in the UK the support they need. Migraine care has been dismissed for too long.

Empowering GPs to make an accurate and rapid diagnosis and to manage migraine

Most people with migraine can and should have their condition managed in partnership with their GP. However, patient surveys and insights from The Migraine Trust's support services show that GP understanding of migraine treatment and care is inconsistent and, in many places, inadequate. This is causing delays in diagnosis, inappropriate treatment plans and problems accessing specialist care, with some people being inappropriately referred and others who need a referral not receiving one. A step change in GP awareness, understanding and training is needed to better support the vast majority of people with migraine to manage their condition.

Patient-centered care at the right place

Where patients require specialist care, there should be a clear and prompt referral route from their GP to a specialist headache clinic. However, too often people are subjected to multiple assessments and long waiting lists to access specialist headache clinics. Our Freedom of Information requests, sent to all NHS Trusts in England

and Health Boards in Scotland, Wales and Northern Ireland, show a patchy picture of services, with many NHS Trusts and Health Boards not providing specialist clinics and varying access to headache specialist doctors and nurses. Local leadership in migraine care is needed to champion migraine care, conduct local needs assessments and plan services to meet those needs.

Equitable access to treatments

Our patient surveys indicate that thousands of people are unable to access the treatment they need. There is a particularly acute issue for many people in accessing newly approved CGRP mAb treatments, with many areas refusing to pay for the drugs. This inequality in healthcare needs to be addressed urgently.

Improving awareness and understanding

A lack of awareness among the public and healthcare professionals has led to migraine being frequently under-diagnosed and under-treated, including increasing numbers of patients ending up in A&E. Raising awareness of migraine is vital to change public, medical and employer perceptions of migraine which would address the stigma surrounding the condition and improve quality of life for those affected.

Investment in research

To understand the condition better, including who is most affected and why, and to make much-needed improvements in treatment, significant research investment is needed.

Impact of Covid-19 and priorities for recovery

The Covid-19 pandemic has had a concerning impact on both the frequency and intensity of people's migraine attacks and their ability to access care. People have told us about the effects of long waiting times on their wellbeing, and clinicians have highlighted their own worries about backlogs and drop-offs in referrals. These compounding factors add to the urgency with which migraine care in the UK needs to be treated as services catch up from the pressures of the pandemic.

ⁱ Steiner, T., Stovner, L.J., Jensen, R., Uluduz, D. and Katsarava, Z. (2020). 'Migraine remains second among the world's causes of disability, and first among young women: findings from GBD2019', in *The Journal of Headache and Pain* 21: 137. Available from: <https://thejournalofheadacheandpain.biomedcentral.com/articles/10.1186/s10194-020-01208-0>

ⁱⁱ The Migraine Trust. (2020). Who is living with migraine in the UK? Population rapid research review. Available from: <https://migrainetrust.org/wp-content/uploads/2021/08/State-of-the-Migraine-Nation-population-rapid-review.pdf>

Recommendations:

1. Thorough and up-to-date training in migraine treatment and care must be a core part of medical student, junior doctor and GP education programmes to ensure all GPs are confident in diagnosing migraine, supporting patients to treat and manage their migraine, and referring to specialists when required.
2. In each nation there should be simple training resources for all current GPs to access up-to-date training on diagnosing and managing migraine, such as through a one-page document outlining the treatment pathway. Work on this is already underway in Scotland; the other nations should work alongside national health bodies, professional bodies, the British Association for the Study of Headache (BASH) and The Migraine Trust on a similar project of work.
3. In England, all Integrated Care System (ICS) commissioners should use the [NHS RightCare Toolkit for Headache and Migraine](#) to review and find opportunities for improvement in pathways and care.
4. Using the Optimum Clinical Pathway for Headache and Facial Pain currently in development, pharmaceutical bodies and The Migraine Trust should work together to develop clear resources to support pharmacists to discuss migraine with their patients.
5. Everyone attending primary care for head pain should be assessed for migraine using appropriate, validated tools. Adequate time should be set aside to discuss the diagnosis which is likely to translate into a number of appointments rather than a single 10-minute appointment.
6. Data collection and analysis needs to be better disseminated to monitor progress and track inequalities. Data on migraine care should be published and analysed annually by each nation's public health body. In particular, data should be recorded on diagnosis of migraine in both GP practices and A&E.
7. ICSs in England and Health Boards in Scotland, Wales and Northern Ireland should review their migraine needs (e.g. numbers of people living with migraine who are diagnosed and not yet diagnosed) and plan services to meet these needs, such as by offering opportunities for training in migraine management to GPs, as well as adequate access to secondary and tertiary specialists.
8. Every ICS in England and every Health Board in Scotland, Wales and Northern Ireland should appoint a Migraine / Headache Lead to champion migraine care, share guidelines among colleagues, and lead needs assessments, service development and health care professional education across the area.
9. Each nation's department of health should support the recruitment of additional headache specialists and consultant neurologists to bring the UK in line with other European countries.
10. NHS England should recruit a National Director of Neurology to steer migraine care at a time when treatment is changing rapidly.
11. Everyone diagnosed with migraine should receive an individualised care plan from their GP or healthcare provider, developed closely with them. This should include information about their treatment plan, migraine as a condition, signposting to other services, and a headache diary. Regardless of whether medication is prescribed, the individual should be able to review their plan as needed with their doctor.
12. Every person with migraine should be able to swiftly access the treatment they are eligible for. This means GPs and neurologists must receive up-to-date information on treatments available, and local commissioning bodies should fund those treatments.
13. Public awareness campaigns should be developed in each of the four nations to improve understanding of the range of migraine symptoms, as well as to reduce the stigma associated with migraine. This should be led by the relevant Government department and public health body, alongside close collaboration with The Migraine Trust and local health systems.
14. Migraine should be included in relevant public health resources for employers, such as Public Health England's 'Health and Work' (not currently included), Public Health Wales' 'Healthy Working Wales' (included but the web page has been shut down), Public Health Scotland's 'Healthy Working Lives' (included) and the Public Health Agency's 'Work Well Live Well' (not currently included). This should encourage migraine-positive workplaces to allow people to stay and thrive at work.
15. The National Institute for Health Research (NIHR) and Medical Research Council should work with other funders to develop a headache / migraine-focused workstream as a priority in order to build on recent breakthroughs and improve understanding of the condition, particularly in relation to how migraine affects different ethnic or socioeconomic groups in the UK.
16. The National Institute for Health Research (NIHR) should commission a full health economics research piece to understand the true cost of migraine across the economy, public services and patient, and compare this to modelling of what could be the case if everyone went through an optimum care pathway.

2. The urgent case for improving migraine care

Around 10 million people in the UK experience migraine attacks regularly. This is greater than the number of people living with diabetes, asthma, and epilepsy combined. Our own UK-wide representative survey from July 2021 indicates that the proportion of the population living with migraine may be even higher than this: over half (52%) said they experienced a migraine attack every month or more, at an average of just over two episodes a month. More than one million people have 'chronic migraine' and experience at least eight migraine attacks per month.

For many of these millions of people, migraine has a significant and devastating impact on all aspects of their lives, from basic daily activities to their ability to work and socialise.ⁱⁱⁱ Many people have told us that the impact migraine has had on their lives has been compounded by the Covid-19 pandemic and changes to care as a result of the pandemic: 68% of people responding to our patient survey in November 2020 said their migraine had worsened during the pandemic.



Impact on quality of life

Migraine can have a significant impact on the health and wellbeing of individuals. People living with migraine consistently report reduced health, wellbeing and quality of life. For instance, studies have indicated that people living with migraine were twice as likely as others to report depression.^{iv} There are also negative impacts on family members and relationships, including people's reduced ability to take part in housework, exercise and social activities and the increased stress placed on close relationships.

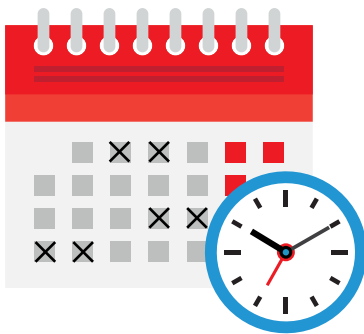
"The impact of migraine at work cannot be overstated and includes having to run to catch up with colleagues, the fear of losing your job, reduced productivity (and importantly the perception of reduced productivity), being perceived as an unreliable colleague, the loss of income and opportunities, the loss of autonomy at work, and having to take time off work."



Impact on the health system

A&E attendance for headache and migraine attacks has increased by **14%** over the last five years. According to NHS England, nearly **16,500** emergency admissions for headaches and migraine attacks could be avoided with the right care pathways, and **£11.5 million** could be saved on non-elective admissions.^{viii}

"My migraines are now daily, and I can't function; I have been unable to do my job as a key worker in education for 2 months, and I am unable to care properly for my severely disabled son. I feel completely useless, and my mental health is suffering."



Impact on workplaces and the economy

A lack of adequate migraine care also affects the UK economy: people are forced to take up to **43 million days off work** due to migraine each year.^v The most recent estimates of the total healthcare and productivity costs of migraine were released in 2018 and estimate that migraine costs the UK economy between **£6 billion and £10 billion per year**, with direct healthcare costs accounting for just **10%** of this.^{vi}

"There are no ways a migraine does not affect my life; it affects every part and is a constant issue for me to do anything. I often hear 'oh it's a headache'. Even my husband and kids comment about me having headaches all the time. It affects your mental health as you just want to be normal and do what everyone else does."

Impact on different groups

While migraine is complex and highly individualised, some groups experience a disproportionate impact from this disease.

- Migraine is between two and three times **more common in women than in men**, likely to be a result of hormonal factors, genetic differences and potential under-reporting among men.^{ix} The National Institute for Health and Care Excellence (NICE) has estimated the prevalence of migraine among women in the UK to be around 24% of the adult population. Our nationally representative survey indicated that the number of women who have ever had a migraine attack is actually much higher at 64%, compared to 41% of men. The same survey showed women consistently reported a higher negative impact across their life from migraine than men.
- Around **one in 10 children aged 5 to 14** years are estimated to have migraine, affecting their ability to flourish in school and socialise with their peers.^x The lack of specialist services and difficulties children face accessing treatment can lead to worse outcomes.
- People living with migraine commonly have other **long term mental and physical health conditions**, meaning that they may have an even greater burden of ill health to cope with.^{xi}

There is a huge gap and need for research to understand the prevalence of migraine among different ethnic or socioeconomic groups in the UK. Without clear data on who is affected, it is impossible to put in place adequate services and care. Investment in research and data on migraine prevalence and need amongst the population and different groups should therefore be a priority.

3. Our research

This report is based on a wide range of evidence sources including direct patient experiences and surveys, opinions from healthcare professionals and data on service availability direct from NHS Trusts and Health Boards. It includes:

- **Patient experience**

People's own perceptions of their care and support are the driving force behind the work we do. The picture of migraine care in the UK that we've developed is informed by what we hear through our support services and by the regular patient surveys we run, which receive several thousand responses. All quotations included in this report are from patients unless otherwise stated.

- **Nationally representative survey**

In June 2021, we commissioned a nationally representative UK survey of 2,000 people to understand public perception of migraine, migraine prevalence and experience of care.

- **Freedom of Information requests to healthcare services**

To understand more about service availability across the country, we asked all NHS Trusts in England and all Health Boards in Wales, Scotland and Northern Ireland about the care they offer to people living with migraine in the form of Freedom of Information requests (FOIs), collected between May and June 2021.¹ For a full list of questions please see Appendix A.

- **Expert feedback from clinicians**

In July 2021, we held a roundtable of experts working across migraine care which included consultants, GPs, nurses and representatives of national groups. The discussion from that event framed the priorities laid out in this report. We also consulted broadly among other organisations and individuals at various stages of the report process. A list of those who took part in the roundtable or who fed into the report can be found in the Acknowledgements.

- **Evidence reviews**

In 2020 we undertook three rapid evidence reviews as part of our 'State of the Migraine Nation' research series. These aimed to understand who is living with migraine in the UK, what migraine care looks like at the moment, and what the impact of migraine is in the UK.



¹ 77% (n=93) of the Trusts we contacted responded to our FOI request. Given the ongoing pressure on capacity in the NHS directly and indirectly caused by the pandemic, some Trusts requested an extension or have not yet responded (August 2021).

4. Challenges and solutions facing migraine care

a. Supporting GPs to make an accurate and rapid diagnosis and to manage migraine

Migraine is the most common neurological reason for consulting a GP, accounting for 2.5 million appointments or around 4.4% of all consultations in primary care every year.^{xii} Additionally, 1 in 20 migraine patients nationally are being diagnosed in A&E, making headache the most common neurological reason for A&E attendance. There has been a 14% increase in A&E attendance for migraine attacks and headache over the last five years, putting additional pressure on our health system at a time when it is already overburdened due to the Covid-19 pandemic and a backlog of patients.^{xiii}

Despite the high numbers of people coming forward, we hear from many that receiving a correct diagnosis can be **time-consuming, stressful and difficult** – if they receive a formal diagnosis at all.

In our nationally representative Censuswide survey from July 2021, over half (52%) of respondents who had experienced a migraine attack in the past had not been diagnosed with migraine by a doctor. Of those who had been diagnosed, half (51%) had waited more than a year for their diagnosis. This is supported by previous patient surveys and is an issue that we have seen exacerbated by the Covid-19 pandemic due to people feeling discouraged from seeking help for their health problems. Our patient survey from 2019 also showed that only around a third of people were diagnosed on their first visit, and 29% had to see a health professional five or more times before they received a correct diagnosis.

The situation appears to be even more concerning for people from Black, Asian, and minority ethnic

backgrounds. Nearly three quarters (73%) of respondents to our 2019 community survey from a Black, Asian or minority ethnic background who had ever had a diagnosis of their migraine said they experienced symptoms for more than a year before seeking help from their GP; only 20% were diagnosed on their first visit; and 41% had to see a health professional five or more times before they received a correct diagnosis.

"Whenever I have taken my children (2 of 3 have migraine) to see a GP or paediatrician, there is always the assumption that the way we live our lives is the cause - too little fluid, sleep, too much screen time. This drives me nuts. My child with no migraine lives the same life after all and me and my kids are all slim, healthy and active. The medical profession needs to stop blaming patients for things which cannot be cured. This attitude has been directed especially toward women for decades. I'm convinced mine and my kids' migraine is genetic with hormone trigger. We don't cause it."

If policy and pathways are going to place the onus on primary care to diagnose and manage migraine, then GPs must have the necessary time and knowledge to support the patient and know when an onward referral is required: without them, the proposed pathways cannot succeed.

"I have found the migraine general knowledge and helpfulness of the GPs I've consulted over the years totally lacking. It took nearly 20 years for me to see an expert and get proper help and that was because I went private."

GP training

As the most common neurological condition GPs encounter, it is essential that they have the necessary tools and knowledge to tackle migraine. Migraine must be covered thoroughly in training for medical students, junior doctors and GPs, as proportionate to its commonality and huge population size.

Toolkits to help plan services and help doctors manage migraine

There are a number of resources available to doctors to help them support patients with migraine, and more are under development. For instance, the National Neurosciences Advisory Group's 'Headache and Facial Pain Pathway' being finalised currently is designed to help doctors to diagnose and support the management of migraine.

In England, the RightCare Headache and Migraine Toolkit developed by NHS England alongside the Neurological Alliance in 2019 aims to support systems to understand the priorities in headache and migraine care and the key actions to take. A similar headache pathway is being developed in Scotland by the Scottish Government's Modernising Patient Pathways Group, which is encouraging.

Uptake of the RightCare Toolkit has so far been poor – likely compounded by the pandemic – and a further push at dissemination among commissioners should be considered. In addition, there should be more of a drive to get doctors to use these toolkits and follow the best practice care pathways they suggest. Professional bodies such as the Royal College of GPs should ensure their members are aware of these resources and confident in applying them in order to improve diagnosis for people needing support for their migraine.

"I had to speak to the doctor more than once about my headaches and had to suggest the diagnosis. The doctors still talk about it as if it is just a headache and I overreact."

Examples of good practice

There are some areas of excellent practice. For instance, at our expert roundtable held in July 2021 to inform this report, we heard about a referral support system for GPs in York. Their website is available to any healthcare professional within the Vale of York CCG to access and includes the British Association for the Study of Headache (BASH) and National Institute for Health and Clinical Excellence (NICE) guidelines on headache within the neurology section. The system makes it far easier for GPs to follow a referral pathway, as well as improving care for the patient.



Reducing medicines overuse and encouraging diagnoses through pharmacies

In addition to GP practices, pharmacies can offer an important opportunity to encourage people who are regular users of painkillers for head pain to see their GP for a formal diagnosis and to discuss treatment options. This could help reduce medication overuse, lessen the load of GPs and support people to effectively manage their migraine at an earlier stage.

"It's trying to influence this medical school curricula to try to make headache and migraine teaching a central part of that. Other long-term conditions – Parkinson's, stroke – double up between neurology and elderly care. Medical students get far more time in elderly care than they do in neurology, so they come out with dozens of tutorials in Parkinson's and stroke but negligible teaching in headache. It's about trying to influence the medical schools to embed migraine as an essential part of the medical school curriculum." – Dr Nicola Griffin, Consultant Neurologist, Circle Bath Hospital

Recommendations:

1. Thorough and up-to-date migraine treatment and care must be a core part of medical student, junior doctor and GP education programmes to ensure all GPs are confident in diagnosing migraine, supporting patients to treat and manage their migraine, and referring to specialists when required.
2. In each nation there should be simple training resources for all current GPs to access up-to-date training on diagnosing and managing migraine, such as through a one-page document outlining the treatment pathway. Work on this is already underway in Scotland; the other nations should work alongside national health bodies, professional bodies, the British Association for the Study of Headache (BASH) and The Migraine Trust on a similar project of work.
3. In England, all Integrated Care System (ICS) commissioners should use the [NHS RightCare Toolkit for Headache and Migraine](#) to review and find opportunities for improvement in pathways and care.
4. Using the Optimum Clinical Pathway for Headache and Facial Pain currently in development, pharmaceutical bodies and The Migraine Trust should work together to develop clear resources to support pharmacists to discuss migraine with their patients.
5. Everyone attending primary care for head pain should be assessed for migraine using appropriate, validated tools. Adequate time should be set aside to discuss the diagnosis which is likely to translate into a number of appointments rather than a single 10-minute appointment.
6. Data collection and analysis needs to be better disseminated to monitor progress and track inequalities. Data on migraine care should be published and analysed annually by each nation's public health body. In particular, data should be recorded on diagnosis of migraine in both GP practices and A&E.

b. Patient-centered care at the right place

Given that everyone experiences migraine differently, decisions about care must be made on an individual basis. The majority of people should be successfully managed in primary care, while some will need to be referred to a specialist headache clinic for treatment and care. When people are supported well, most will be able to manage their own treatment and care independently. Primary care services should be able to help people by supporting them to create an individualised care plan that takes into account their holistic needs, as well as suggesting self-management resources, offering advice on headache diaries, and signposting to further support.

However, as highlighted in the previous section, these aspirations cannot be achieved without the infrastructure and support being available for GPs to offer excellent care. Too often people are subjected to multiple assessments and long waiting lists - in some cases up to two years - to access specialist headache clinics.

Availability of headache specialist clinics

Only 19 (20%) of the 93 NHS Trusts who responded to our FOI request said they had a specialist headache clinic. However, many Trusts who said they did not have a specialist headache clinic still answered questions about providing treatment: for instance, 21 Trusts reported supporting people with migraine, despite not having clinics themselves. This is still a surprisingly low proportion of Trusts.

Across the UK, the picture was marginally more positive: In Wales, three out of seven (43%) Local Health Boards said they provided a specialist headache clinic, in Scotland seven out of 11 (64%) Health Boards said they provided one, and in Northern Ireland three out of five (60%) Health Boards had one.² However, across all nations there should be higher proportions of clinics.

"It's making sure we're getting the right people the right treatment and trying to make sure that that treatment is determined by the patient's need and not where they happen to live and the local expertise. [...] It's very patchy at the moment."
- Mark Weatherall, Consultant Neurologist and Chair, British Association of the Study of Headache (BASH)

Most Health Boards and NHS Trusts in England and Northern Ireland who responded to our FOI question said they had plans to increase headache specialist services in 2021/22 (81% and 67% respectively), such as by increasing doctor or nurse time and funding more treatment. In Scotland and Wales, the proportion was lower – only 33% and 17% respectively – though both areas have a higher proportion of clinics in Health Boards.

Wait times for specialist services

The FOI responses we received and feedback we have heard from patients have not always aligned. For instance, we have heard from people who have waited many months for treatment, but the NHS Trusts who



² The discrepancy in England may be because a lower proportion of Trusts responded to the FOI than health bodies in the other nations, where the return rate was much higher.

responded to our questions indicated shorter waiting lists of between five weeks and 36 weeks from GP referral to first appointment at the specialist headache clinic, with an average of five months.³

Long waits will in part be a result of under-investment resulting in under-staffing – an issue exacerbated by the pandemic.

Every Trust in England and most Health Boards in Wales, Scotland and Northern Ireland reported in their response to our FOI request that Covid-19 had affected services provided by their clinic. In many cases, this had resulted in clinics being run remotely, while a few said clinics had been stopped altogether at various stages of the pandemic. Botox treatment was identified as being particularly affected by Covid-19 pressures. It is critical services are able to bring back treatments like this as quickly as possible to avoid rocketing waiting times.

Access to headache specialist doctors and nurses

Building the neurologist workforce will be critical to improving migraine care and ensuring equitable access to treatment. At just 1.1 full time equivalent (FTE) neurologists per 100,000 population, the UK has a dearth of neurologists compared to France and Germany with more than 4 per 100,000 population.^{xiv}

Our FOI request outlined significant differences between areas about how many doctors and nurses were dedicated to headache and migraine care. This ranged from none to 4 FTE headache specialist doctors in different parts of the UK, averaging at 0.9 in England, 1.1 in Wales, 2.8 in Scotland and 0.7 in Northern Ireland per Trust / Health Board. Many Trusts and Health Boards who reported not having any clinician spending

dedicated time on headache said their consultant neurologists covered this area - still, in England 6 out of 24 Trusts responding to the question said they did not employ a headache specialist.

Even fewer FTE headache nurses were employed, with most health bodies reporting they did not employ any. The average across the nations was 0.2 in Wales and 0.7 in England, Scotland and Northern Ireland.

For access to healthcare professionals to be a lottery of care for people trying to get help for their migraines is unacceptable. We must be far more ambitious if services are to support people into the care they need.

"You're often left to do it [self-management of migraine] on your own. Feels very lonely. The onus is on the individual and it can become overwhelming and exhausting. No-one follows up to see how you're managing."

Innovative pathways

As well as funding additional roles for clinicians, another solution to long waits and unnecessary referral to secondary care is a local triage system for

diagnosis and treatment support, where patients are helped to take an active and informed role in every step of the process. The Oxfordshire headache pathway is one example of where a triage service has been implemented (see opposite).

In Scotland, Health Boards are encouraged by the Scottish Government to establish care interface groups, which cover work in improving the management of headaches.

However, not one of the Health Boards we sent FOIs to said they were aware of care interface groups being active in their area. While Scotland has been proactive in the development of clinical guidelines and frameworks supporting standards of care, these need to be better promoted through care interface groups to ensure policy leads to improvement in outcomes for patients.

"I have permanent migraine with aura. It has destroyed my life. I ring up Samaritans regularly because the condition makes me suicidal [...] My local health area doesn't recognise the condition e.g. funding and treatment for Botox. This has been an uphill struggle to get what NICE says I should be receiving."

³ This may be skewed because only 13 Trusts responded to this question.

Oxfordshire CCG community triage service:

To avoid unnecessary demand on outpatient services, Oxfordshire CCG in partnership with consultant neurologists at the Oxford University Hospitals NHS Trust developed a headache pathway where all headache referrals were triaged by a headache consultant. Patients would either be referred back to the GP with written advice and reassurance, referred to a community headache clinic specially implemented as part of the pathway, or imaged without an appointment. Depending on the outcome of the imaging, they would either be referred back to the GP with written reassurance or sent to a neurology service. This system led to 89% of all referrals being triaged away from the neurology outpatient department, freeing up almost 1,000 appointments over the course of the year.

"The support aspect is key. When I finally spoke to a specialist nurse who 'got it' I was in tears for being recognised."

Recommendations:

7. ICSs in England and Health Boards in Scotland, Wales and Northern Ireland should review their migraine needs (e.g. numbers of people living with migraine who are diagnosed and not yet diagnosed) and plan services to meet these needs, such as by offering opportunities for training in migraine management to GPs, as well as adequate access to secondary and tertiary specialists.
8. Every ICS in England and every Health Board in Scotland, Wales and Northern Ireland should appoint a Migraine / Headache Lead to champion migraine care, share guidelines among colleagues, and lead needs assessments, service development and health care professional education across the area.
9. Each nation's department of health should support the recruitment of additional headache specialists and consultant neurologists to bring the UK in line with other European countries.
10. NHS England should recruit a National Director of Neurology to steer migraine care at a time when treatment is changing rapidly.
11. Everyone diagnosed with migraine should receive an individualised care plan from their GP or healthcare provider, developed closely with them. This should include information about their treatment plan, migraine as a condition, signposting to other services, and a headache diary. Regardless of whether medication is prescribed, the individual should be able to review their plan as needed with their doctor.

c. Equitable access to treatments

There are a huge range of medications available to treat migraine and no standard treatment. While person-centered care recognises that everyone experiences migraine differently, when someone is found to need treatment, they must not be subject to a postcode lottery of care.

Our patient surveys indicate that thousands of people are unable to access the treatment they need in a timely manner, if at all, forcing them to pay privately for their treatment. Very few people are able to afford this, leading to further inequalities in treatment and care. This is a shameful reflection of failure in the system to support people experiencing migraine.

Even before the pandemic, people were not receiving the care they needed. Of the 1,800 people we surveyed in 2019, less than a third (32%) were satisfied with the

care and treatment they were given, a proportion even lower in Wales (17%). In addition, just 15% believed the NHS was able to manage migraine well (compared to 56% who thought it was not). Without access to good quality care, we heard that well over a quarter (28%) of respondents paid to see a health professional privately about their migraine.

"A big problem for me was medication overuse headache. No one ever told me about it until I finally saw a neurologist who diagnosed me. I did the detox treatment and it was effective; this has made a massive difference. I now can take a triptan once per week and that is it."

In particular, our research raises concerns over the new CGRP mAb treatments that have been approved and recommended by medical regulation bodies across the UK. This confirms concerns raised by many patients who have been in touch with our support services because they are unable to access CGRP mAb treatment, despite being eligible, as their CCG refuses to pay for the treatment or their GP is unable to refer them to a prescribing specialist.

CGRP mAb treatment

Recent years have seen the development of medications that block calcitonin gene-related peptide (CGRP), the protein responsible for the pain and nausea associated with migraine. By disabling the activity of CGRP, these drugs - known as CGRP monoclonal antibodies, or mAbs - have been shown to reduce the frequency and severity of migraine attacks. These are the first ever migraine-focused drugs developed specifically for people with migraine.

Since March 2020, certain CGRP mAb treatments have been approved for use in England by NICE: erenumab and galcanezumab have been approved for both chronic and episodic migraine, while fremanezumab has been approved for just chronic migraine. In all cases, NICE requires that patients have tried at least three previous preventative medications. Any doctor who is capable of diagnosing and managing migraine can prescribe CGRP mAbs, including neurologists and GPs with a special interest in headaches, among others. After three months of treatment is a review: if the patient is experiencing at least half as many days with migraine - or 30% for those with chronic migraine - then they can continue the treatment, with another review scheduled for between three and nine months depending on the individual case, after which point clinicians are advised to consider a pause in treatment.

In Scotland, the Scottish Medicines Consortium (SMC) recently allowed the use of galcanezumab, following permittance of erenumab and fremanezumb in 2019. NHS Scotland is not bound to provide the treatment the SMC recommends in the same way NHS England is with NICE, but it is generally expected that if a treatment is advised then it will be provided.

Our FOI requests to health bodies across the UK showed significant variation of which CGRP mAbs were being commissioned and how many patients were being treated. Some Trusts and Health Boards reported having only a handful of patients on CGRP mAbs, while others said they were treating hundreds. On average, Trusts in England were treating around 71 patients per year, while Health Boards in Wales, Scotland and Northern Ireland were treating 33, 59 and 20 respectively. The waiting time average for treatment across the nations was between three and five months, with the longest at 71 weeks.

In England, just 16% (n=15) of all NHS Trusts responding to the FOI said eligible patients could access CGRP mAb treatment, while another 15 explicitly said they could not. Just over half of those who did offer treatment said both fremanezumab and galcanezumab were available, though 45% said only fremanezumab was available. Many of these noted where they would refer patients on to for galcanezumab and said that they were hoping to expand the service and get funding for galcanezumab in the next year or so. All Local Health Boards in Wales reported both fremanezumab and galcanezumab being available to eligible patients, while in Scotland fremanezumab and erenumab were the dominant drugs, with only two Health Boards making

"It is a bit of a lonely battle to conduct, especially as I thought the medication was not too far down the line. Even getting a GP appointment at this present time is incredibly difficult."

"As a former nurse I have found my experience of migraine and treatment terrible. I was not offered triptans until I'd been suffering for over 20 years and then when I was displaying stroke symptoms. I ended up with an untreated encephalitis because my symptoms were considered to be 'psychological'. I lost my memory and my skills and it has been a long road back with little help."



galcanezumab available to patients.⁴ In Northern Ireland, only one Health Board made both fremanezumab and galcanezumab available to patients.

Most health bodies across the nations ensured that the administration of CGRP mAbs was monitored by a headache specialist doctor or nurse.

It is critical that when the relevant medical regulators across the four nations rule that a treatment is safe and cost-effective to be commissioned, access is granted within the appropriate timeframe. We heard from some health bodies that introduction of recently authorised drugs such as erenumab and galcanezumab was imminent but pending approval of a business case for extra resources. With many people potentially eligible for CGRP mAbs, decisions about funding treatment are often left to commissioners, leading to inequitable access to CGRP mAbs across the country and no access in some areas.

⁴ This is most likely due to galcanezumab only being approved by the SMC in April 2021.

In addition, difficulties arise from the fact that some health professionals cannot prescribe CGRP mAbs. Increasing the number of clinicians who can prescribe CGRP mAbs will make it easier for patients to access and relieve the burden on parts of the neurology system.

As we have seen in diagnosis outcomes and waiting times, it is likely that some groups of people will experience inequality of access to treatment and care. Responses to our FOI requests suggest that the vast majority of Trusts do not collect enough data or have a mechanism to monitor local inequalities of access. Just a tiny fraction of health bodies we contacted said they had any evidence of inequalities, though some noted that it was likely certain groups would experience worse care and health outcomes. One NHS Trust highlighted that referrals to their headache services from deprived areas were delayed, and there was limited capacity to deal with this. One Local Health Board in Wales reported they were preparing an Equalities Impact Assessment to monitor this, though it was still in its draft stages at the time of their writing (June 2021).

"The NHS understanding/ support in my experience is appallingly inadequate. If I had not paid privately for medical support and medication I would have suffered even more. [...] I am currently having a row with my local NHS trust over medication they refuse to supply. Even my NHS GP says this is postcode lottery. Migraine remains a misunderstood and poorly respected condition by many health professionals."

***"Theoretically prescribable but not yet practically available. On an individual basis."
– Frimley Health NHS Foundation Trust responding to our question on access to CGRP mAbs***

***"There is no data to suggest obvious inequity. However, this doesn't preclude that there is."
– St George's Healthcare NHS Foundation Trust responding to our question on inequalities in accessing care***

Recommendations:

- 12.** Every person with migraine should be able to swiftly access the treatment they are eligible for. This means GPs and neurologists must receive up-to-date information on treatments available, and local commissioning bodies should fund those treatments.

d. Improving awareness and understanding among the public and employers

A lack of awareness among both the public and healthcare professionals has led to migraine being frequently **under-diagnosed and under-treated**. Large numbers of patients end up visiting A&E or being referred into outpatient neurology services for **unnecessary investigations**, when their migraine should be more appropriately treated and managed in a primary care or community setting. This leads to a clogging of the system which makes it more difficult for people with severe or complex neurological disorders to be seen quickly in secondary care.

In our patient surveys, people affected by migraine told us that raising awareness of migraine is vital to changing public, medical, and employer perceptions of the condition and improve diagnosis and care. Respondents said that migraine is often dismissed or trivialised in wider society, popular culture and the media – if mentioned at all. People who live with migraine report that they are often made to feel that migraine is somehow their fault, and if they had managed themselves better by avoiding triggers they could have prevented the migraine attacks. This has contributed to the sense of burden and invisibility that many people feel when accessing help for their migraine.

Research led by The Migraine Trust in July 2021 evaluated public awareness of common symptoms of migraine. Only 52% of over 2,000 nationally representative respondents identified that headache was a symptom of migraine, and the majority failed to recognise other key identifiers, such as sensitivity to light, visual disturbances, nausea and dizziness. Awareness of migraine symptoms was lower in men than in women.

In addition, the 2018/19 National Neurology Patient Survey from the Neurological Alliance indicated that very few patients diagnosed with headache disorders received adequate explanation or diagnosis during their consultation, with a lack of any focus on co-morbidities. Raising awareness and educating patients will be essential to people being able to access the care they need.

To better support people affected by migraine in other areas of their lives, we also need to see a change in how migraine is treated in a working environment. Too many people are not adequately supported by their employer to manage their migraine. More migraine-positive workplaces would significantly improve productivity and allow people to stay and thrive at work, reducing one of the leading causes of workplace absences in the UK.



Recommendations:

13. Public awareness campaigns should be developed in each of the four nations to improve understanding of the range of migraine symptoms, as well as to reduce the stigma associated with migraine. This should be led by the relevant Government department and public health body, alongside close collaboration with The Migraine Trust and local health systems.
14. Migraine should be included in relevant public health resources for employers, such as Public Health England's 'Health and Work' (not currently included), Public Health Wales' 'Healthy Working Wales' (included but the web page has been shut down), Public Health Scotland's 'Healthy Working Lives' (included) and the Public Health Agency's 'Work Well Live Well' (not currently included). This should encourage migraine-positive workplaces to allow people to stay and thrive at work.

"Migraine is controlling my life and needs more to be done about it: medical professionals and employers don't understand and neither does anyone else who doesn't suffer with them."

"No one understands how debilitating and frightening migraines can be until they have one."

"Migraine has been the bane of my life – definitely misunderstood and people have no idea what it's like suffering. I had to take early retirement mainly because I kept taking time off work and was persuaded to take severance. Never knowing when the next one will strike is a nightmare, and sometimes I've gone for weeks and months feeling ill most days."



e. Investment in research

Migraine remains a critically underfunded topic of research: it is the least publicly funded of all neurological illnesses relative to its economic impact. The National Institute for Health Research (NIHR), the UK's largest public funder of healthcare research, has only funded eight studies into migraine since 2009.

Additional research is crucial to making the economic case for investment into migraine care. It is also critical in understanding who is affected by migraine and making sure services work for them: international research suggests that historically disadvantaged population groups are more likely to live with migraine - including women, those on low incomes and some minority ethnic groups - but there is little research about whether the UK has any ethnic or socioeconomic inequalities in its migraine population or in migraine care.^{xv} This makes it challenging to plan effective support or outreach strategies and to describe the impact that migraine has on individuals, communities, sectors and wider society.

Recommendations:

15. The National Institute for Health Research (NIHR) and Medical Research Council should work with other funders to develop a headache / migraine-focused workstream as a priority in order to build on recent breakthroughs and improve understanding of the condition, particularly in relation to how migraine affects different ethnic or socioeconomic groups in the UK.
16. The National Institute for Health Research (NIHR) should commission a full health economics research piece to understand the true cost of migraine across the economy, public services and patient, and compare this to modelling of what could be the case if everyone went through an optimum care pathway.



f. Impact of Covid-19 and priorities for recovery

Our surveys have indicated that an increasing majority of people with migraine have seen their migraine worsen during the pandemic: in May 2020 the proportion was 58% of respondents; by November 2020 this was 68%. Of these, some reported their migraine had worsened because of stress, some because their lifestyle was harder to manage and others because they couldn't access the treatment they had been receiving for their migraine. An increase in screen time will also have contributed to worsening migraine attacks.

Research led by The Migraine Trust in June 2021 also found that people with migraine were experiencing a deterioration in wellbeing because of the pandemic: 47% said the pandemic had negatively affected their mental health, while one third said they felt more isolated and lonely.

In addition, one in eight (12%) people accessing support for their migraine said they had been unable to access treatment and / or medication for their migraine over the last year, according to our survey run in July 2021. 15% of people said they had been unable to get an appointment with a migraine / headache specialist, while 17% reported they had had appointments with specialists postponed or cancelled. This aligns with the findings of a survey from the Neurological Alliance, which suggested that more than 70% of people with neurological conditions had experienced delays to their medical appointments. Analysis of NHS England datasets indicated a backlog of more than 225,000 neurological appointments and a drop-off in referrals more generally, compounded by an increase in demand from long-Covid patients.^{xvi} This reduction in referrals is concerning and suggests there may be a "lost population" of people with migraine not receiving any support.

Our own FOI research has seen many health bodies across England, Wales, Scotland and Northern Ireland reporting significant impact on headache specialist clinics, including cancellations of Botox treatment during the pandemic which has led to increased waiting lists as services begin to open up. However, there has been a great amount of variation across the nation in how long services were closed down for during the pandemic, and

how far away they are from getting back to normal: in some areas, clinics were stopped altogether, while others operated a hybrid model online and others managed to keep clinics open the whole time. For many, virtual clinics will lead to more convenient care and increased access to services. It is important to recognise that this will not be the case for everyone and that decisions about how care is provided should be decided alongside the patient according to their preference.

We have also seen a mixed picture of how many people were seen by clinics in 2019 and in 2020.

Some services saw a significant expansion of the numbers of people they treated and saw, while others supported many fewer people.

Overall in England, there was an increase of 26% of the total number of new patients seen at headache clinics between 2019 and 2020. There was also an increase in Wales of 44%, while Scotland and Northern Ireland saw reductions in new patients seen at headache clinics by 7% and 53% respectively.⁵ We have also heard from clinicians of fears of a reduction in referrals to services leading to a "lost population" of migraine patients not receiving support.



⁵ It's worth being cautious of this data as it comes from a small sample size.

Conclusion

Recognising the increased burden on health services at a time when services are stretched and fatigued with additional funding and support will be critical. At the same time, it is important services take stock of what has worked well during the pandemic and focus on patient choice going forward.

This report reveals a concerning picture of migraine care across the UK, impacting on lives in a way that should not have to be the case. However, the opportunities for improvement are significant. The arrival of new migraine treatments and gradually increasing awareness make this an exciting time to be working in migraine care: healthcare professionals and policy-makers alike have the power to make a dramatic improvement to the lives of millions of people across the country and relieve pressure on the health system and economy while doing so.

In this report we have set out what we and other experts believe needs to change to increase awareness and understanding, speed up time to diagnosis, provide care that is patient centered and equitable, and improve research in this area. It is clear we need navigatable and efficient pathways for treatment and care, a step change in education and training among GPs, and investment in specialist services.

The landscape is changing quickly, and this report is the beginning rather than the conclusion of a conversation about migraine care. There is much to do if the recommendations set out here are to become a reality.

If you or your organisation would like to discuss our recommendations or any of the issues outlined in this report, please get in touch by emailing Una Farrell (ufarrell@migrainetrust.org). As we move forward into a new era for migraine treatment, we want to work with as many people and organisations as possible to make excellent migraine care in this country a reality.



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About The Migraine Trust

The Migraine Trust is the largest research and support charity for people affected by migraine in the UK. Our role is to fund and promote new research into migraine, provide day to day support for people affected by migraine and campaign for change.

Appendix A: Freedom of Information request questions

Section 1: Specialist headache clinics

1. (a) Do you have a specialist headache clinic in your Trust / Health Board?
(b) (i) If yes, please give details.
(ii) If no, please give details of the clinic you would refer out to.
2. How many people did you support through your specialist headache clinics:
(a) in 2019?
(b) In 2020?
3. What is the average waiting time from GP referral to first appointment at the specialist headache clinics in your Trust / Health Board (current or for when you last had data)?
4. (a) Has Covid-19 affected the services provided by your specialist headache clinic(s)? (E.g. staff redeployment, virtual services rather than face to face, anything else)
(b) If yes, please give details.
5. How many full time equivalent (FTE) headache specialist doctors are employed by your Trust / Health Board (in secondary care or GPs with an extended role)?
6. How many FTE headache specialist nurses are employed by your Trust / Health Board?
7. (a) Do you have plans in 2021/22 to increase headache specialist services?
(b) If yes, please give details.
8. (a) Do you have plans in 2021/22 to do additional work with GPs regarding education, community management or pathways?
(b) If yes, please give details.
(c) If no, please explain any reasons (e.g. budgets / other priorities / another organisations' responsibility).
9. (England only:) (a) Have you completed the Self-Assessment Questionnaire included in NHS RightCare's Headache and Migraine Toolkit within the past year?

- (b) If yes, did this indicate that the requirements of the headache and migraine system were:
 - a. fully met
 - b. partially met
 - c. not met

Section 2: Access to CGRP medication

10. (a) Can eligible patients currently access Calcitonin Gene-Related Peptide (CGRP) medication through your Trust / Health Board?
(b) If yes:
 - (i) How many people are accessing CGRP medication through your Trust / Health Board?
 - (ii) What is the current waiting time to access a prescribing specialist?
 - (iii) Is the administration of CGRP treatments monitored by a headache specialist?
 - (iv) Are both Ajovy (fremanezumab) and Emgality (galcanezumab) available to patients?
- (c) If no, do you refer and fund it out of area? Please give details.

Section 3: Training

11. (a) Do you have any education or training programmes with GPs in your area on migraine (e.g. regarding patient management in the community, patient information or referral pathways)?
(b) If yes, or if any is planned, please give details.

Section 4: Inequalities

12. (a) Are you aware of local inequalities of access to headache specialist services amongst any groups (e.g. by gender, ethnicity, disability, socio-economic groups)?
(b) If yes, please give details of the inequalities and any work you are doing or planning to address this.

(Scotland only:)

Section 5: Care interface groups

13. (a) Are you aware of a care interface group being active in your area?
(b) If yes, what work is ongoing to improve the management of headaches and migraine in your area?

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