



Insights report

The impact of migraine on people in Northern Ireland and opportunities to improve care

the
migraine
trust

May 2024

Contents

1. Foreword	3
2. Background: migraine in Northern Ireland	4
2.1 Freedom of Information data	4
2.2 Regional Review of Neurology Services	5
3. Findings and recommendations from the roundtable	6
4. Primary care: how can we ensure most cases are handled properly in the community?	9
5. Secondary care: how do we boost access to specialist treatment?	11
6. Conclusions	15
7. Roundtable attendees	16
8. References	17

1. Foreword

By **Rob Music**, chief executive, The Migraine Trust

Migraine has a severely debilitating impact on the daily lives, mental health and ability to work of many of the 10 million people affected by the condition in the UK, including more than 270,000 people living in Northern Ireland.

Our recent report *'Heading in the wrong direction'* shone a light on the landscape of migraine care UK-wide. A combination of widespread misunderstanding that migraine is 'just a headache', a lack of support in primary care or adequate provision for specialist care, rising waits and unequal provision of treatments mean many people are left struggling alone with their symptoms. However, our research found that waiting times for headache and migraine referrals are particularly severe in Northern Ireland, and the five Health and Social Care Trusts (HSCTs) varied widely in what services they can promise to residents living with migraine.

Against this backdrop in February 2024, The Migraine Trust held a roundtable in Belfast to unite leading clinical experts in headache care in the country with patient advocates, in order to put their findings to policymakers about what needs to change. This combined the first-hand experiences of both patients and clinicians to explore what better management of most cases of migraine in primary care could look like, how to manage the most severe cases in secondary care, where care should be provided, and by what kind of practitioners. We also looked at potential recommendations for rapid change.

The final report of the long-awaited Regional Review of Neurology Services is due to be completed in the spring, five years after it was originally slated to be released. The publication of the review is urgently needed, so that we can kick-start the work of improving all neurological services in Northern Ireland and make sure that transforming headache and migraine care is a central part of this.

We hope the insights and recommendations we put forward in this paper will help inform that work and enable a badly-needed drive for change.



2. Background: migraine in Northern Ireland

2.1 Freedom of Information data

In 2023 for Migraine Awareness Week, The Migraine Trust published [*'Heading in the wrong direction: challenges in migraine care and why people with migraine deserve better'*](#). This report highlighted how migraine is very common and has wide-ranging impacts on the UK population, but nonetheless has been subject to underinvestment, is treated very inconsistently, and is largely absent from health service plans or local public health strategies. These findings drew on Freedom of Information (FOI) requests that The Migraine Trust sent to all five HSCTs and equivalent local health bodies in the other UK nations in February 2023, as well as surveys of people living with migraine, interviews with GPs and insights from the The Migraine Trust's helpline service.

FOI responses for Northern Ireland found that waiting times for headache and migraine referrals are some of the worst in the UK. The Belfast HSCT neurology department reported that it receives between 150-200 headache referrals per month and that waiting times for its headache clinic are around 18 months on average. The average wait across three of the five Trust areas was more than two years (117 weeks) and two Trusts do not directly provide calcitonin gene-related peptide monoclonal antibodies (CGRP mAbs) treatments, the first ever drugs developed specifically for people with migraine. CGRP mAbs have been approved in England by the National Institute for Health and Care Excellence (NICE) and by the Scottish Medicines Consortium (SMC) in recognition of their effectiveness.¹

UK-wide research for *'Heading in the wrong direction'* also found that although some patients have positive experiences in primary care, many patients feel that their GP does not understand migraine, leading to delays in diagnosis, inappropriate treatment plans and problems accessing specialist care. GPs with Special Interest (GPwSIs, also now known in UK as GPs with Extended Role or GPwERs) in headache that we interviewed emphasised that there is a lack of formal compulsory ongoing training for GPs on migraine, meaning it is patchy, regionalised and often down to a local champion to run. This meant that there was a need for up-to-date and easily accessible guidance on migraine. However, Trusts varied in whether they were undertaking any initiatives to strengthen education and training for local GPs.

2.2 Regional Review of Neurology Services

The Northern Ireland Department of Health (DoH) has been undertaking a Regional Review of Neurology Services, which is tasked with identifying the optimum configuration of neurology services for the next 10-15 years and is chaired by Belfast neurologist Dr John Craig.

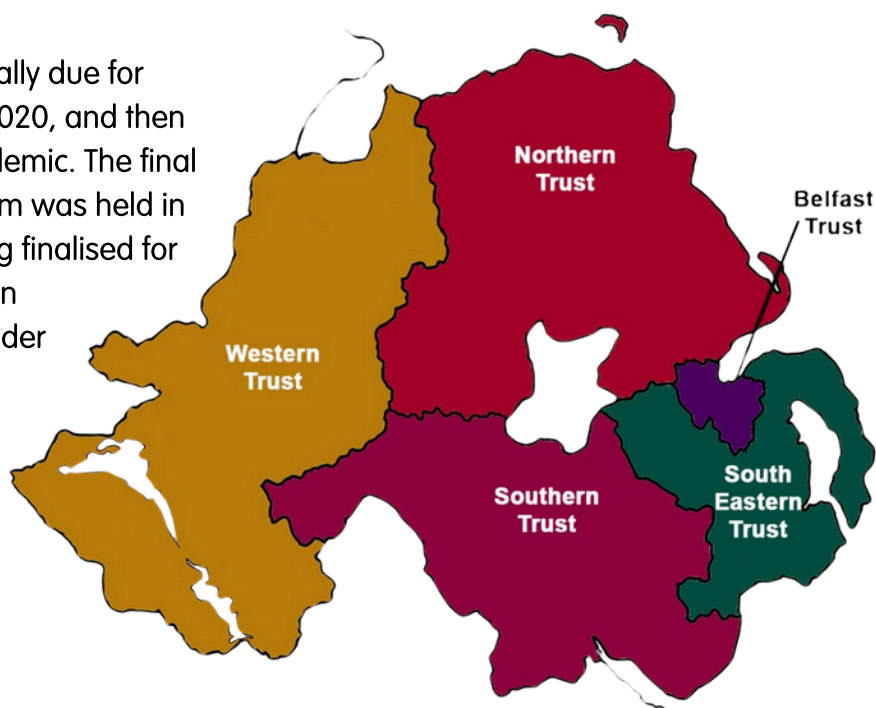
The review was announced in July 2018 and the interim report in October 2019 noted that while neurology services are provided across each HSCT area, there is one Regional Neurosciences Centre based at the Royal Victoria Hospital in the Belfast HSCT. In addition to providing local neurology services to the greater Belfast population, this centre also provides most sub-specialist services, including specialist neurological inpatient care to the wider population.

The then-national Health and Social Care Board² had been taking forward a neurology modernisation programme focused on funding additional training places in neurology to give some junior doctors more experience of the specialty, developing new ways of responding to patients suffering from “some of the more common conditions such as headache”, and “increasing opportunities for different healthcare professionals to work more closely together for neurology patients”.³

Phase two of the review has been exploring seven workstreams:

- First presenters
- Unscheduled care
- Long-term care
- Workforce
- Co-production
- Coordination
- Elective care

The final report of the review was initially due for summer 2019 but delayed to spring 2020, and then delayed further by the COVID-19 pandemic. The final meeting of the Neurology Review Team was held in April 2024 and the report is now being finalised for later in the spring, with feedback taken from patients, carers, charities and wider expert bodies.



3. Findings & recommendations from our roundtable

Primary care

- The goal should be for most people living with migraine to be able to manage their condition in the community with support from primary care.
- Migraine is a very common presentation, but many GPs struggle to even diagnose it. More education and resources should be available for GPs, along with incentives to specialise - development and distribution of these could be driven by HSCNI bodies, the Royal College of GPs and The Migraine Trust.
- Patients sometimes find community pharmacists more accessible or personal than GP services - provision for headache and migraine within Northern Ireland's Pharmacy First scheme should be explored.
- More specialist clinics should be in the community, rather than sitting in hospital neurology departments.
- Multi-Disciplinary Teams (MDTs) and general practice pharmacists are a valuable part of care in the community and should be strengthened.

Secondary care

- There should be consistent access to or referral mechanisms for CGRPs in every HSCT, and the NI DoH should monitor access.
- There should be a minimum level of staffing in every HSCT or adequate resourcing when one Trust area is receiving referrals, monitored by the DoH.
- Though current NICE clinical knowledge summaries on headache and migraine do have some limitations, to set standards the Northern Ireland DoH should formally and consistently adopt NICE guidance on treatments.
- Headache and migraine needs to be a larger part of neurological education.
- As in primary care, MDTs for headache and migraine care are key and should be strengthened - patients do not always feel they need a doctor.
- Consistency of funding, investment in workforce and collaboration across HSCT boundaries are needed to improve access to headache care across Northern Ireland. The DoH and HSCTs should review the availability of headache specialists in workforce planning and opportunities for joint working.

Wider attitudes to migraine

- There should be an effort to reduce stigma in workplaces, led by the DoH and Department for the Economy. The Migraine Trust's Workplace Pledge offers a model for employers to use.⁴
- Migraine should be put on the same footing as other neurological conditions, with investment made in recognition of how disabling it can be for some of those affected and its corresponding impact on quality of life and the economy.
- The impact of poor migraine management on work and the health system also needs to be understood - people with migraine say they want to be living and working, not stuck on and adding to waiting lists. The HSC Public Health Agency should audit available data on treatment for patients with migraine.





MIA TOOLKIT

All about migraine

A toolkit to help you support better migraine care for your constituents

This toolkit will provide you with:

- An overview and definition of migraine
- How to identify and understand your constituents with migraine
- A list of support services available to your constituents
- A list of support services available to your constituents
- A list of support services available to your constituents
- A list of support services available to your constituents

the migraine trust

MIA TOOLKIT

All about migraine

A toolkit to help you support better migraine care for your constituents

This toolkit will provide you with:

- An overview and definition of migraine
- How to identify and understand your constituents with migraine
- A list of support services available to your constituents
- A list of support services available to your constituents
- A list of support services available to your constituents
- A list of support services available to your constituents

the migraine trust

4. Primary care: how can we ensure most cases are handled properly in the community?

“I learnt I had to ‘look corporate’ and not bring my husband with me to be taken seriously by private consultants. They didn’t understand, and the health system failed me for an awfully long time”

– Claire Horne, migraine patient

General Practice

Most people who live with migraine should be successfully supported in primary care by their GP, who can diagnose migraine and advise on medication options and lifestyle adaptations in line with British Association for the Study of Headache (BASH) and NICE guidance.^{5 6} Dr Louise Rusk, a GPwSI working in South Eastern Health and Social Care Trust, started our discussions by outlining the current state of headache and migraine care in primary care in Northern Ireland, and what is currently preventing better management.

Headaches are the most common neurological issue seen by GPs. At least 73% of people presenting to a GP with a headache are suffering from migraine, and it ranks as the second leading global cause of disability (and the first among younger women).^{7 8} Despite this, medical education - both undergraduate and postgraduate - often overlooks migraine and the condition is frequently underdiagnosed. When Dr Rusk looked at a sample of 100 migraine referrals to the headache clinic, she found referring doctors were more frequently asking for diagnosis rather than management.

Perhaps most significantly, the burdens on GPs and short duration of appointments often means that conditions such as migraine cannot be adequately addressed:

“I know that to do it well takes a lot longer than the 10 minute consultation. For me it’s not the dread of the headache consultation, it’s the dread of the length of the headache consultation”

– a GP Partner on challenges with complex migraine consultations

The majority of migraine cases remain within primary care, but greater education is needed to equip all GPs with knowledge about migraine. In the past five years, the Northern Ireland Medical and Dental Agency has supported focused neurology education for GP trainees, and this should be continued, but education and support of this kind is needed for the wider GP community. Although some areas have implemented innovative approaches (such as an advice hotline in Craigavon) or have drawn effectively upon MDTs, patient experience is heavily subject to a “postcode lottery”.

In recent years GPs have provided effective and efficient enhanced services for patients through GP Elective Care Services (GPECS) in community settings - one such area has been women's health, for example. Migraine services could be delivered in a similar way with appropriate support and funding, keeping care local to patients.

Technology can also play a role in improving care. E-referral systems can streamline links between primary and secondary care, while the telementoring initiative Project ECHO aims to improve patient consultations and physician confidence in managing complex disorders. However, migraine must receive due focus within such systems.⁹

It also remains the case that Northern Ireland also suffers from an overall lack of GPwSIs focused on headache and migraine, with only four in the country, partly due to a lack of funding currently available to create or expand GPwSI posts.

Pharmacy

There is potential for a greater role for pharmacists in primary care, potentially within Northern Ireland's Pharmacy First service.¹⁰ In NHS Grampian in Scotland, research for a pilot on expanding access to migraine care through pharmacies found that only 14% of respondents had accessed support from a pharmacist, but 77% would consider doing so.¹¹ Patient voices suggested they had positive experiences reported regarding their accessibility and patient-centred approach:

“You never see the same GP twice, and one said ‘what exactly are you expecting me to do for you here?’ to me. Pharmacists are less restricted by appointment systems, and often are able to advise better on the likes of medication interactions because they know you. You don't feel like it's just five minutes and you're being rushed out”

– Andrea Quinn, Senior Communications Officer at The Migraine Trust and a migraine patient

General practice pharmacists, who are often prescribers, also play an established role in the NI primary care system. Participants cited examples in musculoskeletal care as an area of medicine where they have helped reduce pressures.¹²

5. Secondary care: how do we boost access to specialist treatment?

While many cases of migraine can and should be managed in primary care, people living with particularly severe and complex cases of migraine may need to be referred to a neurologist, often supported by a migraine specialist nurse and physiotherapist. Dr Thomas Peukert, a Consultant Neurologist in Belfast, started off the second segment of our discussion with a presentation highlighting the disparities in secondary care for migraine patients across Northern Ireland's HSC Trust areas.

Migraine accounts for around half of patients attending Emergency Departments with neurological symptoms and approximately one-third of all neurology referrals are for headache and migraine, but Northern Ireland has significant variations in care. The Northern HSCT has an agreement with Belfast HSCT so that patients from the Northern area can be treated in the capital, but this results in even longer waits for care in Belfast. Meanwhile, patients in the Western HSCT face a lack of local access to key migraine treatments and are unable to request treatment in Belfast, due to the lack of a similar agreement. Waiting times vary by Trust area and cases with 'red flag' symptoms can be seen in two weeks, but other patients may wait more than five years.

Workforce challenges are a significant part of these problems with access to treatment. Despite the prevalence of the condition and its disabling nature, it is often overlooked in neurological education ("I had not a single headache clinic during my training", Dr Peukert observed) and it receives less attention and investment relative to other neurological conditions. Few medical professionals choose to specialise in headache and migraine - out of 25 neurological specialists in Northern Ireland, only three are headache specialists - and half of Northern Ireland's neurological specialists are concentrated in Belfast.

Headache nurses, headache physiotherapists (who can prescribe and inject medications) and other roles within MDTs also play a significant role in migraine care.^{13 14} Migraine patient representatives stressed that they were "delighted to see anyone who can help" after bad experiences with the health system. However, even staff in these disciplines are rare at the current time.

	Belfast Health and Social Care Trust	South Eastern Health and Social Care Trust	Southern Health and Social Care Trust	Northern Health and Social Care Trust	Western Health and Social Care Trust
Workforce					
Consultants with Special Interest in Headache	1	1	1	0	0
GPwSIs	0	2	3	0	0
Nurses	2	0	0	0	0
Physiotherapists	2	0	1	0	0
Psychologist	1	0	0	0	0
Specialty and specialist (SAS) doctors	0	0	1	0	0
Fellow	1	0	0	0	0
Treatments					
Botox	Yes	Yes	Yes	Referral to Belfast	No
CGRP MABs	Yes	Yes	Yes	Referral to Belfast	No

Table 3: numbers of specialists and access to treatment across Health and Social Care Trusts (source: presentation by Dr Thomas Peukert)

Participants expressed frustration over this lack of specialists and the perception that migraine is not taken seriously because it is not a life-threatening condition. Migraine cases sometimes progress from episodic to chronic, due to delayed diagnosis and inadequate treatment.¹⁵ Cost implications were also raised, in terms of the significant public expenditure incurred by a lack of rapid diagnosis or referral to effective and proven treatments:

“I feel like I got tested for everything, and no one ever suggested it was migraine. After one scan, a doctor said ‘this shows it's not serious, or you'd be dead by now’. If you went back and costed everything that was spent on me before I was prescribed Aimovig and saw results, an awful lot was wasted”

– Claire Horne, migraine patient

Participants emphasised the need for long-term investment in migraine management to alleviate the burden on healthcare resources, based on an 'invest to save' ethos, as well as the need for an approach that enables collaboration or consistent access to care across Trust boundaries. An optimal care pathway for migraine patients in Northern Ireland, mirroring what has already been rolled out in England, was suggested as a potential solution to address these issues.¹⁶

To strengthen consistent access to treatments and adherence to guidelines across all HSC Trust areas, Dr Peukert also recommended that Northern Ireland should formally adopt NICE guidance, as at present patients may only have access to one dose of CGRP within the local HSCT, for example (after this, the GP is expected to prescribe, but if they are not prepared to do so the treatment will be stopped). The Northern Ireland Department of Health has had formal links with NICE since 2006 but maintains its own process for how guidance is applied "to check for legal, policy and financial consequences related to its implementation in NI" (as opposed to "a reassessment of the clinical and cost evidence used by NICE in forming its advice"), which means NICE guidance "may be endorsed with caveats" in Northern Ireland.^{17 18}



the
migraine
trust



6. Conclusions

“We don’t want to be clogging up waiting lists. Better access to care where we live would benefit everyone”

– Andrea Quinn, Senior Communications Officer at The Migraine Trust and a migraine patient

There is an urgent need to combat stigma surrounding migraine in health systems, the workplace and wider society in Northern Ireland, and to emphasise the importance of normalising the condition. Participants stressed that patients with migraine wish to live and work, rather than being trapped on and adding to waiting lists, but this will require an ethos in society that puts migraine on the same footing as other neurological conditions. Northern Ireland also has some of the most severe waiting times for migraine care in the UK, demonstrating the lack of investment and focus there has been until now.

Policymakers in Northern Ireland need to understand the impact migraine has and to invest more in primary and specialist care workforce and in access to medications, to alleviate strain on both people living with the reality of migraine and healthcare services that are struggling to support them.

The final report of the Regional Review of Neurology Services process will represent an opportunity to transform all neurology services in Northern Ireland, and to ensure that headache and migraine is a focal point of this.

7. Roundtable attendees

Name	Title
Dr Jack Armstrong	Policy and Research Officer, Office of Danny Donnelly MLA
Elliot Bidgood	Policy and Parliamentary Adviser, The Migraine Trust (Facilitator)
Claire Horne	Patient Representative
Donna McElhill	Headache Physiotherapist, Belfast Health and Social Care Trust
Rob Music	Chief Executive, The Migraine Trust (Chairing)
Dr Thomas Peukert	Consultant Neurologist, Belfast Health and Social Care Trust
Andrea Quinn	Senior Communications Officer, The Migraine Trust, and a migraine patient
Ann Robinson	Headache Nurse, Belfast Health and Social Care Trust
Dr Louise Rusk	GP with Special Interest, South Eastern Health and Social Care Trust, and Trustee, The Migraine Trust
Sonya Thomson	Headache Physiotherapist, Belfast Health and Social Care Trust

8. References

- 1 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 Scotland, the Scottish Medicines Consortium (SMC) recently allowed the use of galcanezumab, following permissance of erenumab and fremanezumb in 2019. A fourth CGRP mAb drug, eptinezumab, was approved by NICE and the SMC for preventive use in early 2023. Available at: <https://www.nice.org.uk/guidance/TA871>; <https://www.scottishmedicines.org.uk/medicines-advice/eptinezumab-vyepti-abb-smc2547/>. Accessed 5 March 2024.
- 2 As part of the wider transformation of Health and Social Care (HSC) services, the functions of the Health and Social Care Board (HSCB) were transferred to the Department of Health on 1 April 2022. See: <https://online.hscni.net/about-us/> Accessed 5 April 2024.
- 3 Department of Health (2019) Review of Neurology Services - Interim Report, October 2019. Available at: <https://www.health-ni.gov.uk/review-neurology-services-interim-report>. Accessed 5 March 2024.
- 4 Launched in March 2024, The Migraine Trust's Workplace Pledge aims to enable employers to demonstrate to current and prospective staff that they are committed to supporting their needs of people living with migraine. Employers receive a quarterly email with resources and ideas to increase awareness of migraine in your workplace, details of upcoming events and ways to get involved, and a digital awareness pack with factsheets on migraine, including our Migraine at Work toolkit to raise awareness in the workplace. Available at: <https://migrainetrust.org/get-involved/the-migraine-trusts-workplace-pledge/>
- 5 British Association for the Study of Headache (2022) 'Guidelines'. Available at: <https://www.bash.org.uk/guidelines/>. Accessed 2 April 2024.
- 6 National Institute for Health and Care Excellence (2022) 'Migraine: Update, Last revised in September 2022'. Available at: <https://cks.nice.org.uk/topics/migraine/how-up-to-date-is-this-topic/update/>. Accessed 17 April 2024.
- 7 Kernick, D (2008) 'GPs' classification of headache: is primary headache underdiagnosed?', British Journal of General Practice, Feb 1; 58(547): 102–104. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2233960/>. Accessed 2 April 2024.
- 8 Steiner, T.J. (2020) 'Migraine remains second among the world's causes of disability, and first among young women: findings from GBD2019', Journal of Headache Pain; 21(1): 137. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7708887/>. Accessed 2 April 2024.
- 9 More information on Project Echo is available here: <https://echonorthernireland.co.uk/neurology/>. Accessed 5 April 2024.
- 10 Northern Ireland has had a Pharmacy First service since 2021 which includes Sore Throat and 'Everyday Health Conditions' (acne, athlete's foot, diarrhoea, earwax, groin infection, haemorrhoids, head lice, mouth ulcers, oral thrush, scabies, threadworms, vaginal thrush, and verrucae). However, in contrast to the Pharmacy Independent Prescribing Service in Wales for example, migraine is not currently in scope in Northern Ireland. <https://online.hscni.net/our-work/pharmacy-and-medicines-management/community-pharmacy-services/pharmacy-first/>; <https://nwspp.nhs.wales/ourservices/primary-care-services/primary-care-services-documents/ccps-documents/pharmacy-ip-services/pips-common-ailments-and-contraception-service-specification-april-2024/>. Accessed 17 April 2024.
- 11 A focus group (June 2023) and survey (July 2023) where run with people living with migraine to shape the project in Grampian. More information on the aims of the project here: <https://www.nhsgrampian.org/contentassets/706114c3a7204ca38aa2bf06180ce615/daily-brief-29-september-2023.pdf>. Accessed 17 April 2024.
- 12 Health and Social Care Northern Ireland (2023) 'New Models of Prescribing'. Available at: <https://online.hscni.net/our-work/pharmacy-and-medicines-management/new-models-prescribing/>. Accessed 2 April 2024.
- 13 Minister of Health Robin Swann has indicated that specialist nurses could play a role in reducing waiting times. Nursing Times (2024) 'Specialist nurses 'could tackle wait lists' in Northern Ireland'. Available at: <https://www.nursingtimes.net/news/policies-and-guidance/specialist-nurses-could-tackle-wait-lists-in-northern-ireland-23-02-2024/>. Accessed 2 April 2024.
- 14 For example, a "a scientific session focusing on multidisciplinary headache management was organised at The European Headache and Migraine Trust International Congress (EHMTIC) 2010 in Nice. A summary of the contributions and the discussion is presented. It was concluded that effective multidisciplinary headache treatment can reduce headache frequency and burden of disease, as well as the risk for medication overuse headache." Gaul, C et al (2011) 'Team players against headache: multidisciplinary treatment of primary headaches and medication overuse headache.' Journal of Headache Pain. 2011 Oct; 12(5): 511–519. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3173636/>. Accessed 2 April 2024.

References

- 15 Lipton, R.B., Buse, D.C., Nahas, S.J. et al. Risk factors for migraine disease progression: a narrative review for a patient-centered approach. *J Neurol* 270, 5692–5710 (2023). Available at: <https://doi.org/10.1007/s00415-023-11880-2>. Accessed 2 April 2024.
- 16 National Neurosciences Advisory Group (2023). 'Optimal clinical pathway for adults with headache and facial pain'. Available at: <https://www.nnag.org.uk/optimal-clinical-pathway-for-adults-with-headachefacial-pain>. Accessed 2 April 2024.
- 17 Department of Health (2022) 'Circular Reference: HSC (SQSD) 13/22\, Subject: NICE Clinical Guidelines – Process for Endorsement, Implementation, Monitoring and Assurance in Northern Ireland'. Available at: <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-hsc-sqsd-13-22.pdf>. Accessed 2 April 2024.
- 18 As noted in The Migraine Trust report 'Heading in the wrong direction: Challenges in migraine care and why people with migraine deserve better' (2023), NICE guidance itself has limitations. Heading in the wrong direction noted that NICE clinical knowledge summaries are more often used by GPs, but are not as comprehensive as BASH guidelines and are out of date, so need to be updated with information on recently approved CGRP treatments. Available at: <https://migrainetrust.org/wp-content/uploads/2023/09/TMT-Heading-In-The-Wrong-Direction-2023-FINAL.pdf>. Accessed 5 April 2024



About The Migraine Trust


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.

AbbVie provided arm's-length full funding for this project. AbbVie has had no influence in the project, or the development of any associated materials.

The Migraine Trust
7-14 Great Dover Street
London
SE1 4YR

 migrainetrust.org

 Helpline 0808 802 0066

 @MigraineTrust

 [themigrainetrust](https://www.facebook.com/themigrainetrust)